March, 2000

Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions For Their Children: Is Deference Justified?

Jennifer Rosato
ARTICLES

USING BIOETHICS DISCOURSE TO DETERMINE WHEN PARENTS SHOULD MAKE HEALTH CARE DECISIONS FOR THEIR CHILDREN: IS DEFERENCE JUSTIFIED?

Jennifer L. Rosato*

INTRODUCTION ................................................................. 2
I. THE LIMITS OF THE CURRENT DOCTRINE .......................... 4
   A. A Lack of a Principled Standard .................................. 10
   B. The Extremes of Deference ........................................... 13
      1. Too Much Deference .................................................. 14
         a. Mature Minors Refusing Life-Sustaining Treatment .... 14
         b. Minors Seeking Abortions ....................................... 15
      2. Too Little Deference .................................................. 20
   C. A Lack of Competence ............................................... 25
II. BIOETHICS AND THE ROLE OF FAMILIES IN HEALTH CARE DECISION-MAKING ......................................................... 29

* Professor of Law, Brooklyn Law School. Many thanks to the research assistants who worked tirelessly on the project at different times over the last few years: Jason Arnold, Erin DeLorier, Larry Graham, Leslie Kramer, Christa Santos, Kathleen Donahue, Rachel Simsovits, Rachel Weissman, and Karyn Yaffe.

I am indebted to the readers of an earlier draft of this article, including George Annas, Nan Hunter, Larry Solan, and Spencer Weber Waller. Parts of this work were presented at the ASLME Conference (poster session) in 1997 and the International Law and Mental Health Conference in 1999. Any errors or omissions are my own.

I also thank the faculty of Boston University's School of Public Health who, through its summer bioethics workshop, helped me to appreciate the richness and the relevance of the bioethics discourse to my work on children and the law. Finally, my appreciation extends to Brooklyn Law School ("BLS") and Dean Joan Wexler, who generously financed this project over a few years through the BLS Summer Stipend Program and provided me with generous funds for research assistants.
INTRODUCTION

Mr. and Ms. N. refuse cancer treatment for their three-year-old child based on their religious beliefs. . . . Mr. and Ms. R. seek to discontinue artificial ventilation for their premature infant. . . . Mr. H. demands all available medical intervention for his anencephalic infant, even if the doctors consider it futile. . . . Susan R., a sixteen-year-old, seeks an abortion even though she knows her parents disagree with her decision.

Even though these examples illustrate different kinds of decisions, all involve a parent's authority to make health care decisions for a child. The existing law defining the scope of this authority is problematic on a number of levels. Most notably, many of these cases are inappropriately considered under the legal rubric of abuse or neglect. The adjudication of abuse or neglect usually involves determining whether minimum levels of acceptable conduct have been satisfied, but the health care cases that I have described above are not about minimum acceptable levels of conduct. Instead, they are about making difficult choices for which a social consensus is lacking.

Inconsistencies also abound in the existing law. Some of the health care decisions made by parents are protected by state statutory or common law, others by federal law. A few, such as abortion and sterilization, are limited by

---

1. See infra Part I.C for a discussion of the abuse and neglect context of parental medical decision-making.

2. See infra notes 172-87 and accompanying text for a discussion of issues involved in making decisions in health care cases.
state law and federal constitutional law. Decisions are determined by different standards, depending upon which law governs the issue. The inconsistencies characteristic of the current approach result in too much deference to parents in some situations and too little deference in others. For example, some children with cancer are permitted to receive alternative treatment, but others cannot; parents who demand intervention for their infants are given deference but parents who refuse treatment are not; parents who oppose a daughter’s abortion are presumed to act in good faith, but parents who seek sterilization of a child are not. These disparate results are unfair to both parents and children.

One reason for these problems is that the current doctrine is founded on a rights-based discourse. Rights-based in this context means that the ability to decide for another is based on a sense of entitlement, usually supported by existing law. Constitutional law generally supports the right of parents to make decisions for their children, including health care decisions. When we move away from a rights-based discourse, we no longer can assume that parents possess an inherent right to make these decisions and, therefore, another basis for parental authority must be provided.

This Article proposes that we rethink the existing rights-based discourse using a bioethics discourse. The discipline of bioethics poses difficult questions about who possesses moral authority to decide for others. Moral authority generally means that the decision-maker deserves deference based on one or more of the core principles of bioethics: autonomy, beneficence, nonmaleficence,

---


4. See infra Parts I.A and I.B for a discussion of different governing standards.

5. See infra Part I.B for a discussion of varying levels of deference.


7. See infra Part I.B for a discussion of varying levels of deference.

8. See infra Part I.B.1.b for a discussion of deference to parents in abortion cases. See infra notes 264-75 and accompanying text for a discussion of deference to parents in sterilization cases.


10. See infra notes 20-44 and accompanying text for a discussion of parents' legal rights.

and justice.\textsuperscript{12} In the context of parent-child decision-making, moral authority means a reasoned justification based on beneficence (the child's best interests) or autonomy (respect for the child to make his or her own decisions).

This Article concludes that, guided primarily by the bioethics principles of beneficence and autonomy, parents should retain their status as primary decision-makers for their children, with some reservations.\textsuperscript{13} Part I of this Article critiques the existing law and illuminates the need for an alternative approach.\textsuperscript{14} Part II discusses the basic principles that guide the bioethics discourse, and specifically their application to situations in which family members make health care decisions for incompetent adult patients, such as adult children making decisions for their ailing parents.\textsuperscript{15} When incompetent adult patients are involved, beneficence is the overriding principle. This principle is exemplified in three “lessons” that guide family decision-making: (1) family members do not possess an inherent right to decide for the patient and must justify their role; (2) deference to family usually furthers the interests of the patient; and (3) conflicts of interest provide a sound basis for interfering with family decision-makers.\textsuperscript{16}

Part III of this Article considers the applicability of these bioethics lessons to the parent-child context, and proposes a conflicts of interest framework that would recognize both categorical and situational conflicts likely to interfere with the parents’ decision-making abilities.\textsuperscript{17} This Section recognizes not only the beneficence principle, but also the autonomy principle, by considering the ability of mature minors to make decisions concerning their own treatment.

Significantly, this Article proposes that, if adjudications of medical decision-making for children must be made, they should be made by the courts that ordinarily make health care decisions for incompetent adult patients, and not the courts that decide child abuse or neglect cases.\textsuperscript{18} This jurisdictional change would acknowledge the resemblance of the children’s cases to those of incompetent adult patients and, more fundamentally, would acknowledge the degree to which health care decisions about children involve the exercise of moral authority, and not minimum levels of competence. Resolving cases may not be easier using this approach, but a greater value will be served by acknowledging the medical and ethical aspects of these decisions and the realities of existing familial relationships.

I. THE LIMITS OF THE CURRENT DOCTRINE

The current legal doctrine of parent-child decision-making in the health

\textsuperscript{12} See infra notes 166-83 and accompanying text for a discussion of the core bioethics principles.
\textsuperscript{13} See infra Part III for a discussion of parent-child decision-making.
\textsuperscript{14} See infra Part I for a discussion of the current state of the law.
\textsuperscript{15} See infra Part II for a discussion of bioethics principles in the health care context.
\textsuperscript{16} See infra Part II.B for a discussion of family decision-making.
\textsuperscript{17} See infra Part III.C for a discussion of proposed conflicts of interests framework.
\textsuperscript{18} See infra notes 296-301 and accompanying text for a discussion of which court should adjudicate cases dealing with medical decision-making.
care context is problematic for a number of reasons and warrants reconsideration. First, it lacks guiding principles, which has led to confusion and inconsistency among cases. Second, its unprincipled nature has led to extremes of deference, where some parents are given deference when undeserved, and other parents are denied deference when it is warranted. Third, the failure to recognize the ethical nature of these decisions has led to these cases being decided in the improper context of child abuse and neglect. Most of these cases are not about whether the child has been neglected or abused; rather, they are about whether well-meaning parents possess the moral authority to make health care decisions for their children.19

The existing problems with the current doctrine are rooted in the history of parent-child decision-making. Historically, parents have possessed the right to make health care decisions on behalf of their children, with few limitations.20 Three primary justifications support this right: parental decision-making benefits the parents,21 it benefits society,22 and it benefits the children themselves.23

19. In some cases, the courts have acknowledged the moral dilemma, even if ultimately ruling against the parents. See In re McCauley, 565 N.E.2d 411, 414 (Mass. 1991) (stating court does not question parents' love for daughter or sincerity of wish to follow religious beliefs); Custody of a Minor, 379 N.E.2d 1053, 1064-65 (Mass. 1978) (finding parents were loving and devoted to son when they objected to standard medical treatments for child's leukemia because of suspicions of radiation and concerns about child's discomfort while undergoing chemotherapy), aff'd, 393 N.E.2d 836 (Mass. 1979). In other cases, courts honored the parents' wishes for non-conventional treatment after acknowledging the parents' intense love for their child. See In re Hofbauer, 393 N.E.2d 1009, 1012 (N.Y. 1979) (stating child's parents were "concerned and loving parents who have employed conscientious efforts to secure for their child a viable alternative of medical treatment"); In re Hudson, 126 P.2d 765, 768, 771 (Wash. 1942) (recognizing parents' good character and sincere fear that amputation of daughter's arm would result in death).

20. Early colonial America adhered to patriarchal ideals whereby the father was the king of the family and his children were essentially property of whom he was entitled to make productive use. As part of this family labor system, the father contracted for his child's labor in exchange for wages kept as family income. See Michael Grossberg, Governing the Hearth: Law and the Family in Nineteenth-Century America 235 (1985) (stating dependent children exchanged services and earnings for life and maintenance with fathers); Lee E. Teitelbaum, Family History and Family Law, 1985 Wis. L. Rev. 1135, 1139 (comparing colonial view of parent-child relationship to authoritarian views of sovereignty prevalent in that period); Barbara Bennett Woodhouse, "Who Owns the Child?": Meyer and Pierce and the Child as Property, 33 Wm. & Mary L. Rev. 995, 1037-38, 1044-46, 1050, 1063-64 (1992) (discussing historical treatment of children as property by father). During the nineteenth century, as fathers started working outside the home and leaving their wives to tend for the children, courts recognized the mother's special role in child-rearing by giving them protected rights to their children. See Grossberg, supra, at 281 (stating mothers gained custody and guardianship rights); Teitelbaum, supra, at 1142-43 (discussing mothers' new roles included educator and custodian).

21. See, e.g., Dwyer, supra note 9, at 1439-42 (discussing basis of parental interest in children); Schneider, supra note 9, at 157-58 (discussing parental rights as applied to neonatal euthanasia); Teitelbaum, supra note 20, at 1143 (discussing how children served many practical ends).

Through decisions of the United States Supreme Court, this right has attained constitutional status. Parents possess a fundamental right to the care, control, and custody of their children, which includes making major decisions on their


The diversity rationale is an integral part of the United States Supreme Court's jurisprudence recognizing parental rights. See, e.g., Wisconsin v. Yoder, 406 U.S. 205, 223-24, 226 (1972) (accordance deference to Amish parents to raise children according to cultural preferences, in part because it encouraged diversity of American values); Pierce v. Soc'y of Sisters, 268 U.S. 510, 534-35 (1925) (expressing standardization of education would disrupt plurality by infringing parents' rights to instill in children cultural and religious values); Meyer v. Nebraska, 262 U.S. 390, 402-03 (1923) (finding laws that attempt to establish homogenous society by restricting parents' choices in individual child-rearing practices as against letter and spirit of Constitution). See also Bellotti v. Baird, 443 U.S. 622, 637-38 (1979) (affirming importance of parents in child care because of society's values of individualism and freedom of choice).

23. See infra notes 28-35 and accompanying text for a discussion of how deference to parents benefits children. See also Developments, supra note 22, at 1214, 1353-54 (contending parents are truly aware of what is best for children on account of special relationship with children); Michael S. Wald, Thinking About Public Policy Toward Abuse and Neglect of Children: A Review of Before the Best Interests of the Child, 78 MICH. L. REV. 645, 645-50 (1980) (discussing theories supporting that deference to parents benefits children); Julie Solomon Rappaport, Note, The Legal System's Response to Child Abuse: A "Shield" for Children or a "Sword" Against the Constitutional Rights of Parents?, 9 N.Y.L. SCH. J. HUM. RTS. 257, 262-63 (1991) (noting "parents know . . . what is best for their children, and will act accordingly"). But see Dwyer, supra note 9, at 1426-47 (claiming parents do not necessarily consider children's best interests first because parents have own individual interests); Schneider, supra note 9, at 155-56, 159-60 (summarizing bases for parental deference and finding parents do not always make decisions based on what is best for child).

24. See Pierce, 268 U.S. at 534-35 (holding unconstitutional state laws limiting parents' choice where to educate children to public schools only); Meyer, 262 U.S. at 400-03 (holding statute that forbade teaching school children languages other than English to invade liberty interests of parents and teachers).


The fundamental nature of the right has been questioned. See, e.g., Francis Barry McCarthy, The Confused Constitutional Status and Meaning of Parental Rights, 22 GA. L. REV. 975, 985 (1988) (questioning whether parents' right of control is really fundamental). Other commentators have questioned the parents' right to decide for their children at all. See Dwyer, supra note 9, at 1371-72, 1446-47 (asserting children's rights should be protected first and parents' child-rearing rights are illegitimate); Wendy Anton Fitzgerald, Maturity, Difference, and Mystery: Children's Perspectives and the Law, 36 ARTZ. L. REV. 11, 20-21, 36-37 (1994) (arguing law should respect children's perspectives in disputes affecting children's lives); McMullen, supra note 22, at 569, 596 (asserting privacy interests in child-rearing results in maltreatment of children); Woodhouse, supra note 20, at 1001-02, 1051-56, 1114 (arguing for child-centered, rather than parent-centered, theory of parenthood). They have proposed a number of child-centered theories. See, e.g., Dwyer, supra note 9, at 1374, 1446-47
As a fundamental right, only a compelling state interest can limit it. In an oft-quoted phrase from Parham v. J.R., the Supreme Court articulated its reasons for granting parents such broad decision-making power:

The law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More important, historically it has been recognized that natural bonds of affection lead parents to act in the best interests of their children.

Following this reasoning, the Parham Court upheld the state’s procedure for the voluntary institutionalization of children, finding no violation of due process.

The Court’s justification for this parental deference presumption appeared to be based on the best interests of the child, and reflected the views already held (focusing on children’s temporal interests); Fitzgerald, supra, at 22-23 (advocating personhood theory for children); Barbara Bennett Woodhouse, Hatching the Egg: A Child-Centered Perspective on Parents’ Rights, 14 CARDOZO L. REV. 1747, 1754 (1993) (proposing generism theory).


27. See Von Eiffe v. Azcri, 720 So. 2d 510, 516-17 (Fla. 1998) (finding compelling state interest not shown in grandparent visitation context); In re Application of Dep’t of Human Servs., No. CIV. 91-159, 1995 WL 450466, at **1, 5-9, 17 (D.V.I., Jan. 31, 1995) (stating statute terminating parental rights required sufficient compelling interest to be constitutional). See also McCarthy, supra note 25, at 981, 985, 991 (discussing labeling of parental rights as fundamental); Raymond C. O’Brien, An Analysis of Realistic Due Process Rights of Children Versus Parents, 26 CONN. L. REV. 1209, 1220 (1994) (stating powerful countervailing state interest is required to overcome parental presumption). But see Developments, supra note 22, at 1356 (reporting cases and opinions stating that less than compelling state interest may be sufficient).

28. A number of cases have used the quoted language from the Parham v. J.R. opinion. See, e.g., Halderman by Halderman v. Pennhurst State Sch. & Hosp., 707 F.2d 702, 713 (3d Cir. 1983) (finding parents’ objection to having retarded child transferred to another school was presumed to be in child’s best interests and thus overrode recommendation by hearing master that community living arrangement would be better for child); R.J.D. v. Vaughan Clinic, P.C., 572 So. 2d 1225, 1228-29 (Ala. 1990) (holding request of child’s custodial parent was adequate to admit child to hospital care despite opposition of child and child’s non-custodial parent); In re Doe, 418 S.E.2d 3, 6-7 n.6 (Ga. 1992) (holding hospital could not enjoin Do Not Resuscitate Order without both parents’ consent or legal agreement made by parents); People v. Bennett, 501 N.W.2d 106, 121 (Mich. 1993) (Riley, J., concurring and dissenting) (arguing parents had children’s best interests in mind when choosing home education); In re Penny N., 414 A.2d 541, 542-43 (N.H. 1980) (per curiam) (holding incapacitated minor’s parents are joint guardians and presumed to make decisions for daughter’s best interests); In re Adoption of a Child by W.P. and M.P., 706 A.2d 198, 201-03 (N.J. Super. Ct. App. Div. 1998) (stating court would uphold natural parents’ right to custody of child based on presumption of parents acting in child’s best interests). Cf. Steven R. Smith, Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection, 37 HASTINGS L.J. 765, 771-72 n.25 (1986) (citing cases using deference presumption in health care context).

31. Id. at 620.
32. This Article refers to the language in Parham as the creation of a “parental deference presumption,” even though the Court probably did not intend to create a strict legal presumption, rebuttable or irrebuttable.
by the courts and society-at-large. The Court did not, however, set forth any empirical proof demonstrating that this presumption was based in fact. Instead, by citing certain sources, the Court appeared to base the presumption, at least in part, on the parents' proprietary interests in their children.

Notwithstanding the strength of this deference presumption, the Court has recognized that parents do not possess an unrestricted right to make decisions on behalf of their children. The Court broadly proclaimed that parents are not permitted to make "martyrs" of their children, which meant that the state could interfere when serious harm or death to the child was likely to result from the parents' acts or omissions. This limited intervention was consistent with a vision of a state that respected familial privacy and valued pluralism.

The parental deference presumption and society's desire to protect children exist in constant tension. In the past, the parental deference presumption

---


34. See McMullen, supra note 22, at 592-94 (stating authorities for Parham presumption were philosophical, not empirical) (citations omitted). See also O'Brien, supra note 27, at 1217-18 (stating parental presumption is simply part of American jurisprudence). There is still little empirical proof to support the parental deference presumption. See Preston A. Britner et al., Evaluating Juveniles' Competence to Make Abortion Decisions: How Social Science Can Inform the Law, 5 U. Chi. L. Sch. Roundtable 35, 52-53 (1998) (stating there is little empirical support for parental presumption).

35. Cf. Walter Waddington et al., Cases and Materials on Children in the Legal System 182 (1983) (discussing historical materials cited by Parham Court recognizing natural bond between parents and children are misleading, because materials were solely explaining parents' rights to wages of children).


37. See Waddington, supra note 33, at 315-16 (discussing state interference with parental decision making). See also Robert Bennett, Allocation of Child Medical Care Decisionmaking Authority: A Suggested Interest Analysis, 62 Va. L. Rev. 285, 317 (1976) (discussing when state may intervene in health care decisions for minors); Dwyer, supra note 9, at 1382, 1388 (defining compelling interest as "life-threatening or [causing] grievous physical harm to children" to warrant intervention by state); McMullen, supra note 22, at 584 (stating limited state intervention should be permitted only when child's life is in immediate danger; otherwise, parent has full discretion in child-rearing).

38. McMullen, supra note 22, at 570-73 (discussing family autonomy); David A.J. Richards, The Individual, the Family, and the Constitution: A Jurisprudential Perspective, 55 N.Y.U. L. Rev. 1, 39-40, 50-51, 57-58 (1980) (discussing areas of law that forced courts to balance parental and state interests); Teitelbaum, supra note 20, at 1157, 1174 (discussing cases supporting pluralism and deference to parents).
appeared stronger, limiting state intervention to cases of actual, serious harm.\textsuperscript{39} More recently, societal factors—such as the greater incidence and awareness of child abuse—have resolved the tension in favor of protection.\textsuperscript{40}

Although the parental deference presumption is still articulated,\textsuperscript{41} it does not seem as weighty as it once was. Instead of intervening only when serious harm is threatened, a court now can intervene whenever it believes that intervention will further the child’s best interests.\textsuperscript{42} This increased interference is facilitated by the broad language of many abuse/neglect statutes, language that seems to permit intervention whenever any necessary medical treatment is denied.\textsuperscript{43} Also, the existing societal consensus apparently favors greater intervention in the family, purportedly based on the desire to protect children.\textsuperscript{44}

\textsuperscript{39} See Wadlington, supra note 33, at 318, 320, 325, 331 (discussing cases that allowed court intervention for life-threatening situations). See also Dwyer, supra note 9, at 1399 (noting courts are reluctant to intervene unless necessary to save life of child).

\textsuperscript{40} See Gerald P. Koocher, Different Lenses: Psycho-Legal Perspectives on Children’s Rights, 16 NOVA L. REV. 711, 713-15 (1992) (discussing societal problems facing children that have forced legal system’s involvement). See also McMullen, supra note 22, at 569, 596-97 (concluding maltreatment of children by parents justifies state involvement). Cf. Rappaport, supra note 23, at 260, 277, 291 (reasoning abridging fundamental rights does not solve problem of child abuse); Wadlington, supra note 33, at 325 (stating definition of neglect expanded to include failure to provide medical care and resulted in increased litigation).


\textsuperscript{42} See Barry Nobel, Religious Healing in the Courts: The Liberties and Liabilities of Patients, Parents, and Healers, 16 U. PUGET SOUND L. REV. 599, 654 (1993) (stating courts have taken more active role in requiring medical care for children); Wadlington, supra note 33, at 331 (noting courts are moving away from rules allowing interference only in life-threatening cases).

\textsuperscript{43} See, e.g., CONN. GEN. STAT. ANN. § 46b-120(8) (West 1998) (stating child can be found neglected if “denied proper care and attention, physically, educationally, emotionally or morally or is being permitted to live under conditions, circumstances or associations injurious to his well-being”); MISS. CODE ANN. § 43-21-105(1)(iv) (1998) (defining neglected child as one “who, for any reason, lacks the care necessary for his health, morals or well-being”); N.Y. FAM. CT. ACT § 1012(f)(i)(A) (McKinney 1998) (defining “neglected child” as “one whose condition . . . has been impaired or is in immediate danger of becoming impaired” because of a parent’s failure “to exercise a minimum degree of care in supplying the child with adequate . . . medical, dental, optometrical or surgical care”); UTAH CODE ANN. § 78-3a-103(1)(f)(i)(C) (Supp. 1999) (defining neglected child as minor whose guardian “fails or refuses to provide proper or necessary subsistence, education, or medical care, including surgery or psychiatric services . . . or any other care necessary for health, safety, morals or well-being”). See also Bennett, supra note 37, at 302 (discussing magnitude of medical neglect necessary to justify intervention); Scott Obernberger, When Love and Abuse Are Not Mutually Exclusive: The Need for Government Intervention, 12 ISSUES IN L. & MED. 355, 372, 376-78 (1997) (noting states’ power is broad under ill-defined statutes allowing increased intervention into family life).

