

LEGAL AND PSYCHOLOGICAL CONSIDERATIONS IN ADOLESCENTS' END-OF-LIFE CHOICES

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INTRODUCTION

Each year, thousands of children face life-threatening illness or injury. Many of the parents of these children must grapple with gut-wrenching decisions concerning treatment options. When the child is older, she may have her own ideas about the best course of treatment, and these ideas may conflict with those of her parents.¹ For the most part, such disagreements are resolved privately. In cases where the wishes of the parent and child are firmly at odds, medical professionals, legislators, and courts face complex questions about the appropriate role of a mature minor in decisions about her treatment at the end of life.²

Several developments, including the common law “rule of sevens” and “mature minor doctrine,” include consideration of a minor’s preferences, provided that certain conditions are met.³ Each includes the notion that as a child approaches the age of majority, she becomes increasingly capable of making thoughtful, well-informed decisions. Today, state courts in a number of jurisdictions across the United States have held that a person under the age of eighteen can demonstrate the capacity for independent judgment by meeting certain criteria.⁴ The Supreme Court acknowledged the legitimacy of this approach in *Bellotti v. Baird*, a 1979 opinion requiring states to provide an option for making such a showing in the limited case of minors seeking an abortion without parental consent.⁵ However, despite the fact that courts in some states have provided an avenue for mature minors to weigh in, deference to parents’

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¹ Note, though, that capacity varies a great deal, as discussed *infra* Part II.

² See Committee on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 314 (1995) (“Although physicians should seek parental permission in most situations, they must focus on the goal of providing appropriate care and be prepared to seek legal intervention when parental refusal places the patient at clear and substantial risk. In cases of serious conflict, physicians and families should seek consultative assistance and only in rare circumstances look to judicial determinations.”) (citing John D. Lantos, *Treatment Refusal, Noncompliance, and the Pediatrician’s Responsibilities*, 18 PEDIATRIC ANNALS 255 (1989)) [<http://perma.cc/PH2M-W3W7>].

³ See *infra* notes 41–45 and accompanying text.

⁴ *Id.*

⁵ See *Bellotti v. Baird*, 443 U.S. 622, 643–44 (1979) [<http://perma.cc/JEL5-7FGW>].

choices remains the norm. While the informal practice of many medical professionals is to include the minor in medical decisionmaking, there is no legal obligation to do so.⁶ The current legal default of parental choice risks leaving the child out of the process.⁷

Clearly, not all minors are good decisionmakers. Research reveals cognitive and behavioral differences between adolescents and adults. Adolescent brains are not fully developed,⁸ and teens engage in more risk-taking and are particularly prone to social influence.⁹ These factors are worthy of consideration. However, adults also exhibit irrational behavior, and may be particularly subject to cognitive biases when dealing with a critically ill child. The over-optimism bias, probability neglect, confirmation bias, and availability heuristic are empirically demonstrated decisional biases that, while often adaptive, can influence choice in a way that leads to suboptimal decisions.¹⁰ In particular, these biases may work together to influence parents to choose more drastic, potentially invasive therapies that the child may prefer to avoid. The singular focus on the limits of adolescents' capacity ignores the fact that parents are also limited in their ability to make rational choices. In this Essay, I argue that parents and children make the best decisions when they work together, with the assistance of a bioethical mediator. When the choices of the parent and child are in conflict, a bioethical mediator trained to recognize and neutralize the limitations and biases of all parties can increase the chances of an optimal outcome.

The first Part of this Essay will discuss the basis for the framework of parental deference in the context of adolescent medical decisionmaking. This Part will also briefly discuss the role of the state as *parens patriae*, and the power and limitation of the state in that role. The second Part of this Essay will address the limitations of adolescent decisionmaking from a behavioral, developmental, and brain science perspective, while also discussing how the law treats adolescents. The third Part of the Essay will focus on the cognitive biases that can impede optimal choice formation for adults. Finally, the fourth Part of the Essay will advocate the use of a

⁶ For example, the Committee on Bioethics has written, "Parents and physicians should not exclude children and adolescents from decisionmaking without persuasive reasons." See Committee on Bioethics, *supra* note 2.

⁷ See Kimberly M. Mutcherson, *Whose Body Is It Anyway? An Updated Model of Healthcare Decision-Making Rights for Adolescents*, 14 CORNELL J.L. & PUB. POL'Y 251, 257 (2005) ("For most adolescents, in most circumstances, this period of being in between leaves them stranded in the midst of a legal system in which 'even older children are permitted to decide very little for themselves.'") (quoting Carol Sanger & Eleanor Willemsen, *Minor Changes: Emancipating Children in Modern Times*, 25 U. MICH J.L. REFORM 239, 244 (1992)).