\textsuperscript{44} See Fitzgerald, supra note 25, at 49-50 (calling for affirmative state commitment to support children); McCarthy, supra note 25, at 977 (noting existence of state regulations for parent-child relationships); O’Brien, supra note 27, at 1231-32, 1260 (discussing standard that would consider parents’ interests and children’s due process rights). Recently, Congress passed the Adoption and Safe Families Act of 1997 (“ASFA”), which requires, among other things, more frequent reviews of foster care placements, and requires the state to terminate parental rights sooner than before. See 42 U.S.C. § 675(5)(C) (1994) (providing each child in foster care is assured permanency hearing no later than 12 months after date child is considered to have entered foster care and not less frequently than
The irreconcilable tension between child protection and parental deference is reflected by the lack of a principled approach in the existing law, and by the existence of too much deference to parents in some situations, and not enough in others.

A. A Lack of a Principled Standard

The current doctrine of parental decision-making in the health care context lacks a principled approach, which has led to confusion and a lack of consistency among cases. The primary focus appears to be the child’s best interests: if the benefits of treatment outweigh its risks, then treatment must be given to the child. However, the best interests standard is cast in the shadow of parental rights, through some version of the parental deference presumption.

The decision of the Delaware Supreme Court in *Newmark v. Williams* illustrates some of the fundamental problems of a rights-based discourse, in which the child’s best interests are determined in the context of the parental deference presumption. In *Newmark*, the court addressed whether the parents’


This social consensus is reflected not only by the state of the current laws but also the public’s seeming intolerance of purported incidents of abuse or neglect. See, e.g., Blaine Harden, *A Baby Alone Lands Parents In N.Y. Jail; Pair Arrested for Parking Stroller Outside Cafe*, WASH. POST, May 14, 1997, at A1 (recounting how passers-by phoned police when Danish visitor in New York City enjoyed drinks with friend in restaurant and kept one-year-old child in stroller outside window, which is common practice in Denmark); Katharine Q. Seelye, *Girls Were Hit on Flight, Attendants Say*, N.Y. TIMES, July 15, 1997, at B3 (reporting at least seven passengers missed connecting flights to express comments of disgust and make sure that authorities arrested parents believed to have abused newly adopted children).

45. See supra notes 32-44 and accompanying text for a discussion of the child’s best interests approach.


refusal to consent to chemotherapy for their three-year-old son, Colin, constituted child abuse or neglect. The court identified three different approaches that had been applied by other courts: (1) the ad hoc approach; (2) the best interests approach; and (3) the tripartite balancing approach. The court then attempted to meaningfully distinguish these approaches, which proved to be a difficult task. According to the court, the ad hoc approach lacks a “formal test.” Under the best interests approach, the risks and benefits of treatment must be balanced to determine whether the medical intervention serves the child’s best interests. The tripartite balancing approach requires balancing the interests of the parent, the child, and the state.

Although the court identified three approaches, it ultimately did not adopt a single approach for all cases. It apparently conflated the approaches, leaving it unclear how the approaches differ and when a court would use one approach over another. The court initially seemed to be applying the tripartite approach by analyzing the parental and state interests and recognizing the primacy of parental decision-making. The court then focused primarily on the child’s best interests by carefully considering the treatment’s effectiveness, the child’s chances of survival with or without treatment, and the physical and emotional effects of the treatment on the child. The court concluded that the risks of treatment to Colin and its invasiveness outweighed any potential benefit (at “best” a 40% chance of survival).

Finally, the court seemed to return to the tripartite approach in reaching its ultimate conclusion that the Newmarks could refuse treatment for their child. Following its best interests analysis, the court considered the state’s interest and concluded that it did not outweigh those of the parents and child. The parents therefore were permitted to refuse the chemotherapy.

The Newmark approach is similar to decisions of other courts that still recognize the parental deference presumption, but ultimately allow the best interests of the child to prevail. In these cases, it is not clear whether deference

48. Newmark, 588 A.2d at 1114.
49. Id.
50. Id.
51. Id. A recent example of this balancing approach permitted a mother to refuse AIDS therapy for her child. In re Nikolas E., 720 A.2d 562 (Me. 1998).
52. Newmark, 588 A.2d at 1115.
53. Id. at 1116-17. See also O’Brien, supra note 27, at 1250 n.191 (discussing Newmark court’s decision that child’s interest takes precedence over parents’ interest).
54. Newmark, 588 A.2d at 1118-19, 1120. The court defined survival as living at least two years after chemotherapy was completed. Id. at 1119 n.12.
55. Id. at 1120. Cf. Laura M. Plastine, Comment, “In God We Trust”: When Parents Refuse Medical Treatment For Their Children Based Upon Their Sincere Religious Beliefs, 3 SETON HALL CONST. L.J. 123, 148-50 (1993) (noting curability of underlying illness is important factor to court).
57. Id. at 1120.
58. In a number of cases, courts have considered the child neglected and ordered treatment. See In re Willmann, 493 N.E.2d 1380, 1390 (Ohio Ct. App. 1986) (stating parents’ religious faith did not give legal right to risk child’s death). Cf. In re Petra B., San Diego Dep’t of Soc. Servs. v. Erie B., 265
to parents really is warranted, or whether it is a shibboleth articulated as a vestige of the days when parental rights were weightier. Even if these cases essentially reflect a best interests analysis—regardless of what the approach is called—it still would be problematic.

In other contexts such as a child custody, the application of a best interests of the child standard has consistently been criticized for amounting to an ad hoc balancing of interests that places too much discretion with the individual judge. The resulting lack of predictability is reflected in the decision itself. After reviewing a number of refusal of treatment cases, the only unifying principle that the court could articulate was that the “courts have consistently authorized state intervention when parents object to only minimally intrusive treatment which poses little or no risk to the child’s health.” As a unifying principle, this leaves many important questions unanswered: What is a minimally intrusive treatment? When does a treatment pose little or no risk to a child’s health? From whose perspective is risk assessed? And when other than minimally intrusive treatment is involved, or the treatment poses more than little

---

Cal. Rptr. 342, 346 (Cal. Ct. App. 1989) (acknowledging parental authority, but holding state intervention was warranted where parents treated child’s burns with herbs rather than standard medical treatment because they did not consider condition serious enough for medical attention); People in re D.L.E., 645 P.2d 271, 276 (Colo. 1982) (holding child’s interest outweighed parents’ protection of religious freedom).

In a classic Solomonic manner, other courts have declined to find neglect but have ordered treatment nevertheless. See J.V. v. State, 516 So. 2d 1133, 1134 (Fla. Dist. Ct. App. 1987) (ordering blood transfusion after finding no abandonment, neglect, or abuse).

59. See 2 HOMER H. CLARK, JR., THE LAW OF DOMESTIC RELATIONS IN THE UNITED STATES § 201, at 479 (2d ed. 1987) (writing “[n]early all judicial discussion of custody cases begins with the statement that custody must be so awarded as to promote the child’s best interests”). See also Naomi R. Cahn, Reframing Child Custody Decisionmaking, 58 OHIO ST. L.J. 6, 14 (1997) (stating most states use best interests standard to determine child custody); Fitzgerald, supra note 25, at 53-56 (discussing best interests standard).


61. Newmark, 588 A.2d at 1120.
or no risk to the child's health, what should be the court's analysis?

Even if the Newmark court and others ultimately decided the cases correctly on their facts,62 the courts' failure to adequately resolve the tension between child protection and parental deference leaves the doctrine vulnerable to the extremes of deference that currently exist: too much deference to some parents and too little to others.

B. The Extremes of Deference

Extremes of deference are permitted to thrive because different kinds of medical treatments are considered under different legal doctrines, instead of being considered collectively as the exercise of moral authority to make health care decisions.

---

62. Not only is the utility of this principle severely limited by these unanswered questions, but the principle may not have been applied consistently in cancer cases reviewed by the Newmark court, where different results were reached in seemingly similar cases. Id. For example, in two cases in which a child had cancer, the parents sought to use the experimental treatment laetrile instead of conventional treatment. Laetrile is considered an alternative treatment that involves the injection of the drug amygdalin, which is the natural chemical compound found in apricots, peach pits, bitter almonds, and other similar plants. Custody of a Minor, 393 N.E.2d 836, 840 (Mass. 1979). Even though the treatments sought were the same and the children suffered from similar conditions, the courts reached different conclusions. See id. at 837, 846 (approving court order to administer chemotherapy despite parents' wishes to use laetrile treatment). But see Matter of Hofbauer, 393 N.E.2d 1009, 1014 (N.Y. 1979) (approving parental decision to use laetrile treatment). Commentators have noted this inconsistency. See Charles H. Baron, Medicine and Human Rights: Emerging Substantive Standards and Protections for Medical Decisionmaking Within the American Family, 17 Fam. L. Q. 1, 6-7 (1983) (explaining difference in courts' conclusions as product of "tension between concern for the welfare of the child and deference to the decision-making power of well-meaning parents"); Kathleen Knepper, Withholding Medical Treatment from Infants: When is it Child Neglect?, 33 U. LOUISVILLE J. FAM. L. 1, 7 (1995) (noting conflicting results reached by courts considering similar fact patterns).

A few differences between the cases did exist. In the case allowing alternative treatment, the parents expressed some open-mindedness to conventional treatment: the boy's father stated that he would be willing to allow the doctor to treat his son conventionally if the doctor believed that conventional means were necessary. Hofbauer, 393 N.E. 2d at 1012. Also, at least one doctor supported the parents' unconventional choice. Id. See also Baron, supra, at 7 (pointing out importance of "good faith cooperation" of parents); Elisabeth T. Davis, Note, Judicial Limitations on Parental Autonomy in the Medical Treatment of Minors, 59 Neb. L. Rev. 1093, 1123-25 (1980) (distinguishing Hofbauer case as including medical evidence that alternative treatment was effective); Felicia C. Strankman, Comment, Children's Medical Care in California: Conflicts Between Parent, Child, and State, 36 Santa Clara L. Rev. 899, 917-18 (1996) (stating parents must demonstrate alternative treatment proposed "is viable and has not been 'totally rejected' by the medical community"). One child suffered more severe side effects than the other. Compare Hofbauer, 393 N.E.2d at 1012 (noting minor side effects while allowing alternative treatment), with Custody of a Minor, 379 N.E.2d 1053, 1058 (Mass. 1978) (finding child's condition became significantly worse when parents switched from standard treatment to metabolic therapy). See also Strankman, supra, at 916-19 (reconciling cases based on differing harm to child and some evidence of acceptance of alternative treatment by medical community).

These facts did not justify different results, however. Both situations involved quality-of-life determinations that were best left to the parent.
1. Too Much Deference

The law has given parents greater deference than is warranted where mature minors' health care decisions are at issue. Two examples will be discussed: mature minors refusing life-sustaining treatment, and minors seeking abortions. In these cases, the courts have failed to respect the emerging autonomy of the minor patient, and have failed to recognize the reality of parent-child relationships. Instead, the courts have defaulted to a rights-based approach, presuming the parents have inherent authority to decide for the child, without adequate justification.

a. Mature Minors Refusing Life-Sustaining Treatment

In at least one case involving a mature minor refusing life-sustaining treatment, In re E.G., the court suggested that the parent deserved deference, even though no reasoned justification supported that suggestion. E.G. was seventeen years old and suffering from leukemia. Chemotherapy treatment required that she undergo blood transfusions. E.G., a Jehovah's Witness, refused blood transfusions as a tenet of her religion. Her mother, also a Jehovah's Witness, agreed with her daughter's refusal. Notwithstanding the evidence of E.G.'s maturity, the trial court found E.G. to be neglected and ordered the transfusion against her will. The Illinois Supreme Court reversed, finding no state interest that outweighed E.G.'s right to make her own medical decisions, even though death could result from the denial of treatment. The court considered four state interests: preserving life, protecting the interests of third parties, preventing suicide, and maintaining the ethical


64. 549 N.E.2d 322 (Ill. 1989).
65. E.G., 549 N.E.2d at 322.
66. Id. at 323.
67. Id.
68. Id.
69. Id.
70. Id. at 323.
71. Id. at 328. The intermediate appellate court had reached the same decision as the Illinois Supreme Court, but on different grounds. In re E.G., 515 N.E.2d 286, 291 (Ill. App. 1 Dist. 1987) (deciding on First Amendment freedom of religion grounds).
integrity of the medical profession.\textsuperscript{72}

Although the court found that none of these state interests outweighed E.G.'s autonomy right, the court also recognized her mother's interest as a third party. The court did not find that the interest was strong enough to override E.G.'s right because her mother agreed with her decision to refuse treatment.\textsuperscript{73} Simply by recognizing the mother's interest as a third party, the court deferred to the mother's parental authority more than was warranted. If the court's decision was based on E.G.'s ability to make her own decisions, as it purported to be, then the mother's wishes were irrelevant.

E.G.'s mother had no third-party interest based on a dependency on E.G.\textsuperscript{74} In previous cases involving adults, such a dependence interest had been asserted only when a parent wished to refuse treatment for herself and would end up essentially abandoning her children if she died.\textsuperscript{75} This interest did not override the parent's right to refuse treatment in most cases.\textsuperscript{76} In E.G., there was no evidence that E.G.'s mother was dependent upon her beyond normal family ties or that E.G.'s mother would have been effectively abandoned if E.G. refused treatment.\textsuperscript{77}

Moreover, E.G.'s mother could not base her interest on the assumption that "mother knows best" for her daughter, even if it might have been true. By finding E.G. capable of making her own medical decisions, the court recognized that E.G. possessed an autonomy interest deserving of respect.\textsuperscript{78} As such, the court should have treated her as an adult for purposes of health care decision-making, and found the interests of her mother irrelevant. By articulating a parental interest, even in dicta, the court denied the reality of a mature minor's competence and the reality of the parent-child relationship at this stage, in which the minor will consult with the parent if she wants, but ordinarily will make her own reasoned choices. Requiring the parents' involvement in medical decision-making denies the minor her burgeoning right of autonomy.

\textit{b. Minors Seeking Abortions}

The abortion context provides another example of parents receiving too

\textsuperscript{72} E.G., 549 N.E.2d at 328.

\textsuperscript{73} The court admitted that had "E.G. refused the transfusion against the wishes of her mother, then the court would have given serious consideration to her mother's desires." \textit{Id.}

\textsuperscript{74} \textit{Id.} E.G. was a minor and was not emancipated. \textit{Id.}

\textsuperscript{75} See, e.g., Wons v. Pub. Health Trust of Dade County, 500 So. 2d 679, 688 (Fla. Dist. Ct. App. 1987) (holding mother's refusal of blood transfusions due to religious beliefs would not result in abandonment of her children), \textit{aff'd}, 541 So. 2d 96 (Fla. 1989).

\textsuperscript{76} See Jennifer L. Rosato, \textit{The Ultimate Test of Autonomy: Should Minors Have a Right to Make Decisions Regarding Life-Sustaining Treatment?}, 49 Rutgers L. Rev. 1, 74-75 n.310 (1996) (noting cases where court held that parents did not abandon children by refusing life-sustaining treatment). See also supra notes 73-75 (discussing third-party interests).


\textsuperscript{78} \textit{In re E.G.}, 549 N.E.2d 322, 323 (Ill. 1989).
much deference when mature minors are involved. The abortion decision is arguably different than other kinds of health care decisions because it does not involve the provision of medical care for illness or injury, and because the right to have an abortion, even for a minor, is constitutionally protected.\textsuperscript{79} Notwithstanding these differences, the abortion decision is included under the broad rubric of “reproductive health care decisions” because it does involve the provision of services by a health care provider subject to the same set of ethical constraints as other procedures.\textsuperscript{80} Moreover, abortion law is sometimes considered an exception to the general rule that parents must consent to their children’s medical care,\textsuperscript{81} and has been used as a basis for extending the mature minor exception from abortion to other health care decisions.\textsuperscript{82}

The decisions of the United States Supreme Court that regulate minors seeking abortions show deference to parents without sufficient justification. The Court has considered it self-evident that parents should be involved in these decisions, without articulating a basis in reality or moral authority, consistent with its first articulation of the parental deference presumption in \textit{Parham}.\textsuperscript{83} The Court has perpetuated a romantic view of family relationships that ignores the reality of parent-child relations, particularly when the child is an adolescent capable of making this important decision on her own.

Mature minors possess an autonomy interest that should be respected, and the assumption that “parent knows best” is therefore not warranted. Such an assumption actually harms the minor’s autonomy interests, particularly when


\textsuperscript{81} See Rosato, supra note 76, at 29 (stating abortion is one medical procedure that is exception to parental consent requirement). Some limits on the minor’s ability to decide have been imposed by the states and upheld by the courts as constitutional. See \textit{Planned Parenthood}, 505 U.S. at 899 (upholding one-parent consent requirement for abortion).


minor and parent disagree. Most recently, the United States Supreme Court in *Planned Parenthood v. Casey* summarily deferred to parents when it upheld a law requiring a minor to obtain one parent's consent (or judicial approval) prior to getting an abortion. In *Casey*, the Court simply reaffirmed prior decisions that had permitted states to require parental consent or notice, as long as a means of judicial approval existed. The Court found implicitly that the parental consent provision imposed no undue burden on the minor's privacy rights.

Even though the *Casey* Court purportedly applied the same undue burden standard to pregnant girls and women, it in fact created a double standard. When the Court struck down the spousal consent provision in the same decision, it relied on empirical evidence regarding the dynamics of abusive relationships. In contrast, when it upheld the parental consent provision, the court ignored similar evidence about abused children and defaulted to its traditional views of adolescents and the parent-child relationship. The Court romanticized that this important health care decision would be made in an ideal family of open communication and shared values, rather than in real families of alienation.

85. *Casey*, 505 U.S. at 899.
88. *See Casey*, 505 U.S. at 887-94 (citing statistics and articles on battered women and spousal abuse). The joint opinion, authored by Justice O'Connor, struck down the spousal notification requirement of the statute. The opinion reviewed empirical evidence evidencing the likelihood of violence against women who sought spousal notification prior to obtaining an abortion. The Court considered not only physical abuse, but also emotional abuse, sexual assault, and abuse against children. *Id.* at 887-99.
89. The *Casey* opinion justified this distinction by stating that the minor abortion cases "are based on the quite reasonable assumption that minors will benefit from consultation with their parents and that children will often not realize that their parents have their best interests at heart." *Id.* at 895.
90. This assumption is not persuasive. A similar assumption could be made about married couples, yet the Court did consider the exceptional case of an abusive marriage in striking down the spousal notification provision, but did not do the same in considering the parental consent provision. *See id.* at 894-95 (considering small number of women who would not notify spouses about decision to abort). Commentators have recognized the double standard and urged a unitary standard of undue burden. Katz, *supra* note 87, at 1142. *See also* Leonard Berman, Note, Planned Parenthood v. Casey: *Supreme Neglect for Unemancipated Minors' Abortion Rights*, 37 HOW. L. J. 577, 586 (1994) (arguing Court's concern about "husband veto" could apply equally well to "parental veto").
90. *See Casey*, 505 U.S. at 985-90 (Scalia, J., concurring in part and dissenting in part) (presuming
mistrust, and violence. The Court had assumed that, if parents know about their daughter's pregnancy and her decision to terminate the pregnancy, they will provide her with valuable guidance and support. Such an assumption fails to acknowledge that many young women possess the competence to make these decisions on their own, and thus do not want or need parental assistance. The assumption also fails to consider the relationship that actually exists between some teenage girls and their parents. For example, a young woman may justifiably fear reprisals from one or both of her parents if she is required to tell them about her decision. This reality belies an atmosphere of guidance and open communication exists in families and minors will benefit from consultation with parents). See also Martha Minow, The Role of Families in Medical Decisions, 1991 UTAH L. REV. 1, 11-13 [hereinafter Minow, Families] (stating Court envisions "compassionate and helpful family" in abortion context).

91. See Council Report, Mandatory Parental Consent to Abortion, 269 JAMA 82, 83 (Jan. 6, 1993) [hereinafter Mandatory Parental Consent] (stating "[f]or some children . . . the home falls far short of this ideal and may be a place of physical abuse and neglect and psychological maltreatment"); Maggie O'Shaughnessy, The Worst of Both Worlds?: Parental Involvement Requirements and the Privacy Rights of Mature Minors, 57 OHIO ST. L.J. 1731, 1743 (1996) (declaring Supreme Court has ignored documented evidence of abuse occurring to pregnant teens); Berman, supra note 89, at 586-87, 590-94 (finding Casey Court acknowledged spousal abuse but ignored existence of child abuse).

92. See H.L. v. Matheson, 450 U.S. 398, 409 (1981) (noting parental consultation is often desirable and in best interests of minor) (citing Bellotti, 443 U.S. at 640-41); Hodgson v. Minnesota, 497 U.S. 417, 456, 485-86 (1990) (finding it reasonable to require parental notification); Developments, supra note 22, at 1381-82 (discussing Court's views of parental influence in child's life); O'Shaughnessy, supra note 91, at 1743 (arguing courts assume parents teach and guide children); Berman, supra note 89, at 588-89 (noting courts rely on long-standing assumption that parental consultation benefits minors). See also Planned Parenthood of the Blue Ridge v. Camblos, 155 F.3d 352, 367-72 (4th Cir. 1998) (en banc) (reiterating Supreme Court's view that it is beneficial for unmarried pregnant minor to seek advice of parents for this extremely important decision); Barnes v. Mississippi, 992 F.2d 1335, 1340 (5th Cir.) (stating "[i]t is both rational and fair for the State to conclude that, in most instances, the family will strive to give a lonely or even terrified minor advice that is both compassionate and mature") (citing Akron II, 497 U.S. at 520), cert. denied, 510 U.S. 976 (1993). A number of authorities have concluded that parental notice/consent statutes do not lead to the desired result—enhanced communication. See, e.g., American Academy of Pediatrics, The Adolescent's Right to Confidential Care When Considering Abortions, 97 PEDIATRICS 746, 747-48 (1996) [hereinafter Confidential Care] (discussing effect of abortion legislation on family communication); Margaret Crosby & Abigail English, Mandatory Parental Involvement/Judicial Bypass Laws: Do They Promote Adolescents' Health, 12 J. ADOLESCENT HEALTH 143, 145-46 (1991) (maintaining parental consent requirement not always in child's best interests); Rachael N. Pine, Speculation and Reality: The Role of Facts in Judicial Protection of Fundamental Rights, 136 U. PA. L. REV. 655, 691-92 (1988) (finding parental input into sexuality is characterized by severe discomfort).

93. See Confidential Care, supra note 92, at 748 (maintaining minors ages 14-17 are competent and understand risk involved to make rational decision); Mandatory Parental Consent, supra note 91, at 83 (promoting opinion that parental involvement should not be required). See generally Britner, supra note 34 (stating there is little evidence supporting assumption that parental consent is desirable).

94. See Developments, supra note 22, at 1376-77 (stating parental notification can "lead to serious psychological or even physical harm to the child"); Pine, supra note 92, at 683-84 (stating some minors fear abuse and/or fear revealing pregnancy will disrupt family harmony); Berman, supra note 89, at 600 (explaining minors declining to tell parent had experienced domestic violence and feared additional harm). See also Planned Parenthood v. Miller, 63 F.3d 1452, 1462 (8th Cir. 1995) (stating "studies show that a stressful, but non-abusive, parent-child relationship can become abusive or neglectful after the parents learn of the daughter's pregnancy or desire to have an abortion"), cert.
support, and thus fails to justify the parental deference presumption implicitly adopted by the Court.