⁸ See *The Teen Brain: Still Under Construction*, NATIONAL INSTITUTE OF MENTAL HEALTH, <http://www.nimh.nih.gov/health/publications/the-teen-brain-still-under-construction/index.shtml> (last visited Mar. 27, 2015) (reporting differences in the adult and adolescent brain) [<http://perma.cc/7BUZ-R2NT>].

⁹ See Elizabeth S. Scott, *The Legal Construction Of Childhood*, in A CENTURY OF JUVENILE JUSTICE, at 115 (Margaret K. Rosenheim et al. eds., 2002).

¹⁰ See *infra* Part III.

bioethical mediator both to assist the parties in reaching a compromise and to prevent the breakdown of the supportive parent–child relationship that can be so beneficial for the terminally ill adolescent patient.

I. LEGAL BASIS FOR PARENTAL MEDICAL DECISIONMAKING

The current legal landscape is a function of the traditional role of parents and the prominence of parental rights. It is also a result of court decisions and state statutes. There are two primary bases for the parental decisionmaking model. The first is a rights-based approach. This framework conceives of the right to parent as a fundamental right, tantamount to the right to marry and other rights.¹¹ The second is a best-interest-of-the-child approach. This rationale is rooted in the belief that parents are uniquely suited to make wise choices on behalf of their children because of their knowledge of and affection for their children.¹²

A. Parenting as a Basic Right

There are at least two reasons why the right to bear and raise children as one sees fit is a fundamental right. The first is a functional, exchange-based rationale, namely that rights and responsibility go hand-in-hand. Affording parents the right to make decisions about their children is necessary because of the myriad responsibilities that parents assume in raising children, and fairness requires that the state compensate parents for the long hours, hard work, and considerable associated costs involved.¹³ The second rationale for strong parental rights is motivational; parents are more likely to care for their children when they are given latitude to shape the character of the child and the child's destiny.¹⁴ Conversely, parents who are denied opportunities to shape their children are less willing to make investments in their children.¹⁵

The rights-based approach has also been equated with a second, property-like argument. This argument maintains that when a person creates another human life, assuming that there is no abdication of that relationship right through abuse or neglect, the passing on of one's genetic

¹¹ See *infra* Part I.A.

¹² See *infra* Part I.B.

¹³ See *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 535 (1925) (tying together rights with responsibilities) [<http://perma.cc/R9AG-LR9T>]; Elizabeth S. Scott, *Parental Autonomy and Children's Welfare*, 11 WM. & MARY BILL RTS. J. 1071, 1083 (2003) (discussing the advantages of a parental custody model that rewards "investment in child rearing in the intact family with parental status and authority after divorce") [<http://perma.cc/G3PS-9WKX>].

¹⁴ The Uniform Parentage Act is an example of a legal structure that incentivizes investment in children. Under this Act, a father who resides in the same home as the child for the first two years of the child's life, and openly holds the child as his own, is the presumptive natural father, with rights to the child. UNIF. PARENTAGE ACT § 204(a)(5) (2002) [<http://perma.cc/5LWD-CLTH>].

¹⁵ Cf. Shoshana L. Gillers, Note, *A Labor Theory of Legal Parenthood*, 110 YALE L.J. 691, 695 (2001) (describing the requirement that parents "invest emotionally and physically in their children's development" in exchange for maintaining custody of the child) [<http://perma.cc/W6K3-8Q87>].

material creates a proprietary right in that new life.¹⁶ On this basis, parents have a proprietary interest in making choices on behalf of their children, whose lives they created.

The Supreme Court of the United States has played a limited role in the development of family law, but has spoken to the question of whether parenting constitutes a fundamental right. While acknowledging that resolution of issues relating to “the family” has traditionally been reserved for the various states,¹⁷ the Court has provided some guidance in several key and oft-cited cases. These cases have, for the most part, articulated and justified a framework for parental rights. In *Meyer v. Nebraska*, the Court held that the right of liberty includes the right to engage in the common occupations of life, including the right “to marry, establish a home and bring up children.”¹⁸ The Court explained that the Fourteenth Amendment “[w]ithout doubt” included the right to raise children.¹⁹ Two years later, in *Pierce v. Society of Sisters*, the Court said, “The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.”²⁰ It was several decades later in *Wisconsin v. Yoder* that the Court asserted that “[t]his primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition.”²¹ Most recently, in *Troxel v. Granville*,²² the Supreme Court reiterated that parents have a basic right to raise their children.