The judicial bypass procedure provided by the state may not be an effective alternative to parental notice or consent because the young woman may be too intimidated by the process to use it.\textsuperscript{95} In addition, judges may decide cases in a manner that reflects their own anti-abortion biases or may decline to hear such petitions altogether.\textsuperscript{96} The delays created by the bypass procedure may make the abortion more traumatic.\textsuperscript{97} Some courts have found bypass procedures so burdensome that they interfere with a minor's right to privacy.\textsuperscript{98}

In sum, the previously-discussed cases involving mature minors illustrate one of the difficulties of an ad hoc decision-making approach rooted in a rights-based discourse: it permits courts (and legislatures) to defer to parents too readily. In other areas—such as denying treatment to premature or disabled

\textsuperscript{95} See Hodgson, 497 U.S. at 475-76 (finding judicial bypass process in Minnesota puts significant burden on minors); O'Shaughnessy, supra note 91, at 1734 (showing judicial bypass procedure exacerbates stress); Pine, supra note 92, at 680-81 (arguing judicial bypass procedure produced fear and tension in minors); Veith, supra note 87, at 461 (showing judicial bypass process places burdens on minors).

\textsuperscript{96} See Helena Silverstein, Road Closed: Evaluating the Judicial Bypass Provision of the Pennsylvania Abortion Control Act, 24 L. & SO. INQUIRY 73, 87-88 (1999) (recounting conversation where judge told purported minor he would not hear her bypass petition). See also Scarneccia & Field, supra note 11, at 83 (noting "[b]road discretion . . . opens the door to the conscious or unconscious expression of . . . personal beliefs by the judge"). See generally id. (proposing framework to minimize personal discretion in judicial decision-making for minors seeking abortions).

\textsuperscript{97} See, e.g., Berman, supra note 89, at 594-98 (discussing, through anecdotal evidence, "harmful effects" of delays in judicial bypass process); Confidential Care, supra note 92, at 750 (detailing medical and psychological health risks caused by delays in judicial bypass process); O'Shaughnessy, supra note 91, at 1760-63 (indicating judicial bypass procedure results in increased medical risks due to delays); Pine, supra note 92, at 677-87 (discussing Hodgson case to show that delays in judicial bypass procedure endangers adolescents' medical and psychological well-being). There is some evidence that bypass petitions are easily granted. See ROBERT H. MNOOKIN, IN THE INTEREST OF CHILDREN: ADVOCACY, REFORM AND PUBLIC POLICY 263 (1985) (suggesting judicial bypass process is rubber stamp procedure and no judges in Massachusetts have denied bypass petitioners request); O'Shaughnessy, supra note 91, at 1760-61 (providing opinion of judge that role in judicial bypass procedure was clerical). But see Scarneccia & Field, supra note 11, at 21 (discussing evidence that some judges unwilling to hear bypass petitions). Even if petitions were almost always granted, the minor's negative perception of the process still would be a realistic barrier to access.

\textsuperscript{98} See Planned Parenthood of S. Ariz. v. Lawall, 180 F.3d 1022, 1024 (9th Cir. 1999) (holding statute's lack of specific time limits to expedite minor's judicial bypass option unduly burdened rights of minor to abortion); Causeway Med. Suite v. Ieyoub, 109 F.3d 1096, 1099 (5th Cir.) (stating lack of specific time frame for judge to rule on minor's application for bypass in Louisiana rendered judicial bypass provision unconstitutional), cert. denied, 522 U.S. 943 (1997). But see Manning v. Hunt, 119 F.3d 255, 269-75 (4th Cir. 1997) (upholding constitutionality of bypass procedures); Planned Parenthood of the Blue Ridge v. Camblos, 155 F.3d 352, 372-84 (4th Cir. 1998) (upholding constitutionality of bypass procedures).
infants—the rights-based approach permits the opposite result of too little deference to parents.

2. Too Little Deference

As discussed previously, cases involving parental denial of life-sustaining treatment for a minor generally consider the child's best interests in the shadow of the parental deference presumption. The law does not so readily defer to parents, however, when parents seek to deny similar treatment to disabled or premature infants. In this context, the parents' decisions are distrusted, and thus the parents are denied the ability to make important decisions on an infant's behalf. This result is unjustified because, if decision-making authority were inherent in parenthood, as the rights-based discourse presumes, these parents deserve as much deference as any other parents.

The rights-based law affecting disabled and premature infants is indirectly governed by federal law. Congress conditions its funding for state abuse/neglect programs upon the state's compliance with federal regulations promulgated pursuant to a federal child abuse statute. Under the statute and implementing regulations, physicians must provide adequate medical care, and the withholding of "medically indicated treatment from disabled infants with a life-threatening condition" constitutes medical neglect. There are only three narrow exceptions to this treatment requirement: (1) the treatment would be


On the other hand, some other observers criticize the exceptions for being too vague and, as a result, the exceptions can be construed broadly by physicians and parents when they make these decisions. See Mary Crossley, Infants with Anencephaly, the ADA, and the Child Abuse Amendments,
futile;¹⁰⁶ (2) the child is comatose;¹⁰⁷ or (3) the treatment would be virtually futile and inhumane.¹⁰⁸ "Appropriate" nutrition, hydration, and medication must be provided at all times, regardless of whether other types of treatment are lawfully withheld.¹⁰⁹ Although the statutory language permits physicians to make "reasonable medical judgments,"¹¹⁰ the language and the spirit of the regulations seem to severely circumscribe medical discretion.¹¹¹

The federal standards are designed to prevent inquiry into the infant's quality of life,¹¹² because the right to life, regardless of quality, is considered paramount.¹¹³ The emphasis on a right to life is not surprising, considering the history of the regulations: they were encouraged by members of the pro-life movement, who influenced the Reagan Administration to pass these regulations.¹¹⁴

¹¹ Issues in L. & Med. 379, 394 (1996) (arguing that several terms leave "wiggle room"); Knepper, supra note 62, at 27 (noting inconsistency arises from courts reaching different results); Smith, supra note 28, at 807-09, 820 (suggesting exceptions should be more carefully defined); Bonnie P. Tucker, The U.S. Civil Rights Commission Report, "Medical Discrimination Against Children with Disabilities": A Brief Commentary, 6 Issues in L. & Med. 269, 279-80 (1990) (noting commission finding that terms are subject to differing interpretations).

¹⁰⁶ 42 U.S.C. § 5106g(6)(B) (1994) (creating exception where treatment would "(i) merely prolong dying; (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or (iii) otherwise be futile in terms of the survival of the infant . . . .")


¹¹¹ See Merrick, supra note 105, at 207 (stating physicians' authority is reduced because "they must act within the confines of the child abuse legislation" or be criminally charged); Newman, supra note 105, at 4-5 (explaining "[t]he physician is not free to allow considerations of suffering, medical ethics and burdens of treatment to enter into his 'reasonable medical judgment'"); Patricia M. Phillips, Comment, Treatment Decisions for Seriously Ill Newborns: Who Should Decide?, 21 Cap. U. L. Rev. 919, 954 (1992) (arguing "[m]any physicians have construed this legislation to require relentless, aggressive treatment, no matter how small or sick the infant").

¹¹² See Haddon, supra note 11, at 612 (discussing decisions about neonates); Knepper, supra note 62, at 38 (pointing out courts ignore quality of life); Merrick, supra note 105, at 200, 207 (explaining quality of life was ruled out); Curry, supra note 105, at 648 (stating adopted standard does not acknowledge quality of life); Stokley, supra note 105, at 137, 139-40 (explaining exceptions are construed too narrowly). But see Rhoden, supra note 105, at 1313 (stating statute implicitly requires quality-of-life determinations).

¹¹³ See Clark, supra note 105, at 17-18 (discussing constitutional guarantee of right to life); Cooper, supra note 108, at 334 (noting importance right to life plays); Haddon, supra note 11, at 599 (explaining right to life is unquestioned state interest); Schneider, supra note 9, at 175 (maintaining life considerations are important); Smith, supra note 28, at 781 (discussing right to life for disabled newborns); Curry, supra note 105, at 633-34 (explaining "sanctity of life" approach); Stokley, supra note 105, at 148 (noting preservation of life is important state interest).

¹¹⁴ See Curry, supra note 105, at 639, 641 (discussing President Reagan's platform to respect human life); Phillips, supra note 111, at 922 (detailing Reagan Administration's efforts to enforce Rehabilitation Act of 1973 against health care providers who failed to provide medical care for severely ill handicapped persons); Stokley, supra note 105, at 134-36 (explaining Reagan
Parents of disabled or premature infants were singled out by these regulations, presumably because these parents were considered inherently conflicted and unable to make decisions in their child’s best interests. Following the report of a Down’s Syndrome infant whose parents denied him a life-saving operation,\textsuperscript{115} it was perceived that the denial of treatment for disabled infants was widespread and needed to be curbed.\textsuperscript{116} Parents of these infants were deemed incapable of making sound decisions on behalf of their children, because they were too emotional to decide; they were biased against their handicapped child; or they were overburdened by the physical energy and money required to raise such a child.\textsuperscript{117}

In these cases, parental rights do not even cast a short shadow on the child’s administration’s concerns). Interestingly, the right to life movement was joined by advocates of the handicapped in supporting this legislation. See Haddon, \textit{supra} note 11, at 579-80, 584-85 (discussing support from handicapped community).

115. Specifically, the parents refused to consent to an operation to correct an esophageal defect, a correctable condition. See, e.g., James Bopp, Jr. & Thomas J. Balch, \textit{The Child Abuse Amendments of 1984 and their Implementing Regulations: A Summary}, \textit{1 Issues In Law & Med.} 91, 95 (1985) (describing infant’s condition and parents’ refusal to consent to corrective surgery); Clark, \textit{supra} note 105, at 5-6 (describing considerable government activity generated by Baby Doe case); Haddon, \textit{supra} note 11, at 573-74 (stating case drew “heated response” from handicapped advocates and right to life groups who pushed for political action); Smith, \textit{supra} note 28, at 789 (discussing correctable nature of defect and parents’ failure to consent to surgery). Commentators have discussed the significance of the Baby Doe decision. See, e.g., Crossley, \textit{supra} note 105, at 381 (stating Baby Doe’s death was catalyst for government legislation); Cooper, \textit{supra} note 108, at 353 (discussing public outcry and reaction of Congress); Merrick, \textit{supra} note 105, at 194-95 (dubbing death of Baby Doe “perhaps the most significant event” in debate over treatment of disabled infants); Rhoden, \textit{supra} note 105, at 1284-85 (explaining that when Indiana state courts refused to intervene and Baby Doe died, hosts of commentators denounced decision); Smith, \textit{supra} note 28, at 789 (stating Baby Doe case led to numerous state actions); Curry, \textit{supra} note 105, at 632-39 (explaining how “[t]he death of Baby Doe was the catalyst for a society-wide controversy over decisions regarding the fate of severely compromised newborns”).

116. This perception was fueled by a study published by two physicians at Yale University showing that some doctors favored withholding treatment from Down’s Syndrome infants who had other life-threatening, but correctable, defects. Raymond S. Duff & A.G.M. Campbell, \textit{Moral and Ethical Dilemmas in the Special-Care Nursery}, 289 \textit{New Eng. J. Med.} 890, 892-93 (1973). For a discussion of this study, see Clark, \textit{supra} note 105, at 5, 8 (describing significance of study as first to question common practice); Haddon, \textit{supra} note 11, at 572-73 (describing political response to study); Merrick, \textit{supra} note 105, at 194-95 (outlining primary assertions of study and ensuing controversy).

117. See Cooper, \textit{supra} note 108, at 338-41 (using emotional state as basis for finding parents incapable of making sound decisions); Leslie P. Francis, \textit{The Roles of the Family in Making Health Care Decisions for Incompetent Patients}, 1992 \textit{Utah L. Rev.} 861, 862 (stating shock of disabled newborn compounded by mother’s weakened physical condition may impair some decision-makers); Haddon, \textit{supra} note 11, at 547 (stating parents’ reasoning influenced by emotional and financial considerations); Knepper, \textit{supra} note 62, at 31-32 (describing parents as too emotional and lacking knowledge about child’s handicap); Newman, \textit{supra} note 105, at 52-53 (suggesting financial burden influences parents’ decision); Smith, \textit{supra} note 28, at 766, 785 (describing emotional state as reason to reject parents’ decision); Stokley, \textit{supra} note 105, at 146-47, 151 (stating parents’ decisions depend on emotional and financial factors). See generally Schneider, \textit{supra} note 9, at 159-60 (discussing parents’ inabilitys to care for defective child). Professor Haddon points to legislative history illustrating that the intent of the statute was to protect parents who were often distraught and incapable of rational, infant-focused judgments during their time of grief. Haddon, \textit{supra} note 11, at 585.
interests. Giving parents of disabled or premature children so little deference is unjustified and is inconsistent with the deference generally given to other parents making health care decisions on behalf of their children. Once again, the law seems to ignore the realities of parent-child relationships in determining the parents' moral authority to make these decisions. There is insufficient evidence to support a presumption that parents of disabled or premature neonates are perse unlikely to make decisions in furtherance of their child's best interests. These parents deserve as much deference as other parents who are consenting to or refusing treatment for their children.

There are a number of reasons why the same degree of deference for these parents is justified. First, the initial presumption about the unfitness of parents with neonates was based on reports in which widespread media coverage may have exaggerated the actual scope of the problem.

Second, it is unfair to continue to presume that all parents of premature or disabled infants are inherently conflicted, without evidence to support the conclusion. At this time, the widespread use of prenatal testing enables parents to prepare emotionally and financially for the special needs of a handicapped child. The prognosis for neonates, particularly low birth-weight babies, continues to improve. Parents may become attached to the child regardless of

---

118. See supra notes 46-61 and accompanying text for a discussion of the Newmark case which acknowledged, then largely ignored, parental rights.

119. Haddon, supra note 11, at 600. Professor Haddon argues that, in this "gray area," parents should be allowed to make these decisions until sufficient data is accumulated to show that parents cannot appropriately make these decisions. Id. at 593, 600-05.

120. See American Academy of Pediatrics, Ethics and the Care of Critically Ill Infants and Children, 98 PEDIATRICS 149, 150 (July 1996) [hereinafter AAP, Critically Ill] (supporting parental involvement in medical care decision-making for imperiled infants).

121. Id. Cf. SHERMAN ELIAS & GEORGE J. ANNANs, REPRODUCTIVE GENETICS AND THE LAW 178 (1987) (stating "Amendments appear more a solution to a political problem than to a real world medical one"); George J. Annas, "The Right to Die" in America: Sloganeering from Quinlan to Cruzan to Quill and Kevorkian, 34 DUQ. L. REV. 875, 886 (1996) (stating in numerous cases that were investigated pursuant to Baby Doe regulations, government officials were able to find none where infant was discriminatorily being denied food or customary medical care).

122. See TRACIE HOTCHNER, PREGNANCY & CHILDBIRTH 26-35 (1997) (explaining numerous tests are available for expectant mothers to identify problems early in pregnancy so that "appropriate steps can be taken"). Among the many screening tests available to give information of a woman's risk of having a baby with birth defects are ultrasound, amniocentesis, chorionic villus sampling, and maternal serum screening tests. See, e.g., AMER. COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, PLANNING FOR PREGNANCY, BIRTH AND BEYOND 53, 79-87 (2d ed. 1995) (describing screening tests); CLARK GILLESPIE, M.D., YOUR PREGNANCY MONTH BY MONTH 277-99 (1998); ARLENE EISENBERG et al., WHAT TO EXPECT WHEN YOU'RE EXPECTING 44-51 (1996) (describing several tests for expectant mothers); Clark, supra note 105, at 41 (discussing growing number of pregnant women aware of high-risk status prior to fetus viability). These tests can detect serious debilitating conditions such as Down's Syndrome and spina bifida, but cannot detect many other conditions such as cerebral palsy.

123. See Douglas K. Richardson, et al., Declining Severity Adjusted Mortality: Evidence of Improving Neonatal Intensive Care, 102 PEDIATRICS 893, 896-99 (Oct. 1998) (explaining survivability and weight of low birth-weight babies continues to improve, although many smaller babies remain severely impaired); Mary A. Rutherford, Long-Term Outcomes of Preterm Infants, in PRETERM
his or her condition, before birth or after.\textsuperscript{124} Also, discrimination towards handicapped persons is less tolerated by society,\textsuperscript{125} and thus there is less reason for parents to believe that their child's life is hopeless merely because he is handicapped. This is particularly true for children with Down's Syndrome.\textsuperscript{126}

Moreover, burdens on parents of handicapped infants may be alleviated in a number of ways. The financial burdens of a premature or handicapped child\textsuperscript{127} may be alleviated by health insurance and other supportive services. There are a number of support groups to nurture parents through the unique challenges that they will face.\textsuperscript{128}

It is also unlikely that the regulations are needed to prevent doctors from colluding with parents to deny treatment for an infant. Doctors understand that their obligation is to assist the parents in making an informed decision, and not to make the decisions for them. The doctors' twin desires to value life\textsuperscript{129} and to avoid liability\textsuperscript{130} cause them to err in favor of providing treatment.\textsuperscript{131}

\textsuperscript{124} See Marshall H. Klaus et al., Bonding: Building the Foundations of Secure Attachment and Independence 128-87 (1995) (discussing bonding process between parents and premature or handicapped infants). In particular, the authors discuss the stages that parents of handicapped infants must work through to permit a healthy bond to develop. \textit{Id.} at 172-75.

\textsuperscript{125} One indication of the lack of tolerance for discrimination in society is the promulgation of the Americans with Disabilities Act ("ADA"), which was passed in 1990 to guarantee the disabled rights against discrimination by a private employer, private health service provider, or private facility with public access. See 42 U.S.C.A. § 12101 (West 1995) (stating ADA's findings and purpose); Rosemary E. Mahoney & Allan Gibofsky, \textit{The Americans with Disabilities Act of 1990}, 13 J. LEGAL MED. 51, 53-55 (1992) (reviewing legislative history of ADA).


\textsuperscript{127} The costs of caring for special-needs children, such as neonates, is significant. See Knepper, \textit{supra} note 62, at 23 (stating cost of neonatal care is among highest in medicine); Merrick, \textit{supra} note 105, at 161 (discussing high cost of caring for low birth-weight babies). \textit{See also} Jeffrey W. Stolz & Marie C. McCormick, \textit{Restricting Access to Neonatal Intensive Care: Effect on Mortality and Economic Savings}, 101 PEDIATRICS 344, 345 (Mar. 1998) (estimating total NICU costs are \$93,800 per surviving infant with additional medical and special education costs incurred throughout childhood).

\textsuperscript{128} Support groups include: Alaska Chapter, National Down's Syndrome Congress; Chesapeake Down's Syndrome Parent's Group, Inc.; Down's Syndrome Parent Support Group of Genesee County; Down's Syndrome Parents Network; Fort Wayne Parent Support Group for Down's Syndrome; Families Exploring Down's Syndrome; Riverbend Down's Syndrome Parent Support Group; Whidbey Island Down's Syndrome Parent's Organization; Spina Bifida Association of America; Spina Bifida Association of Central Ohio; Spina Bifida Association of Greater New Orleans; Spina Bifida Group of NSW.

\textsuperscript{129} See Rosato, \textit{supra} note 76, at 80 n.330 (citing AM. ASS'N COUNCIL ON ETHICAL & JUD. AFFS., 2 CODE OF MEDICAL ETHICS REPORTS 51 (1991), AM. MED. ASS'N COUNCIL ON ETHICAL & JUD. AFFS., CODE OF MEDICAL ETHICS (1996-1997), and AM. MED. ASS'N, THE BOARD OF TRUSTEES REPORT 59 (A-96) (1996)).

\textsuperscript{130} Liability may include criminal liability and common law tort liability (e.g., malpractice). \textit{See} 2 MEISEL, \textit{supra} note 63, § 16.27, at 341 (stating statutes enacted to protect children impose criminal penalties for noncompliance). \textit{See generally} Clark, \textit{supra} note 105, at 8-9, 42 (discussing doctors' fear
Overall, children's health care decision-making is governed by separate doctrines that attempt to resolve the tension between protecting children and deferring to parents. The approach is unprincipled and leads to too much deference in some cases, too little in others. Moreover, many of these cases are decided in an inappropriate context—the context of an abuse or neglect adjudication.

C. A Lack of Competence

Most cases involving parents' denial of medical treatment are treated as ordinary medical neglect cases.\textsuperscript{132} The parents' denial of treatment is brought to the attention of the local child protective services office (usually by a health care provider), and an action then is brought in family court or its equivalent to determine whether the child has been neglected.\textsuperscript{133} A finding of neglect usually

\begin{footnotesize}
\footnotesize
\textsuperscript{131} Denying parents the ability to make health care decisions for their neonates may create other problems. The most significant problem is the possibility of over-treatment, as parents or doctors push for treatment that only will prolong the child's suffering. See Clark, supra note 105, at 8-9 (discussing physicians' preference for more treatment when facing concern over legal matters); AAP, Critically Ill, supra note 120, at 149 (suggesting attention on saving lives may have resulted in overuse of life-sustaining treatment). Parents who over-treat, like parents who refuse treatment, may possess conflicts of interest that prevent them from looking out for the child's interests. As such, over-treating parents also should be vulnerable to a finding of abuse or neglect.

\footnotesuperscript{132} See JAMES M. MORRISSEY ET AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS 96 (1986) (stating states consider withholding of necessary medical treatment as abuse or neglect). See also Francis, supra note 117, at 888 (stating some state statutes "define child abuse or neglect generally to include the failure to provide needed medical care" despite case law allowing termination of treatment for terminally ill children); Ann MacLean Massie, Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide, 35 ARIZ. L. REV. 173, 193 (1993) (questioning application of abuse and neglect statutes to life-sustaining treatment cases); Newman, supra note 105, at 13 (discussing application of abuse and neglect statutes to medical decision-making cases). For examples of neglect cases brought to court on account of the parents' denial of medical treatment, see, e.g., In re Eric B., 235 Cal. Rptr. 22, 28-29 (Cal. App. 1987) (affirming trial court's order finding child dependent whose parents refused to consent to chemotherapy and only wished to provide Christian Science treatment); Newmark, 588 A.2d at 1114 (finding boy not neglected when parents refused to consent to chemotherapy because treatment had only 40% chance of success); In re Faridah, 579 N.Y.S.2d 377, 378 (N.Y. App. Div. 1992) (finding girl medically neglected by mother who refused to consent to bladder augmentation surgery); In re Willmann, 493 N.E.2d 1380, 1387 (Ohio Ct. App. 1986) (holding parents' refusal for religious reasons to allow further medical treatment for sick child was sufficient to support finding that child was dependent). Cases involving children in a persistent vegetative state are treated differently under the law. See infra Part III.D for a discussion of persistent vegetative state cases.

\footnotesuperscript{133} See COLO. REV. STAT. § 19-3-102 (1998) (stating child is neglected if "a parent . . . fails or refuses to provide the child with proper or necessary . . . medical care"); FLA. STAT. ANN. § 39.01(46) (West 1998) (providing "neglect occurs when the parent or legal custodian of a child . . . deprives a child of . . . medical treatment"); 750 ILL. COMP. STAT. 50/1 (West 1998) (stating neglected child is "any child whose parent . . . withholds or denies . . . medically indicated treatment"). See generally DONALD T. KRAMER, LEGAL RIGHTS OF CHILDREN § 16.10 (2d ed. 1994 & Supp. 1998) (stating medical neglect also "phrased as a failure to provide necessary, proper, or adequate health care").

In some states, terms other than "neglect" are used. See ALA. CODE § 12-15-30(a) (1998) (using "delinquent, dependent or in need of supervision" in definition); DEL. CODE ANN. tit. 31, § 304 (1998)
\end{footnotesize}
necessitates an order of treatment.\textsuperscript{134} If treatment is ordered, a guardian may be appointed to ensure that the ordered treatment has been administered.\textsuperscript{135}

Medical neglect is simply an inappropriate paradigm for determining decision-making authority. Although the parents’ conduct arguably satisfies the broad statutory language defining neglect,\textsuperscript{136} it does not satisfy the normative definition of neglect that underlies these statutes. The prototypical parent in these denial-of-treatment cases is a parent who denies treatment to the child in good faith, in order to adhere to the dictates of the parent’s or child’s religion, or to reduce the child’s suffering.\textsuperscript{137} This image stands in contrast to the prototypical “neglectful” parent, whose omissions violate the social consensus of good parenting and thus warrant state intervention under the traditional neglect statutes.\textsuperscript{138} As one commentator cogently stated: “The neglectful parent ignores

\textsuperscript{134} See Thomas A. Jacobs, Children and the Law, Rights & Obligations § 2:22, at 40-41 (1995 & Supp. 1998) (stating court will order treatment if neglect is found); Kramer, supra note 133, at 43 (stating “[i]f there is even a remote chance of saving a child’s life through judicial intervention, courts can usually be expected to take jurisdiction and order the necessary care); Massie, supra note 132, at 188, 193 (suggesting “[a]ll states include medical neglect as grounds for state intervention in their child abuse statutes, and a finding of neglect is the common predicate for ordering medical care for a minor over parental objection, even when that objection is religiously based”).

\textsuperscript{135} See, e.g., Willmann, 493 N.E.2d at 1382, 1390 (finding minor child to be dependent and placing child in temporary custody of hospital for medical treatment); In re Hamilton, 657 S.W.2d 425, 429 (Tenn. Ct. App. 1993) (designating Director of Offices of Human Services as child’s guardian to consent to necessary treatment); Winchester Dep’t. of Soc. Servs. v. Roberts, 1992 WL 884504, at *3 (Va. Cir. Ct., Feb. 15, 1992) (finding two-year old child with ventricular septal defect neglected and placing child in custody of Department of Social Services because child’s parents objected to surgery). See generally Kramer, supra note 133, § 16.10, at 43-44 (discussing court-ordered treatment); Knepper, supra note 62, at 1-2, 36 (stating “juvenile court may intervene and appoint a guardian for the child and direct the guardian to assure that the child gets the medical care”); Sher, supra note 80, at 158 (explaining “court may give legal and, if necessary, physical custody to the state agency for as long as necessary to administer the approved medical care”). A change in physical custody, however, usually is not involved.

\textsuperscript{136} See supra note 43 and accompanying text for a discussion of abuse and neglect statutes.

\textsuperscript{137} See, e.g., J.V. v. State, 516 So. 2d 1133, 1134 (Fla. Dist. Ct. App. 1987) (deciding not to pursue traditional medical treatment based on religious beliefs); People v. Labrenz, 104 N.E.2d, 769, 774 (Ill.) (explaining parents simply were acting on sincerity of religious beliefs), cert. denied, 344 U.S. 824 (1952); In re Hofbauer, 393 N.E.2d 1009, 1012-13 (N.Y. 1979) (stating parents had “serious and justifiable concerns about deleterious effects of radiation treatments and chemotherapy”); Willmann, 493 N.E.2d at 1386-87 (stating parents refused to continue treatment because of religious beliefs and chemotherapy was painful and not definite cure); In re Cabrera, 552 A.2d 1114, 1115-16, 1119-20 (Pa. Super. 1989) (explaining child’s mother objected to transfusion based on religious grounds and fear of medical treatment); Hamilton, 657 S.W.2d at 427-28 (explaining father opposed chemotherapy because of religion and because it would make daughter sick and treatment could not guarantee cure); Knepper, supra note 62, at 2, 3 (stating “parents’ unwillingness to consent to this medical treatment may be based upon the parents’ religious beliefs or upon other reasons”). See generally supra note 19 for additional cases where courts acknowledged parents’ beliefs.

\textsuperscript{138} See Newman, supra note 105, at 13-14 (explaining most denial of care situations do not
the basic needs of his child: harm results from and is attributable to the parent's heedless, uncaring behavior.\textsuperscript{139}

It is difficult to categorize most parents who deny treatment as "heedless, uncaring" parents. To the contrary, they are generally considered well-meaning and acting in good faith.\textsuperscript{140} Most of them care for their child's basic needs, and do not deserve the stigma that a finding of "neglect" entails. It does not matter that the finding theoretically results in an adjudication of the child's status rather than of the parent's liability: in both situations, the parent is still adversely affected by the decision.\textsuperscript{141}

The fundamental question posed in these denial of treatment cases is not whether the child has been neglected, but whether the parents possess the moral authority to make these decisions on their children's behalf.\textsuperscript{142} Determining moral authority requires an understanding of complex issues, such as the value and quality of the child's life,\textsuperscript{143} which are beyond the scope of a typical abuse or neglect case. Neglect or abuse standards embody a basic level of care below which society will not tolerate, rather than an aspirational level that all parents should strive to achieve. As stated by Professor Stephen Newman, "it seems beyond rational dispute that [abuse and neglect statutes] were never meant to deal with the medically complex and morally ambiguous problems of bioethics, involve true neglect). See also Knepper, supra note 62, at 41 (stating abuse implies malevolence and parents of handicapped infants do not satisfy this requirement). Cf. Janet L. Dolgin, The Law's Response to Parental Alcohol and "Crack" Abuse, 56 BROOK. L. REV. 1213, 1228, 1255 (1991) (stating legal system has historically labeled poor parents addicted to drugs and alcohol as "bad" parents guilty of neglect).

\textsuperscript{139} Newman, supra note 105, at 13.

\textsuperscript{140} See supra note 19 and accompanying text for an example of how courts characterize these parents.

\textsuperscript{141} See generally Sher, supra note 80, at 202 (stating neglect cases improperly stigmatize parents denying medical care to children).

\textsuperscript{142} The issue of the parents' moral authority has arisen most frequently in the neonate context. See Bopp & Balch, supra note 115, at 97-99 (discussing Baby Doe regulations); Haddon, supra note 11, at 546-47, 581, 594-98, 600-01 (discussing cases involving neonates); Newman, supra note 105, at 10 (discussing Infant Doe treatment dilemmas); Phillips, supra note 111, at 945-46 (discussing Infant Doe cases). It has also arisen in the context of child patients in a persistent vegetative state. See infra Part III.D for a discussion of persistent vegetative state cases.

\textsuperscript{143} See Kramer, supra note 133, § 16.10, at 44-45 (stating consideration of child's quality of life is major criteria in making decision); Kathleen M. Boozang, An Intimate Passing: Restoring the Role of Family and Religion in Dying, 58 U. PITT. L. REV. 549, 560-61, 565-72 (1997) (discussing difference between quality of life and sanctity of life principles used by caregivers and courts to make health care decisions); Rosato, supra note 76, at 14-15 (discussing right of mature minors to refuse medical treatment because minors would be denied personhood if forced to live unwanted quality of life).

morality, and law posed by [these dilemmas]."[144] These problems do not lend themselves to easy resolution, as they continue to perplex doctors, lawyers, and philosophers.[145]

A moral discourse is not entirely lacking in family law, although there is evidence that it has been eroding.[146] Professor Carl Schneider has articulated a number of reasons for this erosion, including the legal tradition of noninterference in parental rights.[147] He has concluded that courts are reluctant to deal with the moral dilemmas presented in the health care decision-making area, and consequently, courts interfere with parental decision-making only when physical or mental injury has resulted.[148] Just because parents satisfy a minimum level of conduct by not affirmatively harming the child does not mean they possess the higher moral authority to make a decision for the child.

Instead of incorrectly compartmentalizing these medical cases as abuse or neglect, the law should be more sensitive to the medico-ethical nature of these decisions and should strive for a more principled response to resolve these problems.[149] We should admit that judges, particularly family court judges, may be limited in their ability to make these kind of decisions within the constraints of the applicable substantive law.[150] Having made that admission, we must look

---

[144] Newman, supra note 105, at 14. The history of the promulgation of the Infant Doe regulations further illustrates the inappropriate “fit” between these problems and child abuse/neglect statutes. When President Reagan first sought to address the Infant Doe problem, he promulgated regulations pursuant to a federal statute prohibiting discrimination against handicapped persons. 48 Fed. Reg. § 9631 (1983); see 45 C.F.R. § 84.61 (1985) (considered denial of treatment violation of Rehabilitation Act). It was only when federal courts found these regulations improper that they were promulgated pursuant to the federal Child Abuse Act. See generally Clark, supra note 105, at 5-7 (discussing congressional response to court actions); Merrick, supra note 105, at 195-200 (discussing promulgation of congressional regulations).

[145] See, e.g., Boozang, supra note 143, at 616-17 (concluding law and medicine must recognize importance of patient’s family, religious faith, as well as qualitist and vitalist principles to reach correct solution to difficult decisions).


[147] Id. at 1835-39. In addition to the courts’ traditional noninterference in parental rights, Professor Schneider also examined other reasons for the erosion of moral discourse in family law. Specifically, he suggests that this trend toward a diminished moral discourse in family law is due to “the legal tradition of noninterference in the family, the ideology of liberal individualism, society’s changing moral views, and the rise of psychologic man.” Id. at 1833.

[148] Id. at 1815-16. Specifically, he states that the present trend is to intervene “specifically and narrowly so that the state may act only when the child suffers or risks severe physical or mental injury.” Id. (citations omitted). Thus, it lessens intervention on “moral” grounds.

[149] Other principled responses have been considered. See Smith, supra note 28, at 822-25 (finding federal law mandating medical treatment for neonates ineffective and proposing interdisciplinary teams to deal with complex medical-legal issues involved). Cf. Rhoden, supra note 105, at 1331-47 (urging quality-of-life determinations be made in considering whether child is neglected).

[150] See, e.g., Merrick, supra note 105, at 207 (suggesting courts are “poor arena for resolving disputes about medical care . . . because attorneys and judges are not adequately trained either in the clinical or ethical aspects of medicine” and decisions often must be made immediately); Newman, supra note 105, at 57-58 (arguing judges have no particular competence to make
beyond family law for guidance. The question then becomes what should replace this rights-based analysis.

II. BIOETHICS AND THE ROLE OF FAMILIES IN HEALTH CARE DECISION-MAKING

The discipline of bioethics—part medicine,\textsuperscript{151} part law,\textsuperscript{152} part philosophy,\textsuperscript{153} and part religion\textsuperscript{154}—deals with the moral issues of health care and medicine.\textsuperscript{155} The bioethics discourse asks difficult moral questions, and provides decision-makers with principles to guide them to answers. These principles have been applied in the context of family members making health care decisions for adult incompetent patients, such as a husband deciding for his wife, or a parent deciding for an adult child.\textsuperscript{156}


\textsuperscript{155} See H. TRISTAM ENGELHARDT, JR., THE FOUNDATIONS OF BIOETHICS 7, 11-12, 100-01 (1986) (discussing moral tensions and issues in bioethics). See also Pellegrino, supra note 153, at 1158-62 (examining conceptual framework of medical ethics); Wildes, supra note 151, at 1220-37 (discussing secular concerns when creating health care policy).

\textsuperscript{156} See, e.g., Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990) (parents/adult daughter); In re Drabick, 245 Cal. Rptr. 840 (Cal. Ct. App. 1988) (brother/sister); In re Longeway, 549 N.E.2d 292 (Ill. 1989) (daughter/mother); In re Jobes, 529 A.2d 434 (N.J. 1987) (husband/wife); In re Conroy, 486
The bioethics discourse does not ordinarily begin with the presumption that family members possess an inherent right to make these decisions by virtue of their status. Rather, the discipline searches for a principled justification for why families should be the preferred decision-makers. Families are treated with qualified deference, which reflects an understandable ambivalence towards them.\footnote{157} The doctrine of parental decision-making should be examined using a bioethics discourse to determine directions for changes in the law.

The bioethics discourse is more appropriate than the modified rights-based discourse currently used by the courts to determine when parents should make health care decisions for their children. Bioethics directly addresses the moral authority of medical decision-making, particularly the issues of who should possess the authority to make health care decisions for others, and what standard should be used to guide the proxy’s decision-making authority.\footnote{158}

This section outlines the general principles that guide the resolution of bioethics issues, principles that will provide the framework for the subsequent analysis.\footnote{159} It then discusses various authorities that have applied these principles in the context of family members making health care decisions for incompetent adult patients.\footnote{160} The consensus of these authorities is that family members deserve deference in making these decisions, unless they possess a conflict of interest.\footnote{161}

The premise of this Article is that parents deserve deference for essentially the same reasons as other family members.\footnote{162} Like other family members, limits on parental authority must be imposed to prevent conflicts of interest from interfering with the parents’ ability to make decisions in the child’s best interests.\footnote{163} This conclusion is not based on natural law, social fact, or constitutional entitlement, as in some of the parent-child cases previously discussed.\footnote{164} Rather, it is based on a sense of moral authority, considered in light

\footnotesize
\begin{itemize}
  \item A.2d 1209 (N.J. 1985) (nephew/aunt); \textit{In re Quinlan}, 355 A.2d 647 (N.J.), \textit{cert. denied}, 429 U.S. 922 (1976) (father/adult daughter). See also \textit{infra} notes 219-26 and accompanying text for a discussion of the application of bioethics principles in the family context.
  \item See \textit{infra} Part II.A for a discussion of the bioethics principalism approach.
  \item See \textit{infra} Part II.B for a review of family members serving as surrogate decision-makers.
  \item See \textit{infra} Part II.B.3 for a discussion of family decision-makers and the conflicts they may face.
  \item See \textit{infra} Parts III.A and B for a discussion of the reasons why parents deserve deference.
  \item See \textit{infra} Part III.C for a discussion of conflicts of interests in parental decision-making.
  \item See \textit{supra} Part I for a discussion of the existing law of parent-child decision-making.
\end{itemize}
of how families really are.  

A. Guiding Principles

Under mainstream bioethics theory, moral dilemmas are resolved using a principialism approach. This approach requires the application of well-established principles that are prima facie binding and that provide the decision-maker with direction for his or her actions and support the decision-maker's authority. The most widely accepted principles are autonomy, nonmaleficence, beneficence, and justice. Reaching a decision in a particular case using these principles requires considered judgment, but does not devolve into unfettered discretion. The decision-maker is limited to a rational process

---


Although principialism remains the primary framework for resolving bioethical dilemmas, it has been criticized extensively. See, e.g., Johnson, supra, at 1060-62 (criticizing principialism paradigm); Pellegrino, supra note 153, at 1159-61 (examining principialism period in medical ethics); Wildes, supra note 151, at 1231-33 (asserting principialism is foundational flaw in bioethics). Beauchamp and Childress have defended principialism against some of these critiques. See, e.g., BEAUCHAMP & CHILDRESS, supra note 152, at 106-08 (responding to criticism of principialism); Beauchamp, supra, at 961-70 (outlining nature of principle-based approach to ethics). Despite this criticism, principialism remains the mainstream approach to bioethics problems, and thus warrants its continued application.

167. See, e.g., BEAUCHAMP & CHILDRESS, supra note 152, at 32-37, 104-05 (discussing differences between prima facie and actual obligations). These principles are considered "middle-level principles," which exist somewhere between a cohesive moral theory and the resolution of a specific case. See Wildes, supra note 151, at 1232 (discussing Beauchamp's and Childress's theory).

168. See BEAUCHAMP & CHILDRESS, supra note 152, at 38, 120-394 (discussing principles seriatim). See also NANCY JECKER ET AL., BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS AND PRACTICE, 117-18 (1997) (examining models of ethical reasoning); Beauchamp, supra note 166, at 956 (explaining principle-based paradigm of biomedical ethics).

Other theorists have articulated taxonomies with similar guiding principles. See, e.g., ROBERT M. VEATCH, A THEORY OF MEDICAL ETHICS (1981) (considering principles including promise-keeping, beneficence, autonomy, truth-telling, avoiding killing, and justice in creating an ethical theory based on covenants).

169. See BEAUCHAMP & CHILDRESS, supra note 152, at 28-37, 105-08 (concluding no single principle can be used when deciding bioethical dilemmas). See also Beauchamp, supra note 166, at 956-57 (explaining principle-based paradigm of biomedical ethics).

This approach has been referred to as "reflective equilibrium," which is characteristic of the Rawlsian theory of justice. See BEAUCHAMP & CHILDRESS, supra note 152, at 20-23 (adopting features of John Rawls concept of reflective equilibrium to analysis of moral justification in bioethics); JECKER, supra note 168, at 123-24 (examining models of ethical reasoning); Beauchamp, supra note 166, at 959-61 (describing need for additional specifications of principles). This approach permits balancing of other moral considerations, where appropriate. See BEAUCHAMP & CHILDRESS, supra note 152, at 39 (defending use of several rules in addition to principialism when making bioethical
of specifying and balancing the principles against each other in the context of a particular case.\textsuperscript{170} Depending on the context, one principle may override the others.\textsuperscript{171}

Ordinarily, in the context of health care decision-making by family members, the resolution of a particular moral dilemma involves reconciling a conflict between the principles of autonomy and beneficence.\textsuperscript{172} The principle of autonomy values the patient’s ability to make medical decisions for him or herself, regardless of the result.\textsuperscript{173} Beneficence requires decision-makers to further the patient’s interests.\textsuperscript{174} Nonmaleficence is considered a principle apart from beneficence, as nonmaleficence requires the providers to “do no harm” and beneficence contains an affirmative admonition to “do good.”\textsuperscript{175} But because both principles essentially require that the benefits of treatment outweigh the burdens (a proportionality analysis), this Article considers both under the broad rubric of beneficence.\textsuperscript{176}

When the patient is competent, the principle of autonomy is often considered the overriding principle in the ethics of health care decision-making.\textsuperscript{177} Competence is commonly defined to mean that the patient

\textit{decisions). See also} Beuchamp, \textit{supra} note 166, at 959 (describing development of biomedical policies through principality and other moral considerations).

\textit{170. See} BEAUCHAMP \& CHILDRESS, \textit{supra} note 152, at 28-37 (discussing concepts used to solve bioethical dilemmas). \textit{See also} Beuchamp, \textit{supra} note 166, at 956, 957, 961 (explaining application of principles to biomedical ethics). \textit{Cf.} VEATCH, \textit{supra} note 168, at 291-323 (limiting discretion by lexical ordering of principles and applying moral rules).

\textit{171.} There is some disagreement whether all the principles are of equal weight, or whether one principle trumps the others. Beuchamp and Childress, who developed the principality approach, concluded that no one principle takes precedence over the others, although one may be considered stronger than another in a particular case. \textit{See} BEAUCHAMP \& CHILDRESS, \textit{supra} note 152, at 32-38 (explaining how to balance principles when making bioethical decisions). \textit{See also} Capron \& Michel, \textit{supra} note 151, at 28 \& n.11 (noting no principle is given unchallenged claim of priority). Other commentators, such as Veatch, have articulated a priority of principles. \textit{Veatch, supra} note 168, at 291-305 (suggesting nonconsequentialist principles outweigh consequentialist principles).


\textit{173. See generally} BEAUCHAMP \& CHILDRESS, \textit{supra} note 152, at 120-88 (discussing concept of autonomy).

\textit{174. See generally} AHRONHEIM, \textit{supra} note 172, at 13, 26-34 (defining patient's best interests); BEAUCHAMP \& CHILDRESS, \textit{supra} note 152, at 262 (discussing beneficence principles).

\textit{175. See, e.g.,} BEAUCHAMP \& CHILDRESS, \textit{supra} note 152, at 190-93, 262-63 (discussing difference between nonmaleficence and beneficence). \textit{See also} Linda Farber Post, \textit{Bioethical Considerations of Maternal-Fetal Issues}, 24 FORDHAM URB. L.J. 757, 760-61 (1997) (discussing difference between nonmaleficence and beneficence).

\textit{176.} Other authorities that have treated the beneficence and nonmaleficence principles similarly include AHRONHEIM, \textit{supra} note 172, at 13; ENGLEHARDT, \textit{supra} note 155, at 83, 96-97; Raanan Gillon, \textit{Physician-Assisted Suicide - Sympathy and Skepticism}, 75 U. DET. MERCY L. REV. 499, 507-08 (1998).

understands the risks and benefits of treatment and can make an informed decision to consent to or refuse treatment.\textsuperscript{178} A competent person possesses a right to refuse treatment unless it is outweighed by a strong state interest, such as the state's interests in preserving life, in protecting the rights of third parties, in protecting the integrity of the medical profession, or in preventing suicide. Although these state interests are still articulated by courts, they are almost never strong enough to override the patient's autonomy right.\textsuperscript{179}

If an adult patient is incompetent, the autonomy principle is not implicated, and a proxy must make a decision on her behalf.\textsuperscript{180} Because children are legally incompetent as a group, the consensus of existing authority is that autonomy is not implicated for any child.\textsuperscript{181} Using this reasoning, decision-making for children should be guided by beneficence, which is the overriding principle that governs proxy decision-making for other incompetent patients.\textsuperscript{182}

The fourth principle is that of justice, which is less developed than the other principles. The justice principle ordinarily is not directly implicated in the context of particular treatment decisions, as it usually addresses access to health care among various subpopulations and not access in a particular case.\textsuperscript{183}

\begin{flushright}
\begin{flushleft}
\textsuperscript{178} See 1 MEISEL, supra note 63, § 3.19, at 100 (proposing consensus that defines capacity to consent to treatment as ability to understand nature, extent, or probable consequences of treatment). Cf. Rosato, supra note 76, at 62-67 (articulating indicia of competence for minors refusing life-sustaining treatment).


\textsuperscript{180} See BEAUCHAMP & CHILDRESS, supra note 152, at 127-28, 170 (explaining autonomy principles should not be used for persons not able to act in autonomous manner). See also Jean K. Cipriani, Note, The Limits of the Autonomy Principle: Refusal of Life-Sustaining Medical Treatment for Incompetent Persons, 22 HOFSTRA L. REV. 703, 710-12 (1994) (distinguishing incompetent person's liberty and right to make decisions).

\textsuperscript{181} See BEAUCHAMP & CHILDRESS, supra note 152, at 273 (explaining paternalism of children remains widely accepted). A corollary of this principle is that the substituted judgment standard should not be used for children because they never possessed the competence to express their wishes. See Rosato, supra note 76, at 41 & n.170 (supporting use of best interests analysis for never-competent patient). Some courts have used the substituted judgment standard for children, even infants. See In re Barry, 445 So. 2d 365, 371 (Fla. App. Dist. Ct. 1984) (stating court must be guided by parents' judgment when judicial intervention for child is necessary).