B. Parental Control and the Best Interest of the Child

Another basis for granting parents the right to make decisions on behalf of their children is the notion that parents are in a unique position to act in the child’s best interest. The Supreme Court articulated this rationale for granting parents broad decisionmaking power in *Parham v. J.R.*²³

¹⁶ See, e.g., *Dutkiewicz v. Dutkiewicz*, 957 A.2d 821, 830 (Conn. 2008) (“[The] parent’s interest in the care, custody and control over his or her child is a fundamental right.”) [<https://perma.cc/7CWZ-MWQD>]; *Punsly v. Ho*, 105 Cal. Rptr. 2d 139, 144–45 (Cal. Ct. App. 2001) (asserting that “the custody, care and nurture of the child reside first in the parents”) [<http://perma.cc/Z7MW-KRZ5>]. There is a considerable literature pushing back on the child-as-property framework. See generally Kevin Noble Maillard, *Rethinking Children as Property: The Transitive Family*, 32 CARDOZO L. REV. 225 (2010) [<http://perma.cc/2ZWU-FC2M>]; Barbara Bennett Woodhouse, “Who Owns the Child?”: *Meyer and Pierce and the Child as Property*, 33 WM. & MARY L. REV. 995 (1992) [<http://perma.cc/XW8Y-UYX3>]. Starting in the 1960’s, child advocates began talking about children’s rights. For a brief review of this development, see Martin Guggenheim, *Maximizing Strategies for Pressuring Adults to Do Right by Children*, 45 ARIZ. L. REV. 765, 771–774 (2003) [<http://perma.cc/32RN-P93A>].

¹⁷ There is a domestic relations exception to federal jurisdiction. See *Ankenbrandt ex rel. L.R. v. Richards*, 504 U.S. 689, 693–701 (1992) [<http://perma.cc/AP2M-BTWN>].

¹⁸ 262 U.S. 390, 399 (1923) [<http://perma.cc/L42Z-CV27>].

¹⁹ *Id.*

²⁰ 268 U.S. 510, 535 (1925) (coupling “rights” with “obligations,” which captures the rights–responsibility notion).

²¹ 406 U.S. 205, 232 (1972) [<http://perma.cc/KS4P-4JDF>].

²² 530 U.S. 57 (2000) [<http://perma.cc/F98Q-U7XK>].

²³ 442 U.S. 584, 602–04 (1979) [<http://perma.cc/X9HY-FRV3>].

Parents generally have knowledge of the particular habits, preferences, and reactions of their children.²⁴ Unlike doctors or teachers, and certainly unlike judges, parents see their children from birth (or adoption) through the years, in a wide range of circumstances, as the child develops and gains a variety of experiences. Because of this long-term involvement, the parent understands how the child appears to be functioning contemporarily, and knows the child's history. To a great extent, the child's history is intertwined with that of her parents, as happens for those who have a great many shared experiences.²⁵

The parent also has unique insights into the child because the parent has helped to shape the child, through the exercise of religious practices, the teaching of moral codes, the enforcement of social norms, and the fostering of specific social relationships and educational priorities. Parents often choose to pass down cultural values and traditions.²⁶ Sometimes parents consciously steer their children away from the dominant culture or certain aspects of society. The teachings and norms of the parents and the family can increase or decrease sensitivity to certain environmental inputs and can dramatically alter how a child interprets experiences. As the person with the greatest insight into these variables, a parent holds a great deal of information relevant to what choices will most benefit a child.

C. *Parens Patriae: The Role of the State*

Any discussion that calls into question the absolute right of a parent to make medical decisions for a child generally starts with the notion of *parens patriae*. The Latin phrase *parens patriae*, literally translated, means "parent of the nation." This doctrine grants the state the right to exercise control to protect those citizens who are most vulnerable. When a parent's wishes regarding the treatment of a child conflict with generally accepted practices, the state may step in as *parens patriae*.²⁷ The idea that a parent's

²⁴ *Id.* at 601–04.

²⁵ However, there are times when the courts must be involved. One situation in which an older child's preference sometimes conflicts with that of a parent is with respect to custodial arrangements in the event of marital dissolution. Child advocate Judith Wallerstein has argued that with respect to custody, courts "should be responsive to the child's voice, amplifying it above the din of competing parents. Only in this way can it ascertain and respect 'the best interest of the child.'" Judith S. Wallerstein & Tony J. Tanke, *To Move or Not to Move: Psychological and Legal Considerations in the Relocation of Children Following Divorce*, 30 FAM. L.Q. 305, 323 (1996).