\textsuperscript{182} See BEAUCHAMP & CHILDRESS, supra note 152, at 273 (discussing disputes regarding primacy of beneficence).

\textsuperscript{183} See, e.g., AHRONHEIM, supra note 172, at 34-37 (discussing justice consideration in medical resource allocations). See generally BEAUCHAMP & CHILDRESS, supra note 152, at 326-87 (discussing justice concept). But see Brock, supra note 11, at 6, 10-12 (discussing how proxy decision-making implicates distributive justice principle).
\end{flushleft}
\end{flushright}
Even when beneficence is the only principle implicated, the resolution of a particular case still may be difficult because each case poses a unique moral dilemma. In each case, the decision-maker must ascertain what care serves the patient's needs most effectively. It is a type of best interests standard that is analytically distinct from the best interests analysis articulated in the children's rights context. The bioethics analysis is more focused on the needs of the child-patient, more informed by moral considerations, and more sensitive to the realities of familial relationships. To satisfy beneficence, the decision-maker must not only "do good" in a general sense, but must do the particular "patient's" good.\textsuperscript{184} This task is made increasingly difficult when the patient has not articulated her desires clearly or at all,\textsuperscript{185} and when there is a lack of moral consensus over what constitutes a person's good in a pluralistic and secular society.\textsuperscript{186} Also, it is not clear whether beneficence should be evaluated from the individual patient's perspective or from that of a reasonable person in the patient's situation.\textsuperscript{187}

With these difficulties in mind, various authorities have grappled with the issue of the extent to which family members should be given deference when making medical decisions for incompetent adult patients. These authorities include courts, legislatures, professional organizations, and commentators. The consensus seems to be that families deserve a substantial degree of deference, but with some limitations to reflect the realities of existing relationships. Ultimately, these authorities presume that family members have authority to make health care decisions for the patient unless their ability to decide is impaired, such as when the family decision-maker possesses a conflict of

\textsuperscript{184} See ENGLEHARDT, supra note 155, at 66-101 (discussing tension contained in physicians' twin duties of preserving their patients' life and complying with their medical choices); EDWARD PELLEGRINO & DAVID THOMASMA, FOR THE PATIENT'S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE 76-83 (1988) (discussing various aspects of benefiting patient). See also Lynn E. Lebit, Note, Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine, 7 J.L. & HEALTH 107, 127-29 (1992) (discussing tension between the law's competing purposes of ensuring incompetent and minor patients receive needed medical services while still complying with those patients' medical wishes).

\textsuperscript{185} Even with a federal requirement to provide information to patients, most persons still have not made advance health care directives such as living wills. See, e.g., Boozang, supra note 143, at 559 n.42 (discussing study showing that people rarely execute living wills or advance directives). Furthermore, even those patients who have signed such directives lack adequate appreciation of the relevance of these documents. See, e.g., Schneider, supra note 157, at 844 (noting those patients with living wills and durable power of attorney often do not consider or understand the implications of these documents before signing them). Especially when the patient's desires are articulated orally, the applicability of these statements to the medical procedure sought to be administered may be unclear. See, e.g., In re Martin, 538 N.W.2d 399, 411-13 (Mich. 1995) (examining how much weight should be accorded to patient's oral statements), cert. denied, 516 U.S. 1113 (1996); In re O'Connor, 531 N.E.2d 607 (N.Y. 1988) (discussing problems with interpreting and applying patient's oral statements).

\textsuperscript{186} See Wildes, supra note 151, at 1223 (discussing search for secular bioethics).

\textsuperscript{187} See In re Conroy, 486 A.2d 1209, 1232-33 (N.J. 1985) (distinguishing between limited-objective and pure-objective standard for proxy decision-makers); BUCHANAN & BROCK, supra note 158, at 123-26 (distinguishing between quality of life to society and to patient); Griffith, supra note 11, at 304-07 (articulating several versions of best interests test).
interest.\textsuperscript{188}

The bioethics approach admits an ambivalence towards families.\textsuperscript{189} It takes into account that some families are sensitive, loving, and generous, while others are insensitive, uncaring, and even cruel.\textsuperscript{190} In applying this approach, the role of the law is to protect the family decision-maker to the extent she is able to further the patient's interests, and thus further beneficence.

B. Lessons About Family Decision-Makers

Traditionally, family members were trusted to make decisions for incompetent family members, with the consultation of the patient's doctor.\textsuperscript{191} Courts and ethics committees were not involved. A few courts had expressed the sentiment that a more detached decision-maker was necessary (especially for life-sustaining treatment decisions), and a judge became the logical choice.\textsuperscript{192} Most courts, legislatures, and commentators, however, have concluded that health care decisions should continue to involve family members, without court intervention in most circumstances.\textsuperscript{193}

Specifically, a review of this extensive literature reveals important lessons regarding the role of family decision-makers that further define beneficence when proxies make health care decisions for incompetent patients. The three most important lessons are: (1) family members do not possess an inherent right to decide for the patient; (2) deference to family members usually furthers beneficence; and (3) conflicts of interest provide a reasoned basis for interfering with family decision-makers.

\textsuperscript{188} See infra Part II.B.3 for a discussion of applicable conflicts of interest.

\textsuperscript{189} See supra note 157 and accompanying text for a discussion of ambivalence toward families.

\textsuperscript{190} See, e.g., Minow, \textit{State Intervention}, supra note 126, at 947-50, 974-75, 1001 (discussing alternative views of family as medical decision-maker). See also infra notes 195-209 and accompanying text for a discussion of the courts' views of families as decision-makers.

\textsuperscript{191} See, e.g., Stephen A. Newman, \textit{Treatment Refusals for the Critically and Terminally Ill: Proposed Rules for the Family, the Physician, and the State}, 3 N.Y.L. SCH. HUM. RTS. ANNUAL 35, 44-45 (1985) (justifying designation of family as decision-maker for critically and terminally ill incompetent patients). However, it was actually the doctors—not the patients or their families—who made the medical decisions. See, e.g., Haddon, supra note 11, at 552 (examining history of informed consent); Ardath A. Hamann, \textit{Family Surrogate Laws: A Necessary Supplement to Living Wills and Durable Powers of Attorney}, 38 VILL. L. REV. 103, 134 (1993) (stating "medical decisionmaking was exercised almost exclusively by the patient's personal physician" between the late 1950s to early 1960s).


\textsuperscript{193} See infra Part II.B.2 for a discussion of preference of families as medical decision-makers.
1. No Inherent Right to Decide

The first lesson is that family members do not possess an inherent right to decide for others. Instead, the most important question is whether the family member possesses the moral authority to make the decision. Where beneficence will not be served, the family member lacks moral authority and another decision-maker must exercise the choice in accordance with the patient’s interests.

Courts disagree regarding the extent to which family members are likely to further the patient’s interests. Some expect the best of families, while others expect the worst. For example, in *In re Quinlan*, the New Jersey Supreme Court expected the best and concluded that Karen Quinlan’s father deserved respect in making decisions for his daughter. In that case, the court permitted Karen’s father to act as her guardian and to authorize removal of her respirator. The court carefully reviewed the record, considering the evidence in the light most favorable to the family. The court did not seem to think that Mr. Quinlan was burdened by his child or that he was trying to serve his own religious values or emotional needs. Instead, the court found that the record revealed a “high degree of familial love,” which was reflected in the father’s thoughtfulness and his consultation with religious authorities. In approving him as a guardian, the court pointed to his high character; his sincere moral, ethical, and religious views; and “his strength of purpose and character.”

In contrast, the United States Supreme Court in *Cruzan v. Director, Missouri Department of Health*, expected the worst, and concluded that family members did not deserve deference in making life-sustaining treatment decisions for the patient. Nancy Cruzan’s parents sought the removal of artificial nutrition and hydration after an accident caused her to be in a persistent vegetative state. Although the Court noted that it did not doubt that Nancy’s parents were loving and caring, it suggested that a family member may lack sufficient love and care to protect the patient’s interests, and thus presumed family members should not be trusted to ascertain what the patient would have wanted. This mistrust justified the Court’s conclusion that the state could

---

194. See Brock, *supra* note 11, at 599 (addressing question of family member’s moral grounds).
197. *Id.* at 664.
198. *Id.* at 657-59, 671.
199. *Id.*
200. *Id.* at 657.
201. *Id.*
202. *Id.* at 671.
205. *Id.* at 265.
206. *Id.* at 286.
207. *Id.* at 286-87. See also John A. Robertson, *Cruzan and the Constitutional Status of*
require clear and convincing evidence of Nancy's intent to withdraw her nutrition/hydration without violating her constitutional rights.\footnote{Cruzan, 497 U.S. at 282.}

On its face, the \textit{Cruzan} opinion deals with the autonomy principle rather than beneficence because the Court was examining the family's ability to ascertain the patient's intent, i.e., could the family ascertain what the patient would have wanted if she had been competent? Although the Court's rationale appears limited to autonomy-related intent, it is also relevant to interpreting the limits of the beneficence principle. According to the Court in \textit{Cruzan}, the decision-maker's lack of love and care generally impairs his or her judgment, which may not only prevent him or her from knowing what the patient would have wanted, but also from being able to ascertain the patient's best interests.\footnote{Id. at 286-87.}

The fact that the \textit{Quinlan} court ultimately deferred to family members and the \textit{Cruzan} Court did not is less important than the manner in which the courts reached their decisions. Instead of relying on a rights-based discourse to determine a family member's claim of entitlement, both courts considered whether deference to the family would serve the patient's interests. By doing so, the courts faithfully attempted to apply the beneficence principle.\footnote{See Boozang, supra note 143, at 591-92 (noting many states enacted and liberalized living will laws following \textit{Cruzan} decision). See also Hamann, supra note 191, at 123 (explaining in response to \textit{Cruzan}, state legislatures looked to living wills and power of attorney statutes that applied to patients who made wishes known while competent).}

After the \textit{Cruzan} decision, this patient-focused perspective was translated into living will and health care proxy statutes that permitted a competent person to express her wishes in advance.\footnote{See Hamann, supra note 191, at 130-32 (stating state legislatures adopted surrogate decision-making statutes after realizing deficiencies in living will and health care proxy statutes). \textit{See generally} 2 Furrow, supra note 179, § 17-23, at 364-65 (pointing out states began to adopt "family consent" statutes because vast majority of Americans do not execute advance directives).} Other statutes were intended to apply to patients who had not executed any advance care directive before becoming incompetent or who were never competent.\footnote{See 2 Meisel, supra note 63, § 14.10, at 268, table 14-1 (listing surrogate decision-making statutes).} These statutes, commonly called surrogate decision-making statutes, have been adopted in over thirty states.\footnote{See Boozang, supra note 143, at 593 & n.248 (finding most statutes list hierarchy of proxy decision-makers).}

They generally provide that if the patient has not made any advance directive, a proxy will be chosen pursuant to the priorities set forth in the statutes.\footnote{Cindy Rushton and Elizabeth Hogue have concluded that the \textit{Cruzan} decision constitutes "a schizophrenic regard for families" that is "both isolating and destructive to the institution of family in our society." Cindy H. Rushton & Elizabeth E. Hogue, \textit{The Role of Families as Surrogate Decision-makers after Cruzan v. Director, Missouri Department of Health}, 7 J. CONTEMP. HEALTH L. & POL'Y 219, 223 (1991).} The patient-centered nature of these statutes accords with the beneficence

principle.214 The surrogates listed in the statutes are almost all family members.215 The statutory priorities also seem to reflect a sense that the family members who are likely to know the patient better are prioritized higher than other family members.216 For example, it is assumed that a patient’s spouse is closer and more knowledgeable than the patient’s adult child, and that an adult child is closer and more knowledgeable than the patient’s parent or sibling.217 Many of these surrogate decision-making statutes operate without any intervention by the court.218

In sum, the existing common law and statutory law dealing with family decision-makers has a locus that is not rights-oriented, but patient-oriented and reflective of the beneficence principle. This approach does not square with the law governing parent decision-makers, whose health care choices for their children are reviewed in the shadow of a parental deference presumption based in history and constitutional law.

2. Deference Serves Beneficence (Usually)

The second lesson is an extension of the first: family members should be given power to decide, not because of their inherent authority, but because giving such power directly furthers beneficence. Specifically, family members should be permitted to make health care decisions because they are better able to further the patient’s best interests or to determine what the patient would have wanted if she were competent. By supporting the patient in these ways, the

214. See 2 Furrow, supra note 179, § 17-23, at 368 (stating statutes formalize long-accepted practice of deferring to family members rooted in common sense). See also 2 Meisel, supra note 63, § 14.1, at 249-50 (arguing purpose of statutes is to clarify existing practice of using family members as surrogates). Cf. Boozang, supra note 143, at 592-93 (finding degree of restrictions placed on family members in statutes reflect concerns about dysfunctional families).


216. Beauchamp & Childress, supra note 152, at 245.

217. See Elena N. Cohen, Refusing and Forgoing Treatment, in 3 Treatise on Health Care Law § 18.04(1)(b)(i) (Michael G. MacDonald et al. eds., 1991) (explaining how most of surrogacy statutes prioritized list of surrogates that favor family members). See also 2 Meisel, supra note 63, § 14.4, at 253-54 (arguing focal point of surrogacy statutes is list of potential surrogates which tends to favor spouse, adult children, parents, and adult siblings); Boozang, supra note 143, at 593 n.248 (listing examples of statutes that include family members as preferred surrogates). Cf. Schneider, supra note 157, at 831 (explaining why certain core members of patient’s family such as spouse or parents are generally the preferred decision-makers).

218. See 2 Furrow, supra note 179, at 366 (arguing most statutes discourage surrogates from seeking judicial review and citing cases that illustrate reluctance of courts to adjudicate these matters).
family decision-maker possesses the moral authority to decide on the patient’s behalf.

Courts, commentators, and medical organizations have articulated various beneficence-oriented reasons for deferring to family members. Some courts do not expressly say that they are deferring to the family or explain why they should, but, in the end, implicitly defer.219 Other courts, such as the New Jersey Supreme Court, have expressly stated that families should be trusted because it is better for the patient.220 In In re Jobes,221 for example, the court concluded that families know best because they have the best “understanding of the patient’s medical attitudes and general world view” and are more concerned than others about the welfare of the patient.222 Families “treat the patient as a person, rather than as a symbol of a cause.”223 Based on this strong trust of families, the Jobes court permitted a husband to refuse life-sustaining nutrition for his wife, who was in a persistent vegetative state.224

Legal commentators and bioethicists also favor the family for beneficence-oriented reasons. First, families know the patient best: they have specific knowledge based on what the patient has communicated to them, and they have general knowledge of the patient’s experiences, values, and tolerance for pain.225

219. See, e.g., In re Drabick, 245 Cal. Rptr. 840, 841 (Cal. Ct. App. 1988) (authorizing patient’s brother to discontinue noncurative treatment); John F. Kennedy Mem’l Hosp. v. Bludworth, 452 So. 2d 921, 922 (Fla. 1984) (holding close family members wishing to exercise right to refuse treatment on behalf of competent patient may do so without judicially-appointed guardian); Brophy v. New England Sinai Hosp., 497 N.E.2d 626, 629 (Mass. 1986) (authorizing family to move incompetent patient to hospital that would honor request to remove life-sustaining treatment); In re Spring, 405 N.E.2d 115, 117-18 (Mass. 1980) (authorizing withholding of hemodialysis, relying in part on family’s opinion that patient would have wanted to discontinue treatment). See generally 1 MEISEL, supra note 63, § 5.18, at 200 n.159 (citing cases to support conclusion that courts assume family members to be best surrogate decision-makers); Boozang, supra note 143, at 551 n.5 (citing cases to support assertion that nearly every state’s law allows families to act as surrogate decision-makers).

220. See In re Jobes, 529 A.2d 434, 445 (N.J. 1987) (stating “[f]amily members are best qualified to make substitute judgments for incompetent patients not only because of their particular grasp of the patient’s approach to life, but also because of their special bonds with him or her”). See also Mack v. Mack, 618 A.2d 744, 769-75 (Md. 1993) (Chasanow, J., concurring and dissenting) (explaining why families are in best position to act as surrogate decision-makers for incompetent patients); In re Fiori, 673 A.2d 905, 912 (Pa. 1996) (holding “close family member is well-suited to the role of substitute decision maker”).

221. 529 A.2d 434 (N.J. 1987).

222. Jobes, 529 A.2d at 445.

223. Id. See also In re Farrell, 529 A.2d 404, 414 (N.J. 1987) (noting family members and friends care most and best for patient). See generally 1 MEISEL, supra note 63, § 5.18, at 199-204 (stating family members are and should be considered best surrogate decision-maker for incompetent patient).


225. See Hamann, supra note 191, at 164 (arguing family members know patient’s general life views and attitude towards medical care). See also Nancy K. Rhoden, Litigating Life and Death, 102 HARV. L. REV. 375, 437-38 (1988) (stating families are best decision-makers because they are more likely to have heard patient’s statements about medical treatment and have long-standing knowledge of patient); Splaine, supra note 179, at 931 (suggesting incompetents are best protected with family members as decision-makers because family members know each other better than others and have specific knowledge of patient’s views regarding medical treatment).
Second, families are the most concerned with the patient’s welfare, and this concern will motivate the family member to act more consistently in the patient’s best interests.226

Even medical organizations and committees have shown their respect for the family based on satisfying the patient’s best interests.227 For example, the American Medical Association’s Code of Medical Ethics provides that, when the patient has not executed an advance directive, family members should be designated as surrogate decision-makers.228 In 1983, the President’s Commission articulated five reasons to prefer family members, including their greater concern for the patient’s “good” and their greater knowledge “about the patient’s goals, preferences, and values.”229

Another interest sometimes articulated, the burden on the family, is not a morally justifiable reason to defer to the family because it is not beneficence-oriented.230 Proponents of this interest argue that considering such a burden is necessary because it is the family who must ultimately live with the health care decision.231 For example, a decision by a court or committee to continue nutrition for an elderly person in a persistent vegetative state carries financial and emotional burdens for her children. Such burdens, however, are not relevant to beneficence, which requires focusing directly on the patient’s interests, not the interests of others.232 Existing legal doctrine accords with this conclusion.233

226. See Yuen, supra note 192, at 603 (arguing families are most concerned about patient’s welfare and more apt than another party to serve patient’s best interests). See also Hamann, supra note 191, at 161 (explaining families generally exhibit most concern for patient’s welfare); Splaine, supra note 179, at 931 (stating family members usually provide most of patient’s care and show great concern for patient’s health and well-being).

227. See 1 MEISEL, supra note 63, § 5.10, at 174 (citing various medical sources to support proposition that reliance on incompetent patient’s family is routine and approved within medical community).


229. PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 128 (1983). See also 1 MEISEL, supra note 63, § 5.19, at 202-03 (quoting from President’s Commission study).

230. Considering the burden on the family also does not satisfy the bioethics principles of autonomy or justice.


232. See supra notes 174, 184 and accompanying text for a discussion of the beneficence principle.

233. See Mack v. Mack, 618 A.2d 744, 760 (Md. 1993) (refusing to change common law to consider interests or burdens of anyone other than patient); In re Jane Doe, 583 N.E.2d 1263, 1269 n.15 (Mass.) (stating trial court was correct in not considering whether incompetent’s continued care
Some commentators have questioned the conclusion that family decision-makers deserve deference, particularly since it has not been demonstrated that family members make the best decisions. Notwithstanding this lack of proof, a number of reasons justify continued deference. First, there is an intuitive sense (not yet proven) that families are better able to make these decisions. This sense manifests itself in a collective belief that families are better, and then the consensus becomes a sociological fact relied upon by the courts and other policymakers. This conclusion is supported by evidence that individuals consistently want their families to make health care decisions for them when they become ill.

would pose either human or financial burdens on patient’s family), cert. denied, 503 U.S. 950 (1992). See also Boozang, supra note 143, at 550-51 (asserting state law consistently disallows surrogate decision-makers to consider impact of decisions on themselves).

234. See James Bopp, Jr. & Richard E. Coleson, Child Abuse by Whom?—Parental Rights and Judicial Competency Determinations: the Baby K and Baby Terry Cases, 20 OHIO N.U. L. REV. 821, 829-30 (1994) (arguing for reasons including potential financial conflicts of interest, financial concerns, and lack of information, families should not be automatically referred to as proxy decision-makers without procedural safeguards); Lebit, supra note 184, at 129 (stating “parent’s or guardian’s decisions should not be given greater weight than the decision of the guardian ad litem” in medical cases involving minors). It is more likely the commentator will acknowledge conflicts but ultimately conclude families are the best decision-makers. See, e.g., Rhoden, supra note 225, at 437-39 (suggesting family members are in best position to make decisions); Hamann, supra note 191, at 160-64 (discussing advantages of family as decision-maker).

235. See Boozang, supra note 143, at 552 (acknowledging research exists that suggests “families are poor substitute decision-makers”); Bopp & Coleson, supra note 234, at 830-31 (pointing out lack of empirical basis for assumption that family members can accurately predict what incompetent patient would have wanted); Ezekiel J. Emanuel & Linda L. Emanuel, Proxy Decision Making for Incompetent Patients, 267 JAMA 2067, 2068 (Apr. 15, 1992) (citing studies suggesting that patients and family rarely discuss use or withdrawal of life-sustaining technologies); Jacqueline J. Glover, Should Families Make Health Care Decisions?, 53 MD. L. REV. 1158, 1162 n.21 (1994) (citing sources challenging assumption that family members will know what incompetent patient wants). See also Schneider, supra note 157, at 832 n.27 (recognizing although most people prefer family members as surrogate decision-makers, some research indicates that families do not accurately predict patient’s preferences).

236. Cf. Hamann, supra note 191, at 164-65 (arguing families intuitively and instinctively know what patient would want even though knowledge is difficult to translate); Rhoden, supra note 225, at 437 (claiming many family members “just know” what incompetent patient would have wanted in way that transcends logical explanation); Yuen, supra note 192, at 603 (proposing one reason families are best surrogate decision-makers is because of intuitive knowledge of patient’s predilections).

237. See Rhoden, supra note 225, at 437 (acknowledging “deep rooted” sense in society that families are best able to make health care decisions for incompetent patients). See also Schneider, supra note 9, at 155 (noting “popular feeling” that parents are appropriate decision-makers). This recognition of sociological fact arguably occurred in Parham with the parental deference presumption. See supra notes 28-38 and accompanying text for a discussion of the parental deference presumption.

The assumption that families are better decision-makers may not hold true for gay patients, however, whose partners may be better decision-makers than their biological families, even though the biological ties are ordinarily recognized. See Robert Steinbrook et al., Preferences of Homosexual Men with AIDS for Life-Sustaining Treatment, 314 new eng. J. med. 457, 458 (Feb. 13, 1986) (suggesting assumption that families are better decision-makers may not hold true for gay patients).

238. See Bernard Lo et al., Family Decision Making on Trial: Who Decides For Incompetent Patients?, 322 new eng. J. med. 1228, 1230 (Apr. 26, 1990) (citing various authorities to support
Second, even if families are not necessarily good decision-makers based on an objective standard, they are at least better than the existing alternatives.²³⁹ Courts and commentators have criticized extensively judges and doctors as decision-makers.²⁴⁰ Some of the common concerns with judges as decision-makers are that the judicial process takes too long, judges do not know the patient or her situation well enough, and they possess their own set of biases.²⁴¹ Even more significantly, judges cannot weigh the moral and ethical considerations that are integral to these decisions, because they are circumscribed by existing law.²⁴² Doctors, like judges, possess biases and lack knowledge of the patient as a person, which may prevent doctors from fairly considering the patient’s best interests.²⁴³ Doctors also are no better than judges at making moral judgments.²⁴⁴ Consequently, families serve beneficence at least in a relative sense.

Although the moral authority for family members to decide may not be overwhelming, it is strong enough to warrant deference. All the reasons set forth above, considered together, further beneficence: families are better, we think they are better, or at least they are better than other possible decision-makers. Deference therefore directly serves the patient’s interests, as long as the interests of a patient whose family does not reflect this reality is adequately protected. A conflict of interests approach is an adequate way to ensure this protection.

---

²³⁹ See Brock, supra note 11, at 607-08 (arguing family members, even though not proven as good decision-makers, are better than alternatives).

²⁴⁰ See generally Hamann, supra note 191, at 161 (asserting family members are better decision-makers than either doctors or judges); Spline, supra note 179, at 934 (discussing why family decision-making is superior to physician or court models).

²⁴¹ See, e.g., Hamann, supra note 191, at 135-38 (providing extensive critique why personal medical decisions should not be made by judges). See also supra note 143 for authorities discussing the complexity of quality-of-life issues. See generally Krasik, supra note 192, at 563-64 (explaining reasoning behind objections to judicial intervention, including court’s lack of expertise and cumbersoness of judicial process).

²⁴² See, e.g., Rushton & Hogue, supra note 207, at 229 (explaining dispassionately applied legal standards may prohibit inclusion of values and goals benefiting incompetent individuals). See also Hamann, supra note 191, at 137-40 (arguing court is not appropriate forum for medical decision-making because issues are infused with moral, ethical, and theological concerns); Yuen, supra note 192, at 605 (asserting judges not competent to decide questions involving moral and theological issues).

²⁴³ See, e.g., Baron, supra note 62, at 18-19 (arguing doctors lack training, authority, and institutional framework needed to make “life and death” decisions for incompetent patients). See also Spline, supra note 179, at 935 (explaining concern that doctors’ professional biases may preclude them from acting in best interests of patient); Developments in the Law: Medical Technology and the Law, 103 Harv. L. Rev. 1519, 1608-09 (1990) [hereinafter Medical Technology] (asserting medical professionals’ judgments are vulnerable to distortions).

²⁴⁴ Buchanan & Brock, supra note 158, at 139-41.
3. Conflicts May Disqualify Family Members

Although generally families are the favored decision-makers, exceptions may exist where the family member is unlikely to make decisions in the patient's best interests. If the decision-maker possesses a strong conflict of interest, it divests the family decision-maker of moral authority. A conflict of interest exception is an appropriate way to balance the overall need for deference with the need to protect the patient's interests if the family decision-maker's judgment is impaired. If a conflict exists or is likely to exist, it indicates that the decision-maker no longer deserves the deference generally accorded to family members. Therefore, if a conflict exists or is likely to exist, it indicates that the decision-maker lacks moral authority to act on behalf of the patient. The burden then shifts to the proxy decision-maker to show that, despite a perceived conflict, beneficence would be served by allowing him to make the proposed decision. The nature of this burden depends on whether the conflict of interest is categorical or situational.

a. Categorical Conflicts

Although not explicitly named, categorical conflicts have been found to exist in types of cases where the risk of conflict is so high that court intervention is deemed necessary. These instances include those in which the decision-maker makes treatment decisions that fall outside the range of reasonableness, where extraordinary medical treatment is involved, or where the treatment decision involves a countervailing constitutional right of the patient that, when exercised, is likely to interfere with the family member's decision. When a categorical conflict exists, a neutral third party, such as a judge, must determine whether the decision of the proxy accords with the beneficence principle. Specifically, the court will need to decide whether treatment is warranted under the state's standard of beneficence. This standard could be an objective best interests standard or even a substituted judgment standard (if the patient were previously competent).

The first categorical exception is for a decision that is outside the range of

245. See infra Part II.B.3.a for a discussion of categorical conflicts and Part II.B.3.b for a discussion of situational conflicts.

246. See generally BUCHANAN & BROCK, supra note 158 (creating similar taxonomy for incompetent patients).

247. See generally Baron, supra note 62, at 7-10 (identifying exceptions for parental decision-making in cases involving donors, sterilization, and abortion because of potential for conflict).

248. See infra notes 253-60 and accompanying text for a discussion of reasonableness.

249. See infra notes 261-75 and accompanying text for a discussion of extraordinary medical treatment.

250. See infra notes 261-75 and accompanying text for a discussion of countervailing constitutional rights.

251. Such a conflict usually would be identified initially by the health care provider. If a dispute arises as to whether a conflict exists, a court then may need to define the scope of the categorical conflict at issue.

252. See Parts I.A and II.A for a discussion of these various standards.
reasonableness. A number of commentators have recognized such an exception but have not clearly articulated its scope. When viewed from the perspective of beneficence, the category is justifiable, albeit hard to define precisely. If a decision is outside the range of what reasonable people would choose, it is unlikely that the decision would be in a particular patient’s best interests, assuming that what serves the welfare of almost all patients is likely to serve the welfare of a particular patient. Moreover, if a family decision-maker makes a decision contrary to the majoritarian view of best interests, it is more likely that the decision is made to serve his or her own interests—such as religious or personal values—rather than those of the patient.

This “unreasonableness” exception has been articulated by commentators in various ways, such as: “not a decision that could reasonably be judged to be in the patient’s best interests,”253 “the family’s choice is unreasonable,”254 or “no responsible physician would implement the choice or the decision is outside the boundaries of acceptable medical practice.”255 Professor Bozang, who strongly argues that the family’s interests (particularly religious) deserve greater respect than given under existing law, would allow intervention where the “physician’s medical judgment indicates a significant chance of recovery for the patient, and the family nevertheless wishes to terminate treatment.”256 She also mentions specific instances of unreasonableness where deference to families is not deserved: if there is a complete refusal of conventional medical treatment or a denial of blood transfusions for children, or if female genital mutilation is involved.257

Buchanan and Brock also have articulated their conception of an unreasonableness exception, although they have not specifically labeled it as such. To determine the unreasonableness of a family’s decision, these commentators would ascertain whether most “reasonable and informed persons” would choose differently from the family.258 If most persons would choose differently, then outside intervention is required, unless the harm caused by the family’s choice is slight and unlikely to occur.259

These definitions all imply that unreasonableness will be found only in “the rare case,”260 thus permitting deference to the family in most instances. Unreasonableness should not be found simply because a doctor disagrees with

254. Rhoden, supra note 225, at 437, 441. See also Newman, Treatment Refusals, supra note 191, at 88 (providing for exception to deference when family’s decision “is contrary to society’s widely shared ideals about human rights”) (citation omitted); Rushton & Hogue, supra note 207, at 235 (suggesting to honor decisions “within the range of morally acceptable action”).
255. Hamann, supra note 191, at 159-60.
256. Bozang, supra note 143, at 613 n.346.
257. Id. at 612 n.340.
258. BUCHANAN & BROCK, supra note 158, at 143-45. They also would require that the treatment chosen by the family be within the range of medically-sound alternatives. Id. at 143.
259. Id.
260. Bozang, supra note 143, at 613 n.346.
the family’s view of the patient’s best interests. To be unreasonable, the decision regarding treatment must be contrary to what most decision-makers would decide in the same situation. In other words, it must be against the prevailing social consensus.

The second and third categorical exceptions for “extraordinary medical treatment” and “countervailing constitutional rights” also have been defined narrowly. For example, Buchanan and Brock would find limited exceptions to familial deference where the population is particularly vulnerable (including those willing to be organ donors, and those who are institutionalized), where “momentous” decisions are involved that would considerably shorten the patient’s life if denied\textsuperscript{261} or would cause a permanent or unavoidable loss or impairment of important physical or psychological functions.\textsuperscript{262}

Some guardianship statutes contain categorical exceptions that resemble those set forth above. Guardianship statutes govern the appointment, authority, and removal of those persons appointed to represent the interests of an incompetent. An exception for withholding of “life-saving”\textsuperscript{263} is essentially an unreasonableness exception because it is singling out a category in which denial of this type of treatment would not be acceptable to most persons. If life-saving treatment is warranted, it should be ordered, and those that do not choose such treatment are acting unreasonably. Other existing exceptions for institutionalization,\textsuperscript{264} sterilization,\textsuperscript{265} and organ donation\textsuperscript{266} may be considered examples of extraordinary medical treatment decisions.\textsuperscript{267} Because many of

\textsuperscript{261} See Buchanan & Brock, supra note 158, at 142-43 (citing example of correcting blocked intestine of baby with Down’s Syndrome).

\textsuperscript{262} See id. at 143 (citing examples of sterilization and psychosurgery). Buchanan and Brock also would find an exemption where there is a “high likelihood of conflict” because strong familial attachments do not exist and treatment alternatives would impose great burdens on the surrogate. Id. at 142. I would not identify this high conflict exception as categorical, because it depends more on the facts of a particular case. As such, I would analyze it as a situational conflict. See infra Part II.B.3.b for a discussion of situational conflicts.


\textsuperscript{267} The sterilization and institutionalization exceptions also could be categorized as exceptions for competing constitutional interests.
these exceptions seem to involve situations in which the likelihood of a conflict between guardian and ward is high, the statutes require that a guardian receive court approval for making this kind of decision.268

One state has apparently created a categorical exception in its common law, using a factor analysis. According to this doctrine, if the factors favor court intervention, then such intervention will be necessary for all cases of this type, not just the case before the court. For example, in Guardianship of Roe,269 the Supreme Judicial Court of Massachusetts analyzed the following factors in reaching its decision that administering anti-psychotic drugs against the patient’s will always requires court approval: the intrusiveness of the proposed treatment, the possibility of adverse side effects, the absence of an emergency, the nature and extent of prior judicial involvement, and the likelihood of conflicting interests.270 Notably, the court concluded that the probability of abuse in administering these drugs was too high for the guardian to be trusted with the decision.271

In another case,272 the same court followed Roe and concluded that cases involving forced sterilization required court intervention.273 The court concluded that sterilization fell within the categorical exception for “extraordinary medical treatment that had been created by Roe and other cases.”274 Therefore, through its common law the Massachusetts courts have appeared to reach the same conclusion as other commentators and legislators: in narrow circumstances, categorical exemptions should be created to adequately protect the patient’s or ward’s best interests.275

b. Situational Conflicts

A situational conflict is a fact-based conflict that exists when the proxy’s ability to decide in the patient’s best interests has been impaired severely.276 A


270. Roe, 421 N.E.2d at 52-56. The court followed Matter of Spring, 405 N.E.2d 115 (Mass. 1980), which had articulated a more comprehensive set of factors.


273. Id. at 724.

274. Id. at 716-17. The court pointed to the extraordinary and highly intrusive nature of the procedure, and its effect on the woman’s right of procreation. Id.

275. See supra notes 263-68 and accompanying text for a discussion of statutes creating categorical exemptions.

276. See infra Part II.B.3.b for a discussion of situational conflicts. A number of guardianship statutes seem to recognize the existence of situational conflicts. See Cal. Prob. Code. § 2650(f)
situational conflict may be emotional, value-based, or financial.\textsuperscript{277} When a situational conflict is found,\textsuperscript{278} the familial deference presumption is rebutted. The decision-maker then has the burden of showing either that the situational conflict does not exist, or that the health care decision being made nevertheless comports with the beneficence principle.\textsuperscript{279} Because the familial deference presumption is strong,\textsuperscript{280} situational conflicts do not arise often.

Existing law provides examples of how narrowly these disqualifying conflicts have been defined. The first type of situational conflict, an emotional conflict, is characterized by an emotional state that prevents the decision-maker from considering the patient’s best interests. Scholars have acknowledged that emotional conflicts can disqualify family members, but have not clearly defined when such disqualification might occur.\textsuperscript{281} Emotional conflicts might be evidenced by a fundamental lack of understanding of the patient’s condition or course of treatment,\textsuperscript{282} emotional detachment from the patient,\textsuperscript{283} or the presence of extreme emotions such as shock, fear, or anger.\textsuperscript{284} To be sufficiently respectful of the family decision-maker, a showing of emotion should not be sufficient, in and of itself, to disqualify the proxy decision-maker. It must be

\textsuperscript{277} See infra notes 281-91 and accompanying text for a discussion of the three types of situational conflicts. I have organized these subcategories as ones that are commonly found, but the list is not intended to be exhaustive.

\textsuperscript{278} Such a conflict is usually identified by a health care provider who may need to bring the matter before a court, if agreement regarding treatment cannot be resolved informally.

\textsuperscript{279} See supra notes 245-46 and accompanying text for a discussion of the shifting burden of proof.

\textsuperscript{280} See supra Part II.B.2 for a discussion of deference to family in medical decision-making.

\textsuperscript{281} See, e.g., Francis, supra note 117, at 862 (discussing existence of conflicts between family members and patients); Glover, supra note 235, at 1162 (noting conflicts of interest may exist between patients and family members); Thomas J. Marzen, Medical Decisionmaking for the Incompetent Person: A Comprehensive Approach, 1 Issues in L. & Med. 293, 313 (1986) (stating families experience emotional conflicts of interest); Newman, supra note 191, at 51 (discussing emotional conflicts of interests); Yuen, supra note 192, at 607 (suggesting patient’s families experience conflict of interests).

\textsuperscript{282} See Yuen, supra note 192, at 607 (stating family should not decide when unable to comprehend relevant medical facts). It is important to distinguish a lack of understanding caused by the doctor’s unwillingness or inability to explain the relevant aspects of the treatment decision, which should not be considered a conflict of interest.

\textsuperscript{283} Cf. Windishar v. Windishar, 731 P.2d 445, 446-47 (Or. Ct. App. 1986) (removing guardian in part because of “emotional remoteness,” which detrimentally affected ability to protect ward’s interests).

\textsuperscript{284} See Marzen, supra note 281, at 304 (asserting guilt and hostility may render family member unable to make decision). Cf. In re Guardianship of Mason, 669 N.E.2d 1081, 1085 (Mass. App. Ct. 1996) (failing to appoint son guardian due to inability to take care of mother’s needs based on strong emotions such as hostility and distrust).
demonstrated that the emotional state is sufficiently severe to interfere with his ability to consider the patient’s best interests.\textsuperscript{285}

With the second kind of situational conflict, a value-based conflict, the decision-maker’s values may be so strongly held, or contrary to those of the patient, that they are likely to impair the decision-maker’s ability to consider the patient’s well-being. A value conflict may manifest itself as a powerful religious belief, a strong fear of dying, or perhaps a bias against handicapped persons.\textsuperscript{286} A disqualification, however, should not be found automatically simply because the decision-maker is religious, fearful, or even biased. The values must be of such a nature and strength that beneficence no longer can be served.\textsuperscript{287} This assessment is made most appropriately in the context of the individual case because a general standard cannot address the myriad situations in which such a conflict might arise.

The third type of situational conflict, a financial conflict, may significantly impede the decision-maker’s objectivity under the circumstances.\textsuperscript{288} For example, family members forced to pay exorbitant medical bills for long-term care may become overly concerned with the economic burdens of the treatment decision on the family.\textsuperscript{289} The family decision-maker may stand to gain financially from the death of the patient, which may further cloud her ability to think rationally about the patient’s needs.\textsuperscript{290} Depending on the circumstances, a

\textsuperscript{285} See Rushton & Hogue, supra note 207, at 228-29 (defining conflicts narrowly because existence of emotions does not necessarily impair decision-making). See also Newman, supra note 191, at 52 (noting emotions may positively affect decisions). Emotional conflicts are recognized in the guardian and trustee areas, such as where hostilities between family members may interfere with the ward/beneficiary’s best interests. See, e.g., In re Guardianship of Vesa, 892 S.W.2d 491, 491 (Ark. 1995) (removing guardian due to hostilities); In re Estate of Johnson, 579 N.E.2d 1206, 1209 (Ill. App. Ct. 1991) (removing guardian due to evidence of feud). Cf. Kerper v. Kerper, 780 P.2d 923, 938 (Wyo. 1989) (stating hostile feelings between trustee and beneficiary are insufficient grounds for removal, unless it interferes with administration of trust).

\textsuperscript{286} See, e.g., Marzen, supra note 281, at 304 (noting philosophical and religious considerations may not be shared by incompetent person); Splaine, supra note 179, at 934-35 (noting family may impose own interests onto patient); Yuen, supra note 192, at 607 (suggesting differing ethical and religious beliefs may lead to decisions contrary to patient’s wishes).

\textsuperscript{287} Cf. Rhoden, supra note 225, at 440 (stating patient’s treatment can be cut off when patient’s condition is more painful to decision-maker than to patient).

\textsuperscript{288} See In re Estate of Longeway, 549 N.E.2d 292, 300 (Ill. 1989) (requiring intervention where surrogate’s refusal of life-sustaining treatment caused in part by greed). But see Newman, supra note 191, at 53 (asserting financial conflicts may be “more theoretical than real”).

\textsuperscript{289} See Kenneth E. Covinsky et al., The Impact of Serious Illness on Patient’s Families, 272 JAMA 1839, 1839 (Dec. 21, 1994) (finding life-threatening illness caused severe financial burden to family members); Marzen, supra note 281, at 313 (suggesting economic conflicts of interest); Newman, supra note 191, at 54 (discussing economic burden of care on family); Rhoden, supra note 225, at 440 (noting economic conflict of interests); Yuen, supra note 192, at 607-08 (discussing economic conflict of interests).

\textsuperscript{290} See Longeway, 549 N.E.2d at 300-01 (stating courts must “guard against” decisions affected by greed). See also Splaine, supra note 179, at 935 (stating economic concerns may create conflict of interests); Yuen, supra note 192, at 607-08 (suggesting existence of economic conflict of interests). In the guardianship context, financial conflicts may form the basis for disqualification or removal. See Hill v. Jones, 773 S.W.2d 55, 57 (Tex. Ct. App. 1989) (stating guardian should be disqualified if
financial stake or burden may not, in and of itself, be sufficient to disqualify the proxy: prejudice to the patient's existing interests is the overriding consideration.291

If a court finds that any of these situational conflicts exists, the realities of the family situation outweigh the deference ordinarily accorded to family members. In response, the decision-maker can provide evidence that she actually is not conflicted, or that the decision she has made serves the beneficence principle. If this burden is not satisfied, the court is obliged to order the treatment that will best serve beneficence.

These lessons from bioethics about moral authority are equally applicable to parents and children, and will permit a refocusing of the existing doctrine from the rights of parents to the welfare of the child.

III. LEARNING LESSONS FOR PARENT DECISION-MAKERS

The previous section articulated some valuable lessons derived from bioethics discourse and incorporated into existing law and legal scholarship.292 The question remains whether those lessons apply to the law governing parents as readily as the law governing other family decision-makers. The answer to this question is a qualified "yes." This Part considers how each lesson applies to the parent-child decision-making context and how the law should be modified to ensure that these lessons are learned. Parents are much like other family members: parents do not possess an inherent right to make health care decisions for others; deference to parents generally serves beneficence; and parental conflicts of interest must be identified to determine when deference is no longer deserved. Doctors, courts, and families must recognize that a medical decision made on behalf of another is a medico-ethical decision. A similar analytical framework should be applied, regardless of whether the decision-maker is a spouse, parent, or child.

A. Parents Possess No Inherent Right to Decide

Parents should not be entitled to make decisions on behalf of their children merely because they are parents. As discussed previously, the parental deference presumption articulated by the courts is based on sociological fact rather than actual fact.293 It is purportedly rooted in natural law, and the courts have granted it constitutional status.294

---


292. See supra Part II for a discussion of how bioethics principles have influenced the existing law of family decision-makers.

293. See supra notes 28-38 and accompanying text for a discussion of the reasoning behind parents as decision-makers.

294. See supra notes 20-27 and accompanying text for a discussion of the roots of the parental deference presumption.
If parents lack an inherent right to decide, then their power to make decisions cannot be based on entitlement or the unqualified sense that “father (or mother) knows best.” The relevant inquiry must shift to whether beneficence would be served by allowing parents to decide.\textsuperscript{295} This approach focuses directly on the interests of the child, and it is not muddled with a consideration of the rights of third parties. It also better reflects the realities of existing parent-child relationships, which range from intimate to abusive.

Accordingly, the first fundamental change to the legal treatment of parent decision-makers would be to adjudicate most of these cases in the same court as other denial of treatment cases,\textsuperscript{296} not as abuse or neglect cases.\textsuperscript{297} Deciding these cases outside of the child abuse/neglect context would produce practical and symbolic benefits. Practically, having the same court decide medical decision cases would lead to greater systemic efficiency, because this court will address the same medico-ethical issues, regardless of the patient’s age. These issues include determining competence,\textsuperscript{298} weighing expert opinions on the patient’s medical state,\textsuperscript{299} and balancing the benefits and burdens of treatment.\textsuperscript{300} Cases would be decided more consistently, because false dichotomies between the incompetent adult patient and the child patient would be eliminated. Symbolically, the jurisdictional change would acknowledge that the parents have not failed to attain minimum levels of acceptable conduct, but rather are wrestling with complex medico-ethical issues. Removing these cases from the abuse/neglect context would allow parents to make the kind of quality-of-life determinations that other family members make when dealing with adult patients, without the stigma imposed by a judicial finding of abuse/neglect.\textsuperscript{301}

B. Deference to Parents Serves Beneficence (Usually)

There are a number of reasons why parents should be considered effective decision-makers, perhaps even more so than other family decision-makers. Ideally, the relationship between parent and child is closer than the relationship that an adult has with any other family member. Parent and child have a

\textsuperscript{295} See supra notes 174, 184 and accompanying text for a discussion of the beneficence principle.

\textsuperscript{296} These cases should be decided as proxy decision-maker cases in the appropriate courts, such as probate. See, e.g., In re Martin, 538 N.W.2d 399, 407 (Mich. 1995) (applying subjective analysis in life-sustaining treatment decision), cert. denied, 516 U.S. 1113 (1996).

\textsuperscript{297} See supra Part I.C for a discussion of the abuse and neglect context of parent decision-making adjudications.

\textsuperscript{298} See supra notes 177-78 and accompanying text for a definition of competence.

\textsuperscript{299} For example, the court may need to hear testimony as to whether the child is in a persistent vegetative state. See, e.g., In re Barry, 445 So. 2d 365, 370 (Fla. Dist. Ct. App. 1984) (resolving disagreement over child’s condition).

\textsuperscript{300} See In re Conroy, 486 A.2d 1209, 1231-33 (N.J. 1985) (applying balancing test for adult patient). See also infra Part III.C.1 a for a discussion of whether treatments should be administered based on effectiveness.

\textsuperscript{301} See supra Part I.C for a discussion of the current abuse and neglect context of parent decision-making.
uniquely symbiotic relationship: children are dependent on their parents for all of their physical and emotional needs, and parents provide for all of those needs; in turn, the child responds to the parents’ efforts with love and trust.\textsuperscript{302}

Because of this mutual love and concern, the parent usually will act in the child’s best interests,\textsuperscript{303} thus serving the beneficence principle. Because parents know the child best, they are probably most knowledgeable about the child’s likes and dislikes, as well as his sensitivity to pain. Moreover, they are likely to know the child’s value system most intimately, not only because they know their child, but also because they were integral in shaping his values.\textsuperscript{304} Therefore, it appears that parents deserve deference for essentially the same reasons other family decision-makers deserve deference, and perhaps to a greater degree.

At the same time, we must recognize that parents, like other family decision-makers, face conflicts of interest that may significantly impede their ability to act in their child’s best interests.\textsuperscript{305} The conflicts may be categorical or situational, and situational conflicts may be financial, emotional, or value-based.\textsuperscript{306} If these conflicts are likely to interfere with the parents’ ability to act in their child’s best interests, then the parents’ decisions will not serve beneficence.\textsuperscript{307}

Although the intimate nature of the parent-child relationship may make it more likely that a parent would act in accordance with the child’s best interests, that intimacy also may make certain conflicts more likely. For example, a financial conflict may be more likely because parents often bear sole responsibility for the financial burdens of their child’s medical care.\textsuperscript{308} They are likely to consider the financial impact of continued treatment on themselves and other family members who also depend on them.\textsuperscript{309}

Emotional conflicts also may be more likely. For example, if the child becomes seriously ill or dies, the parents may suffer a more immediate and deeper loss than any other survivor. It is therefore possible that the parent may

\textsuperscript{302} See generally Klaus, supra note 124, at 188-209 (discussing attachment and bonding between parents and children).

\textsuperscript{303} See Linda Sorenson Ewald, Medical Decisionmaking for Children: An Analysis of Competing Interests, 25 St. Louis U. L.J. 689, 727 (1982) (noting parent is in best position to evaluate child’s interests); Massie, supra note 132, 186-209 (discussing parents’ decision-making for children).

\textsuperscript{304} See Matthew S. Feigenbaum, Comment, Minors, Medical Treatment, and Interspousal Disagreement: Should Solomon Split the Child?, 41 DePaul L. Rev. 841, 853 (1992) (noting parents impact child’s value system).

\textsuperscript{305} See Koocher, supra note 40, at 719 (noting conflicts of interests exist).

\textsuperscript{306} See supra Part II.B.3 for a discussion of the taxonomy of conflicts.

\textsuperscript{307} See supra notes 245-46 and accompanying text for a discussion of the impact of a conflict of interest on a proxy’s decision-making authority.

\textsuperscript{308} Parents are responsible for paying the child’s necessaries until the age of majority. See generally 1 Kramer, supra note 133, § 4.02, at 165-66 (discussing parents’ legal obligations for children).

\textsuperscript{309} See Bennett, supra note 37, at 312 (stating parents “may have a bias against seeking medical care for [their] child[ren], or against a relatively expensive treatment” because they are responsible for financial costs of medical services).
make a health care decision based on his own fear of loss or fear of death.\(^{310}\) Even emotional detachment by parents towards their children could constitute a conflict of interest, if the circumstances warranted.\(^{311}\)

Parents also are particularly susceptible to value-based conflicts of interest. A parent may make a particular decision to ensure that his or her values are imposed on the child, not necessarily because it is in the child’s best interests or is what the child herself would value.\(^{312}\) For example, when a parent makes a decision for a sick child based on her own religious beliefs, it is unclear whether the parent truly believes that she is benefiting the child by furthering the child’s religious values or protecting the child’s physical well-being, or whether the parent is simply trying to ensure that her religious beliefs are followed.\(^{313}\) This does not mean that any parent with a strong religious belief is per se untrustworthy, but a more searching inquiry will be necessary.

For all situational conflicts, the challenge is to ensure that beneficence is served and that, in serving that principle, the realities of familial relationships are considered.

C. Conflicts May Disqualify Parents

For the reasons previously discussed,\(^{314}\) a conflict of interest approach would best protect the interests of children, while still allowing for a zone of privacy in which family decision-makers could make health care decisions without court intervention. Because a court would decide the parent’s moral authority to act, abuse and neglect adjudications (or their equivalent) are an improper means to resolve cases when a dispute arises.\(^{315}\) Instead, these cases should be decided using a conflict of interests approach similar to the one used when family members or guardians make decisions for adult incompetent

\(^{310}\) See Rosato, supra note 76, at 79 (suggesting parents’ fear of loss and death may affect decision). Cf. 2 MEISEL, supra note 63, § 15.3, at 280 (noting parents may find it more difficult to accept loss of child than adult family member); Obernberger, supra note 43, at 378-79 (suggesting “relational proximity” may negatively affect parents’ ability to think clearly).

\(^{311}\) See supra notes 281-85 and accompanying text for a discussion of emotional conflicts of interests.

\(^{312}\) See generally Dwyer, supra note 9, at 1401 n.114, 1431 (stating that parents’ decisions based on religious beliefs may be inappropriate for children).

\(^{313}\) See Bennett, supra note 37, at 313 (discussing possible conflicts of interests based on parents’ religious beliefs). For examples of value conflicts, see Lupu, supra note 80, at 1363-64 (discussing conflicts of interests surrounding abortion); Fiengenbaum, supra note 304, at 854-55 (discussing conflicts of interests surrounding transfusion); Ferdinand Schoeman, Parental Discretion and Children’s Rights: Background and Implications for Medical Decision-making, 10 J. MED. AND PHIL. 45, 53-54 (1985) (suggesting parents’ decisions regarding children are often based on parents’ own values). Cf. Strankman, supra note 62, at 921-22 (noting parents may be too close to child to objectively weigh pain).

\(^{314}\) See supra Part II.B.3 for a discussion of conflicts of interests that may disqualify family members.

\(^{315}\) See supra notes 136-45 and accompanying text for a discussion of why medical decision-making dilemmas should not be considered under the rubric of abuse and neglect.
patients.  

To that end, a two-part framework should be adopted. First, a set of statutory categorical conflicts should be created and enforced by the courts. Second, the courts (through common law) should define the situational conflicts that would disqualify parents from making health care decisions. If the health care provider identifies a conflict and a satisfactory result cannot be negotiated through the hospital’s processes, the filing of a petition in the appropriate court may be necessary. If no categorical or situational conflict exists, a parent should be able to make the decision unimpeded.

This framework would improve the current doctrine in a number of ways: it would be based on sound principles; it would be more predictable; and it would acknowledge that these kinds of decisions are fundamentally exercises of moral authority that involve the weighing of competing values.

1. Categorical Conflicts

Initially, I propose identification of a number of categorical conflicts that would divest parents of decision-making authority in certain types of cases. To provide clearer guidance to parents and to the courts, these conflicts should be delineated by statute, rather than by case law. If a categorical conflict is identified, the court then should determine whether the parent’s decision serves beneficence under the applicable state law standard.

The notion of categorical exceptions to the parental deference presumption is not new to the law of parent-child decision-making. Statutory exceptions already exist to provide relief from the general rule that parents must give consent to their child’s treatment. States have created a variety of exceptions, such as when minors are sufficiently mature to consent to their own treatment.  

---

316. See supra Part II.B.3 for a discussion of conflicts of interest in family medical decision-making.

317. See infra Part III.D for a discussion of the standards the court should apply.

318. A number of authorities have suggested that these types of issues are better suited to a legislative determination. See Medical Technology, supra note 243, at 1609-10 (favoring legislative approach to neonate issues); Splaine, supra note 179, at 925 n.125 (citing cases urging legislative action); id. at 929-30 (providing reasons for why legislature should decide treatment refusal decisions). See also In re Longeway, 549 N.E.2d 292, 301-02 (Ill. 1989) (urging legislative action in refusal of life-sustaining treatment decisions). Cf. Hamann, supra note 191, at 158-60 (proposing legislative solution to give more deference to families).

319. See, e.g., Rosato, supra note 76, at 17-34 (discussing statutory and common-law exceptions to general rule). See also Oberman, supra note 80, at 130-31 (citing statutes that permit unemancipated minors to receive medical care without parents’ consent); Jessica A. Penkower, Comment, The Potential Right of Chronically Ill Adolescents To Refuse Life-Saving Medical Treatment - Fatal Misuse of the Mature Minor Doctrine, 45 DEPAUL L. REV. 1165, 1176-78 (1996) (discussing statutory and common-law rights allowing minors to receive medical treatment absent parental consent).

or when a minor is seeking treatment for venereal disease or substance abuse.\textsuperscript{321} This latter category is based on public policy, where a failure to treat would cause harm to the minor or to the public.\textsuperscript{322} The categorical exceptions proposed here would be based on a similar public policy goal, that of serving the minor's best interests.

I propose using the taxonomy of categorical exceptions already applied to other family decision-makers: when the family member's decision is outside the range of reasonableness; when extraordinary medical treatment is involved; or when the treatment decision involves the exercise of a constitutional right that potentially conflicts with the family member's decision.\textsuperscript{323} If these categories are not considered sufficiently specific, a legislature could create narrower exceptions.\textsuperscript{324} Creating a number of categorical exceptions that codify existing law or reflect social consensus would provide some principled guidance to the lower courts that is currently lacking.\textsuperscript{325}

\textit{a. Unreasonableness}

In a previous Section, I discussed how family members can be divested of their authority based on the unreasonableness of their decision.\textsuperscript{326} Because this category is based on a notion of social consensus,\textsuperscript{327} its scope may be difficult to define without knowing the context of the particular case. Some specificity, however, is warranted, to ensure that the trial court's discretion is appropriately circumscribed and to provide sufficient guidance to parents and health care providers who are making important decisions.\textsuperscript{328} Moreover, to satisfy the beneficence principle, the standard should be focused on the needs of the incompetent patient.\textsuperscript{329}

\begin{itemize}
\item \textsuperscript{321}See, e.g., Oberman, supra note 80, at 130 (explaining states permit unemancipated minors to seek certain medical care without parental consent); Penkower, supra note 319, at 1178 (noting statutes exist permitting minors to consent to seek medical care for sexually-transmitted diseases); Rosato, supra note 76, at 29-31 (discussing exceptions to parental consent requirement).
\item \textsuperscript{322}See Oberman, supra note 80, at 131 (noting minor treatment statutes do not assess maturity, but allow low risk treatment for benefit of public health); Penkower, supra note 319, at 1178 (explaining "motivating force" behind treatment statutes was preventing spread of disease); Rosato, supra note 76, at 31 (noting "disease exception" to parental consent reflects public health concerns, not minor's maturity).
\item \textsuperscript{323}See supra Part II.B.3.a for a discussion of categorical conflicts.
\item \textsuperscript{324}For example, instead of creating a generic category of "extraordinary medical treatment" requiring judicial interpretation, the legislature could delineate particular kinds of treatment, such as organ donation and sterilization, that would satisfy the criteria.
\item \textsuperscript{325}See supra Part III.C.1 for a discussion of proposed categorical exceptions.
\item \textsuperscript{326}See supra notes 253-60 and accompanying text for a discussion of unreasonableness in the context of family decision-making.
\item \textsuperscript{327}See BUCHANAN & BROCK, supra note 158, at 143-47 (noting society determines reasonableness of actions).
\item \textsuperscript{328}See supra notes 41-44 and accompanying text for a discussion of courts' broad authority to intervene. With more guidance, there should be less litigation.
\item \textsuperscript{329}See supra notes 174 and 184-87 and accompanying text for a discussion of the beneficence principle and patient's interests.
\end{itemize}
As such, I propose a categorical exemption for life-saving treatment, defined as treatment that has a significant probability of either curing the condition or disease or alleviating all of the major symptoms of the condition or disease in the foreseeable future. The initial burden of proof would be on the party challenging the family member's authority to demonstrate that the facts fit this exemption. The idea behind such an exemption is that, in these rare circumstances, the balance of risks and benefits are so one-sided that it is unlikely that a parent who would deny this type of treatment is looking out for the child's best interests. It creates a minimum acceptable level of conduct that parents cannot fall below.

The definition includes a number of important components. First, the proposed treatment must either effectuate a cure, or alleviate all the major symptoms of the condition or disease. If the treatment is less effective, reasonable people could disagree about whether the treatment should be administered.

Second, the probability of cure or symptom-alleviation must be significant. Without such a likelihood, there is less justification, and thus less moral authority, for intruding on the decision-making authority of patients, even those who require a proxy to exercise those rights. For similar reasons, the cure or symptom-alleviation must occur in the foreseeable future. The more remote the effectiveness of the treatment, the less likely a consensus will exist that it should be administered.

One example of a curative treatment that has been judicially recognized as an exemption is a parent refusing a blood transfusion that would restore the child to his prior health. Courts overwhelmingly order transfusions in these circumstances, and have not found persuasive the parents' argument that refusal to provide a transfusion is necessary to adhere to the tenets of their religion. Thus, the existing law already appears to reflect the social consensus

---

330. For other similar definitions of life-saving treatment, see, e.g., In re Dinnerstein, 380 N.E.2d 134, 138 (Mass. App. Ct. 1978) (defining term as “treatments administered for the purpose, and with some reasonable expectation, of effecting a permanent or temporary cure of or relief from the illness or condition being treated”); Kenneth R. Thomas, Confronting End-of-Life Decisions: Should We Expand the Right to Die?, THE FEDERAL LAWYER, May 1997, at 34 (stating life-saving treatment “could be defined to include those treatments that will keep an individual alive, but need not be maintained on a continuous basis, because the underlying condition can be arrested, reversed or cured”). I proposed a similar standard in the context of when mature minors should be limited in making treatment decisions for themselves. Rosato, supra note 76, at 83.

331. For further discussion of these components, see Rosato, supra note 76, at 84-85 (discussing situation required for state to override parents' refusal for treatment).

332. For references to a transfusion as life-saving, see In re Baby Girl Newton, 1990 WL 54916, at *1 (Del. Ch. Apr. 12, 1990) (noting transfusion of red blood cells would save baby’s life); Nobel, supra note 42, at 639-40 (stating courts have ordered transfusions to save infants' lives).

333. Newton, 1990 WL 54916, at *1; Nobel, supra note 42, at 640 n.254. See also Feigenbaum, supra note 304, at 854-55 (noting courts have overridden Jehovah's Witnesses refusal to allow blood transfusion for children).

334. For a discussion as to why Jehovah's Witnesses refuse blood transfusions, see Julie A. Koehne, Comment, Witnesses on Trial: Judicial Intrusion Upon the Practices of Jehovah's Witness
that these parents are inherently conflicted and unable to ascertain their child’s best interests.335

The use of insulin to control the symptoms of diabetes is an example of symptom-alleviating, rather than curative treatment. Assuming the insulin essentially restores the patient’s health, the health care provider should order medication over the parent’s objection.336 Resort to the court should not be necessary in these cases, unless the parents fail to recognize the existence of the exemption or continue to assert that their decision serves beneficence.

Although this definition of life-saving treatment is not a perfect one, it is an improvement over the other alternatives: an exception for “necessary” treatment or treatment in the child’s “best interests.” The life-saving treatment exception set forth above is comparable to a “necessary” treatment exception, but provides more guidance. The life-saving exemption is better than a “best interests” determination, which permits too much intervention into the parents’ legitimate decision-making authority and provides insufficient guidance to judges, parents, and health care providers.337

Contrary to existing law, disabled/premature infants should not be automatically exempted from the general presumption in favor of parental decision-makers.338 It is unfair for the law to presume that parents of neonates are categorically conflicted.339 Instead, these parents deserve the benefit of the deference given to other parents, based on the presumption that they will love their child and provide him with the proper care.340

Any conflicts that arise in the neonate context can be addressed effectively under the rubric of categorical or situational conflicts.341 Some conflicts can be addressed through the life-saving treatment exemption.342 For example, denying a Down’s Syndrome child an operation that would cure a life-threatening condition (like a bowel obstruction) would be unreasonable, and the operation could be provided even without parental consent.343 In most instances, such an

---

335. See generally Dwyer, supra note 9, at 1427-28 (noting religious parents do not necessarily protect child’s temporal interests, and instead may reflect own religious interests).

336. See Rosato, supra note 76, at 90 (discussing examples in mature minor context).

337. See supra notes 236-44 and 302-04 and accompanying text for a discussion of why parents are better decision-makers.

338. See supra notes 99-117 and accompanying text for a discussion of existing law regarding parents of disabled and premature infants.

339. See supra notes 118-31 and accompanying text for a discussion of the reasons why parents of disabled and premature infants deserve deference.

340. See AAP, Critically Ill, supra note 120 (suggesting physicians treat neonate parents like other parents).

341. See supra Part II.B.3 for a discussion of categorical and situational conflicts in the context of family decision-makers.

342. See supra notes 330-37 and accompanying text for a discussion of the proposed life-saving treatment exception.

343. The court could find that the parents demonstrated that denial of treatment in a particular case violated the beneficence principle.
operation would have a significant probability of curing a life-threatening condition in the immediate future. Because of the complexity and variation in the prognosis and nature of treatment for children with other conditions (such as prematurity), parental decisions regarding these children should not be categorically excluded.

In addition to categorical conflicts, some problems with parents of neonates can be addressed through the previously-described situational conflicts analysis. For example, some of these parents may show inconsolable grief or severe distress that interferes with their rational decision-making process, and thus would warrant finding a situational conflict. The important point here is that a categorical or situational conflict must be affirmatively demonstrated: it is paternalistic and unjustified to assume that all parents of neonates are in this impaired state.

b. Extraordinary Medical Treatment

As with the unreasonableness category, the state could define the extraordinary medical treatment category broadly—by simply designating it “extraordinary medical treatment”—or could define it more narrowly with specific examples. An example of an extraordinary medical treatment that already has been identified in existing law is organ donation by a minor. In the typical case, one sibling is seriously ill, and the parent seeks to have another sibling provide the needed donation.

In this context, assuming a parental conflict of interest is justified because a parent who is considering the benefits of donation to the ill child would be unable to consider fairly the risks and benefits to the donor child. Moreover, donation constitutes an extraordinary medical treatment because it is, by definition, non-therapeutic.

Current legal doctrine recognizes this inherent conflict and has found ways to protect the donor child. Courts are directly involved in deciding these

344. As such, a social consensus favors treatment in this situation. See AAP, Critically Ill, supra note 120, at 149 (noting good medical practice supports initiation of treatment).


346. See, e.g., Baron, supra note 62, at 7-8 (noting possible existence of conflict of interests); Janet B. Korins, Curran v. Bosze: Toward a Clear Standard for Authorizing Kidney and Bone Marrow Transplants Between Minor Siblings, 16 VT. L. REV. 499, 519 (1992) (discussing existence of conflict of interests for parents); Jennifer K. Robbenolt et al., Advancing the Rights of Children and Adolescents to be Altruistic: Bone Marrow Donation By Minors, 9 J.L. & HEALTH 213, 216-17 (1994-95) (suggesting parents' ability to think clearly has been questioned). See also Hart, 289 A.2d at 391 (recognizing need to protect against parental conflict).

347. See, e.g., Korins, supra note 346, at 503 (stating proxy consent for organ donor is problematic because procedure is nontherapeutic); Rachel M. Dufault, Comment, Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze, 24 CONN. L. REV. 211, 220 & n.47 (1991) (noting organ donation is nontherapeutic for donor).
cases, which often require a showing that the donation affirmatively serves the best interests of the donor child. For example, the court may closely examine the relationship between the siblings to ascertain whether the donor will receive a psychological benefit from the donation.

Another extraordinary medical treatment that has been identified by courts and legislatures is the forced sterilization of women, including minors. Parents may seek sterilization of their child for a number of reasons, including avoidance of menstrual pain, preventing the negative psychological effects of menstruation and sexuality, and preventing the birth of an unwanted child for which the mother is incapable of caring.

348. See Korins, supra note 346, at 505-08 (discussing court involvement in donor cases). See also Dufault, supra note 347, at 220, 228 (noting judicial approval in cases is necessary). But see Robbenolt, supra note 346, at 218 (observing most cases are resolved through hospital procedures).


I acknowledge that some litigation may be motivated by the desire to reduce the health care providers' legal liability, and not because of any perceived harm to the minor. Although this motivation may be the reason for the courts' intervention, it does not diminish the extraordinary nature of this treatment, for the reasons I have set forth above.

349. See Harr, 289 A.2d at 389-91 (examining positive effects on organ donor); Curran, 566 N.E.2d at 1343-44, 1345 (noting psychological benefits derived by donor); Strunk, 445 S.W.2d at 146, 149 (noting positive impact derived from saving donor's life); Little, 576 S.W.2d at 498-500 (concluding donor receives benefit from nontherapeutic procedure). Cf. Dufault, supra note 347, at 228-29 (discussing older unpublished Massachusetts cases that considered "grave emotional impact" of donee's death on minor donor as psychological benefit). Where the courts were unable to find a benefit to the donor, the transplant was not approved. See Robbenolt, supra note 346, at 224 & n.60 (listing cases where court refused to authorize transplant due to lack of benefit to donor).

350. See, e.g., Curran, 566 N.E.2d at 1342-44 (concluding donor receives psychological benefit).

The minor's welfare is protected not only by the substantive requirements, but also by procedural requirements. These requirements may include a full hearing, and an attorney appointed for the child. See, e.g., Little, 576 S.W.2d at 499-500 (discussing required legal procedure).

351. Sterilization may include a hysterectomy or a tubal ligation. See In re P.S., 452 N.E.2d 969, 974 (Ind. 1983) (discussing sterilization by hysterectomy); In re Terwilliger, 450 A.2d 1376, 1378 (Pa. Super. 1982) (discussing sterilization through tubal ligation). Although less frequent, sterilization may be sought by or on behalf of an incompetent boy or man. See In re Grady, 426 A.2d 467, 483 n.10 (N.J. 1981) (noting it may be more difficult to meet best interests standard for males); American Academy of Pediatrics, Committee on Bioethics, Policy Statement, Sterilization of Minors With Developmental Disabilities, 104 Pediatrics 337, ¶ 13 (Aug. 1999) [hereinafter Sterilization of Minors] (noting sterilization of males is sometimes requested to decrease aggressiveness) <http://www.aap.org/policy/re9849.html>.

Forced sterilization falls under this exception for a number of reasons. A social consensus exists that sterilization is an “extraordinary and highly intrusive form of medical treatment” that has been characterized by a history of abuse. Moreover, the likelihood that parents will possess a conflict of interest is high, and the conflict impairs them from deciding in the minor’s best interests. For instance, sterilization may allow parents to avoid complicated issues such as menstruation, pregnancy, abortion, and adoption at the expense of the child’s well-being.

Existing authorities have implicitly recognized the extraordinary nature of this treatment and legal doctrine is more protective of the minor patient than in other areas. For example, leave of court is usually required to authorize a sterilization, and an extensive procedure may be required before a petition is granted. A number of states require that the petitioner demonstrate, by clear

---


355. See A.W., 637 P.2d at 370 (discussing potential conflicts encountered by parents of mentally-retarded persons when approving sterilization); Hayes, 608 P.2d at 640 (concluding mentally-retarded persons need independent representation when parents request sterilization). See generally Scott, supra note 354, at 818 (discussing conflict between right of procreation and parental fear of pregnancy).


358. See, e.g., Wentzel v. Montgomery Gen. Hosp., 447 A.2d 1244, 1253-54 (Md. 1982) (delineating procedure required in Maryland); Grady, 426 A.2d at 482-83 (discussing procedure
and convincing evidence, that the sterilization is either in the patient's best interests\(^\text{359}\) or medically necessary.\(^\text{360}\) The parents' reasons for sterilization should be focused on the minor herself, and not other interests.\(^\text{361}\)

The standard may be even more rigorous for minors because, in cases where a child is mentally impaired, it is difficult to ascertain whether the impairment is permanent, or whether the minor will acquire the necessary competence once she reaches maturity.\(^\text{362}\) Recognizing a categorical exemption for sterilization serves the beneficence principle because the interests of minors will be furthered by allowing a disinterested party to make this type of decision.\(^\text{363}\)

c. Countervailing Constitutional Rights

Although the United States Supreme Court has not concluded that sterilization may infringe on a constitutionally protected interest, other courts have so ruled.\(^\text{364}\) Sterilization directly and significantly interferes with the right of procreation.\(^\text{365}\) Therefore, a state also could consider sterilization within the categorical exception for countervailing constitutional rights that implicitly or explicitly conflict with a family member's decision. Decisions regarding abortion and the institutionalization of minors also would fall into this category.

---

\(^{359}\) See, e.g., Grady, 426 A.2d at 475, 481 (requiring best interests analysis); Terwilliger, 450 A.2d at 1383-84 (requiring clear and convincing evidence that sterilization is in incompetent's best interest); Hayes, 608 P.2d at 640-41 (suggesting sterilization should be last resort). See also Minn. Stat. Ann. § 525.56 (West 1975) (delineating guardian's powers and duties to serve ward's interests). C.f. Va. Code Ann. § 54.1-2977 (Michie 1998) (setting forth factors resembling best interests). See generally In re Romero, 790 P.2d 819, 821 n.10 (Colo. 1990) (citing cases adopting best interests standard); Scott, supra note 354, at 822-23 (outlining various approaches taken by courts).


\(^{361}\) See, e.g., Wentzel, 447 A.2d at 1254 (using best interests of minor analysis); Grady, 426 A.2d at 483 (suggesting most weight should be given to minor's interests). See also In re Moe, 432 N.E.2d 712, 723 n.12 (Mass. 1982) (concluding best interests of minor is determinative).


\(^{363}\) See supra notes 174 and 184 and accompanying text for a discussion of the beneficence principle.

\(^{364}\) See Cepko, supra note 352, at 131-38 (criticizing how constitutional right to sterilization is regarded under existing law); Richard A. Estacio, Comment, Sterilization of the Mentally Disabled in Pennsylvania: Three Generations Without Legislative Guidance Are Enough, 92 Dick. L. Rev. 409, 429 & n.115 (1988) (citing decisions from several states ruling that choosing sterilization is fundamental right).

\(^{365}\) See Estacio, supra note 364, at 429 n.115 (noting jurisdictions recognizing that sterilization impinges upon right to procreate).
Under existing law, the abortion rights of minors are protected by constitutional law, although they are less protected than the rights of an adult female. Any statute regulating abortion should recognize a right of minors that is as strong as the right of adults, and that parents may possess value-based and emotional conflicts that interfere with their ability to decide on behalf of their daughter's best interests. The existing evidence of parental retaliation, for example, supports strengthening the protection for minor's abortion rights by clearly delineating an exemption for these decisions. The good faith of parents cannot be presumed in this context.

Another example of an inherent conflict involving a countervailing constitutional right is the institutionalization of minors, either entirely involuntary or based on the parent's admission of the child. The United States Supreme Court has recognized that minors, like adults, have a liberty interest that would be deprived by being institutionalized against their wills. Institutionalization affects this interest because it involves the deprivation of physical liberty and the imposition of stigma. Although the Court in Parham presumed that parents would place their child into an institution for the child's benefit and not "dump" them into institutions, significant evidence to the contrary now exists. Desperate parents seek solutions for their difficult or "out-of-control" children, and institutionalization is often the solution chosen. The incentive to institutionalize with insufficient cause is exacerbated by financial considerations. For example, a number of insurance companies pay for inpatient but not outpatient care. Because of empirical and anecdotal evidence that illustrates the widespread abuses of authority in this context, the

366. See supra notes 84-89 and accompanying text for a discussion of the limits on abortion rights of minors.
367. See supra notes 88-94 and accompanying text for a discussion of abusive relationships.
368. See supra notes 92-98 and accompanying text for a discussion of the inadequacies of current legal procedures for minors' abortions.
369. An institutionalization based on parental consent is considered a voluntary institutionalization, even though it may be involuntary from the child's perspective. See Alexander V. Tsesis, Protecting Children Against Unnecessary Institutionalization, 39 S. TEX. L. REV. 995, 1000, 1002-3, 1011 (1998) (noting difference between voluntary commitment of adult and minor).
371. Id. at 600-01.
372. Id. at 611-13.
373. See, e.g., Jan C. Costello, Making Kids Take Their Medicine: The Privacy and Due Process Rights of De Facto Competent Minors, 31 LOY. L.A. L. REV. 907, 918 & n.50 (1998) (commenting that parents often seek treatment when child's behavior conflicts with parents' moral or religious beliefs); Richard E. Redding, Children's Competence to Provide Informed Consent for Mental Health Treatment, 50 WASH. & LEE L. REV. 695, 697-98 (1993) (stating presumption of parents acting in child's best interests is not tenable in area of mental health treatment). See also Tsesis, supra note 369, at 1002-03, 1011-12 (suggestions parents are influenced by many factors not directly related to child's best interests).
374. See Tsesis, supra note 369, at 1012 (stating parents' overreaction to child's behavior may result in institutionalization).
375. See id. at 1009-10, 1013-15 (noting insurance often pays for inpatient, but not outpatient, mental care).
presumption in favor of families is rebutted by a categorical exception.

Once the legislature determines which categorical exceptions it will recognize, the courts will be available to interpret the scope of these exceptions where ambiguity still exists. Moreover, in the rare instance that an exception applies, the court will need to conduct a best interests determination consistent with the state’s definition. The court’s additional role will be to determine the existence of situational conflicts when they cannot be resolved through extra-judicial means.

2. Situational Conflicts

As discussed above, a situational conflicts analysis is a way to continue to respect parental decision-making while protecting the child in those cases where parental conflicts of interest are likely to exist. By focusing on a decision’s effect on the child, beneficence continues to be furthered.

The situational conflicts analysis requires a court to determine, based on the existing facts, whether parents possess a conflict of interest that is likely to significantly impair their ability to make a health care decision in furtherance of the child’s best interests. As with other family members, these conflicts may be financial, emotional, or value-based. The initial burden should be on the petitioner (usually a health care provider) to demonstrate, by a preponderance of the evidence, that a situational conflict exists. The preponderance standard is chosen over clear and convincing evidence because evidence of a conflict is likely to reside with the parent, and thus a higher standard would be too onerous for the petitioner. Once a conflict is proven, the parent’s burden is to show, also by a preponderance, either that the conflict actually does not exist or that the parent’s decision does serve beneficence, despite the conflict.

Where appropriate, a hospital ethics committee can assist in determining whether such a conflict exists. Indicia of an emotional conflict include, but are not limited to: severe emotional distress that appears to be impeding the parent’s ability to act rationally, a lack of emotional attachment between parent and child, prior findings of parental neglect or abuse, an inability to understand the child’s needs, a focus on the parent’s own needs or the needs of other family members, hostility against or failure to cooperate with health care providers, or an inability of the parent to separate his or her own needs from those of the

376. See supra notes 46-58 and accompanying text for a discussion of the Newmark court’s confusing best interests determination.

377. Where possible, disputes regarding treatment should be resolved informally or through the hospital process, such as ethics committees and mediation.

378. See supra Part II.B.3.b for a discussion of situational conflicts.

379. Id.

380. See supra notes 281-91 and accompanying text for a discussion of the three types of situational conflicts.


382. See supra notes 278-79 and accompanying text for a discussion of how to overcome a situational conflict in the context of family decision-making.
Indicia related to a financial conflict may include a lack of insurance coverage to cover exorbitant medical expenses, or the parents' overt expressions of concern regarding the costs of medical care. No one single fact should be determinative: each case must be considered in context.

Although the range of situational conflicts that might exist are too numerous to list, experience with adult patient cases shows that situational conflicts should not be defined too broadly. A broad definition would weaken the parental deference presumption (which generally furthers beneficence,) and would perpetuate unprincipled and inconsistent decision-making. The balance to be struck is concededly a delicate one.

3. Autonomy-Based Conflicts

The third type of conflict is created when the core bioethics principle of beneficence collides with the autonomy principle. In these situations, the minor is asserting a position contrary to her parents and/or the health care provider. For example, an adolescent with cancer may refuse chemotherapy while the parents or health care providers seek to impose such treatment on the child.

Because the autonomy principle is a bioethics concept, as distinguished from a legal concept, the autonomy of a mature minor can be recognized to the degree appropriate for that individual, even though she has not reached majority. For an autonomy-based exemption from parental deference, the conflict stems from a true conflict, rather than an inherent conflict of interest. Because active resolution of the conflict is necessary, it is appropriate to seek court intervention. The threshold determination for the court will be whether the child is mature enough to make the medical decision at issue. If the child is not deemed mature, then the autonomy principle is not implicated, the beneficence principle remains predominant, and the previously discussed beneficence-oriented standard should apply.

On the other hand, if the child is sufficiently mature to make her own medical decisions, then the child's autonomy interest is a counterweight to beneficence. There are various ways in which the law could respect the autonomy of the minor: by having the legislature create a bright-line age in

383. See supra notes 281-85 and accompanying text for a discussion of emotional conflicts in family health care decisions.
384. See supra notes 288-91 and accompanying text for a discussion of financial conflicts in family health care decisions.
385. See supra notes 302-04 and accompanying text for a discussion of how parental deference furthers beneficence.
386. See supra Part II.A for an overview of the bioethics principles.
387. See Rosato, supra note 76, at 88-90 (discussing case study in which minor refuses chemotherapy).
388. See generally id. at 51-67 (discussing factors to be considered in deciding whether minor is competent to make health care decisions).
389. See supra notes 172-82 and accompanying text for a discussion of the interplay between autonomy and beneficence.
which minors are considered competent to make these decisions;\textsuperscript{390} or by allowing a court to determine the minor's competency under a mature minor doctrine.\textsuperscript{391} A mature minor doctrine could be created legislatively or through common law, and provides a mechanism for courts and doctors to assess the appropriate degree of autonomy to be granted to the individual minor, based on maturity. It reflects the value that autonomy does not apply to adults alone.

Once the child is considered capable of making decisions, the issue then is how to ensure that the beneficence principle is balanced properly against the minor's autonomy. The state will need to decide what limits are necessary to protect the child's best interests. To strike the balance, a state should respect the mature minor's decision, as long as it is within the range of reasonableness. This standard would allow the minor to make most medical decisions for herself, but would also preserve a "safety net" so that the child is not permitted to make irreversible, life-threatening decisions.\textsuperscript{392} Using this standard, autonomy and beneficence would be properly balanced.

In this balance of principles, the parents' interests are irrelevant. Both the autonomy and beneficence principles are patient-centered, and thus the effect of the minor's decision on the parents should not be considered. The court in \textit{In re E.G.} reached the right result by allowing the mature minor to refuse treatment, but it wrongly inferred that E.G.'s mother possessed the authority to override E.G.'s decision to refuse treatment.\textsuperscript{393} If society is to be true to the principle of autonomy, which governs health-care decision-making for competent adults, courts and other decision-makers should allow a mature minor to make her decision unimpeded by any parental interest.\textsuperscript{394} Like adults, mature minors should have the right to make mistakes, even when their parents or doctors disagree with them, as long as the decision is not unreasonable.

A similar balance of beneficence and autonomy might lead to changes in the law governing minor abortions.\textsuperscript{395} If a minor is sufficiently mature to make the decision to abort a pregnancy, the autonomy principle demands that she receive treatment unimpeded by legal obstacles.

Even when the minor is immature and autonomy is not yet an applicable principle, beneficence requires a more patient-centered approach than is currently followed. For example, courts should consider available evidence (empirical and otherwise) regarding parental retaliation and other ways in which

\begin{itemize}
\item \textsuperscript{390} See, e.g., ALA. CODE § 228-4 (1997) (stating minors can consent to medical decisions if over 14 years of age).
\item \textsuperscript{391} See, e.g., ARK. CODE ANN. § 20-9-602(7) (Michie 2000) (providing unemancipated minor can consent to medical treatment if minor can appreciate consequences of decision); \textit{In re E.G.}, 549 N.E.2d 322, 327-28 (Ill. 1989) (stating mature minor doctrine should be used to determine if child is competent to make decisions regarding medical care).
\item \textsuperscript{392} See Rosato, supra note 76, at 85-86 (describing factors used to determine if treatment is life-saving).
\item \textsuperscript{393} E.G., 549 N.E.2d at 328. See supra Part I.B.1 a for a discussion of the case.
\item \textsuperscript{394} See supra Part I.B.1.a and Part I.B.1.b for a discussion of decision-making for mature minors.
\item \textsuperscript{395} See supra Part I.B.1.b for a discussion of law governing minors' abortion rights.
\end{itemize}
real families differ from the romantic ideal of the family espoused by the United States Supreme Court; courts and legislatures should recognize that requiring parental notification can cause the same detrimental effects as requiring parental consent; and that the judicial bypass should exist as a realistic alternative to parental consent, rather than a formidable or useless obstacle to the exercise of a constitutional right. Beneficence requires an approach that is focused on the short-term and long-term interests of the patient, not the interests of the parents, the courts, or the right-to-life movement.

The existing law could better reflect the moral authority of parent decision-makers if it considered the approach currently reflected in the law governing withdrawal of treatment for children who are in a persistent vegetative state, which is discussed in the next section.

D. Hope for the Future: Building on Existing Doctrine

A few cases involving minors in a persistent vegetative state ("PVS") provide hope for a more beneficence-oriented doctrine of parent-child decision-making. In each of these cases, the child was in a PVS and the parents sought removal of life-sustaining treatment, such as ventilation, nutrition, or hydration. The cases are patient-centered, as demonstrated by their recognition of the parents’ decision as an exercise of moral authority. They also acknowledge the limited role of the courts in resolving these medico-ethical decisions. The courts trust the parents to make these wrenching health care decisions when there is no social consensus as to appropriate treatment.

Overall, these courts seemed to employ more of a bioethics than a rights-based discourse. The court in In re L.H.R. noted that the decision to

---

396. See supra notes 83-92 and accompanying text for a discussion of the romantic view of the family adopted by the Supreme Court.

397. See Confidential Care, supra note 92, at 749 (describing adverse affect of notification requirement); Friedman, supra note 87, at 446-47 (suggesting notification requirement can have as preclusive effect on minor seeking abortion as consent requirement); Catherine Grevers Schmidt, Where Privacy Fails: Equal Protection and the Abortion Rights of Minors, 68 N.Y.U. L. REV. 597, 603 (1993) (noting parental notification can create problems similar to parental consent requirement in abortion context). But see Planned Parenthood of the Blue Ridge v. Camblos, 155 F.3d 352, 370-72 (4th Cir. 1998) (stating notice requirement is qualitatively different from consent and requires less constitutional protection).

398. See supra notes 95-98 and accompanying text for a discussion of the existing judicial bypass procedure.


400. This Article eschews any qualitative distinction between persistent vegetative state and other conditions. PVS is simply one end of a continuum that involves the weighing of quality-of-life considerations.

401. See supra Part II for a discussion of bioethics discourse as it applies to family decision-
withdraw life support from a child in a persistent vegetative state was a “moral and ethical decision.”[403] The probate court in In re Guardianship of Myers[404] stated explicitly that it was weighing the quality of life of a child in an indefinite persistent vegetative state against the death of that child from a lack of nutrition/hydration.[405] Using the language of bioethics, the court concluded that keeping the child alive was “inhumane” and “futile.”[406]

These beneficence-oriented decisions focus on the patient’s rights or interests, not those of the parents. They start with the premise that the patient possesses a common law or constitutional right to make decisions regarding treatment, and it is the surrogate’s role to effectuate the patient’s right.[407] The surrogate’s power to decide is not simply assumed: it is based on a reasoned justification. In In re Myers,[408] for example, the court justified its deference to the parents on the close relationship between the particular parents and child.[409]

Furthermore, the cases recognize the moral nature of the choices in part because they were not decided as abuse or neglect cases. Instead, they were given the same analysis as cases of family members deciding on behalf of


403. L.H.R., 321 S.E.2d at 723. See also Barry, 445 So. 2d at 369 (stating “some very real moral and ethical judgments” are involved in PVS cases).


405. Myers, 610 N.E.2d at 670-71.

406. Id. at 670. Neurologists testified that Carla’s prognosis was poor and that she “had no chance of a meaningful recovery” and “no cognitive function could be expected from Carla in the future.” Id. at 665. They also found that Carla’s body and muscles would deteriorate, but that she could exist in this state for years until she ultimately died from infection as a result of her physical deterioration. Id. After hearing this testimony, the court concluded that a PVS diagnosis is “abhorrent,” and decided that it would be wrong to require Carla’s parents to keep her in this state for possibly decades. Id. at 670-71.

407. See In re Barry, 445 So. 2d 365, 370 (Fla. Dist. Ct. App. 1984) (stating all persons possess right to refuse treatment); In re Doc, 418 S.E.2d 3, 6 (Ga. 1992) (noting parents were legally responsible to discuss child’s health care decisions); L.H.R., 321 S.E.2d at 722 (stating right to refuse treatment extends to minors); In re Rosebush, 491 N.W.2d 633, 636-37 (Mich. Ct. App. 1992) (finding parents should effectuate child’s decision regarding treatment); In re Crum, 580 N.E.2d 876, 881-82 (Ohio Prob. Ct. 1991) (stating parents may exercise child’s constitutional right to refuse treatment). See also Mary Kathleen Robbins, Note, New Life Given to the Right to Die in Michigan: In re Rosebush, 10 T.M. COOLEY L. REV. 727, 733 (1993) (stating “[s]everal states have found that an incompetent, who has never been competent, may have his or her right to refuse medical treatment asserted by surrogates”).


409. Myers, 610 N.E.2d at 670-71. Specifically, the court stated that “[the parents] are the ones who know [the child] best, who have suffered with her, who have consulted with her doctors, who have watched her deterioration, and who have the natural instinct of parents for her best interest.” Id. See also Barry, 445 So. 2d at 371-72 (noting parents’ decision was made in consultation with church and supported by medical evidence); Rosebush, 491 N.W.2d at 637 (finding parents should make best approximation of child’s preference based on best interests standard); Crum, 580 N.E.2d at 880 (noting child’s parents have “stood by her side during her long illness and are in agreement with the application to terminate life support”).
incompetent adult patients.\textsuperscript{410} As such, the courts implicitly acknowledged that these cases are about well-meaning parents making difficult ethical decisions, not "heedless, uncaring parents" in need of state supervision under the guise of parens patriae.\textsuperscript{411}

Finally, these beneficence-oriented decisions seem to agree that courts should have a limited role in passing judgment on the decisions of family members. Court intervention should only be necessary in rare instances, such as when the parties disagree, the parents are suspected of abuse, or an affected party seeks a judicial order.\textsuperscript{412} The courts' acknowledgment of such limited intervention in familial decision-making implicitly affirms the uniquely personal and moral nature of these decisions.

The approach of these cases involving PVS patients should provide some guidance for other cases, even though it is easier to defer to parents in cases involving PVS. With PVS, a medical consensus usually exists that the child will never regain consciousness, and the parents and health care providers generally agree that life-sustaining treatment should be withdrawn or withheld.\textsuperscript{413} The parent's moral authority to decide in these cases is therefore quite strong. But just because these are easy cases does not make them less appropriate examples. The courts' sensitivity to issues of moral authority and avoidance of a rights-based discourse can and should become an integral part of the legal discourse regarding health care decision-making by parents on behalf of their children, regardless of the child's underlying condition. If accomplished, the law then would better reflect core bioethics principles, especially beneficence.\textsuperscript{414}

\textsuperscript{410} See Doe, 418 S.E.2d at 6 (endorsing case law which held that medical decision-making for incompetent patients is most often best left to patient's family and patient's doctor); Care and Protection of Beth, 587 N.E.2d 1377, 1381 (Mass. 1992) (listing factors that should be considered in making decision for any incompetent person); Rosebush, 491 N.W.2d at 636 (finding "right to refuse lifesaving medical treatment is not lost because of the incompetence or the youth of the patient" and citing several cases holding principle); Myers, 610 N.E.2d at 666-67 (discussing cases that allow removal of respirator, but not nutrition and hydration, for adults in PVS condition); Crum, 580 N.E.2d at 878 (discussing existing case law in reaching decision).

\textsuperscript{411} See Massie, supra note 132, at 179-81 (stating "[b]ecause withdrawal of treatment is a medically reasonable choice for a PVS patient, no such justification for state intrusion exists when parents make that decision on behalf of their minor child;" however, under concept of parens patriae, State has power to intervene in parent-child relationship in instances of abuse or neglect).

\textsuperscript{412} See Barry, 445 So. 2d at 372 (stating courts should be available "where doubt exists, or if there is a lack of concurrence among the family, physicians, and the hospital, or if an affected party simply desires a judicial order"); L.H.R., 321 S.E.2d at 723 (stating decisions regarding termination of life support should be made without judicial intervention unless there is "disagreement between the parties, any case of suspected abuse, or other appropriate instances"); Rosebush, 491 N.W.2d at 637 (holding decision-making process should generally occur without resort to courts, although courts should be available to assist in decision-making when impasse is reached).

\textsuperscript{413} See, e.g., L.H.R., 321 S.E.2d at 718 (describing child's PVS condition and neurologist, parents, and guardian ad litem agreed to remove life-sustaining measures).

\textsuperscript{414} The precise means to that end is up to the legislatures and courts of a particular state.
CONCLUSION

Law and medicine both contribute to the resolution of difficult moral issues as to who should make medical decisions and what the applicable standard should be. As Professor George Annas has concluded: "American law, not philosophy or medicine, is primarily responsible for the agenda, development, and current state of American bioethics." It is time for the law to take a few lessons from bioethics and integrate its principles into existing legal doctrine.

And what difference would it make? In some cases it might not make a difference at all: doctors, parents, and young patients will continue to make difficult medical decisions together. In other cases, doctors will know when they can contravene parents' decisions and courts will know when their intervention is warranted.

Parents making these decisions will be treated with more parity than currently exists. For example, parents of mature minors may be given less power than they currently have, and parents of handicapped newborns may be given more. Most importantly, these decisions will be considered exercises of moral authority, not simply instances of abuse and neglect. And that is the greatest lesson that bioethics can teach us.

415. Annas, supra note 152, at 3.