²⁶ *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 532, 534–535 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 398 (1923).

²⁷ In order to challenge the parent's right to make decisions, the state must have the parent adjudicated neglectful or the child a "child in need of assistance." "The statutory definition of child neglect varies by state but falls within the range provided by the Child Abuse Prevention and Treatment Act (CAPTA). CAPTA defines child abuse and neglect as 'at a minimum, any recent act or failure to act on the part of a parent or caretaker, which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act which presents an imminent risk of serious harm.'" Denise Cohen, Note, *Childhood Obesity: Balancing the Nation's Interest with a Parent's Constitutional Right to Privacy*, 10 CARDOZO PUB. L. POL'Y & ETHICS J. 357, 380 (2012) (quoting Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5106g (1996) [<http://perma.cc/GQ9P-RXLX>]).

choice for her child can be challenged (by anyone, state *or* child) contradicts the common law notion that the parent has property-like rights in the child.²⁸ In the 1944 case, *Prince v. Massachusetts*, the Supreme Court famously asserted the limits of parental discretion.²⁹ The *Prince* decision represents an important caveat to the general parental authority. This case is invoked when there is a question of the extent to which a parent may categorically exclude the state from intrusion into the private sphere of family life.

II. DEFINING THE SCOPE OF ADOLESCENT CHOICE

As the *Prince* decision makes clear, children are protected by the U.S. Constitution and the various state statutes, but they are protected in a different way than are adults. Children, unless they are emancipated, are presumed not to have the life experience or cognitive ability to make good decisions for themselves.³⁰ Courts and lawmakers use several justifications for this policy. One justification is that adolescents' bodies and brains are not fully developed, which may impair decisionmaking. Adolescents likely lack an ability to financially support themselves; indeed, child labor laws have severely limited opportunities available to children to earn a wage.³¹ Minors also possess limited life experience and knowledge, and remain relatively susceptible to peer pressure and other social influences during this period of life. Because of these characteristics of adolescence, the parent is still presumptively in charge—meaning that consent derives from the parent—until a child attains the age of eighteen.

A. Brain Development and Maturation Issues in Adolescence

Proponents of parental control over medical care for minors cite a number of biological and social factors supporting a default to parental decisionmaking. Some research indicates that adolescents may lack the capacity to make optimal decisions about their own medical care. The adolescent brain is different from the adult brain in important ways.³² Moreover, adolescence is a period of life in which the child's body is still developing, new chemicals in the form of hormones flood the bloodstream, and new expectations and responsibilities confront the child. The

²⁸ For a discussion of the notion of child as property, see generally, Woodhouse, *supra* note 16, at 1036–50. See also Maillard, *supra* note 16, at 237 (“At common law, children were treated as chattel.”).

²⁹ *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944) (“Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”) [<http://perma.cc/Q9VN-E672>].

³⁰ See generally Sarah-Jayne Blakemore & Suparna Choudhury, *Development of the Adolescent Brain: Implications for Executive Function and Social Cognition*, 47 J. CHILD PSYCHOL. & PSYCHIATRY 296 (2006).

³¹ See The Fair Labor Standards Act of 1938, as amended 29 U.S.C. § 212 (2012) [<http://perma.cc/WN4G-2SPV>].

³² See generally Kendall Powell, *Neurodevelopment: How Does the Teenage Brain Work?*, 442 NATURE 865 (2006).

achievement of sexual maturity during this period of life is relatively recent, and many adolescents spend a significant portion of these years acclimating to physical changes that signal the impending transformation from childhood to adulthood.

Research investigating behavior during this unique time of life has revealed certain patterns that bear on decisionmaking. Adolescents are particularly susceptible to peer influence.³³ They have a tendency to focus more on immediate rather than long-term consequences.³⁴ In addition, minors are less risk averse and thus more inclined to make risky choices than are adults.³⁵

Investigations involving MRI scans have indicated that the adolescent brain may not be fully developed until the age of twenty-one to twenty-three.³⁶ Importantly, the most evolved parts of the brain—those essential for making complex choices—reach maturity last. Research indicates that the prefrontal cortex activity necessary for responsible decisionmaking is not fully engaged until around twenty-one years of age.³⁷ Complementing this research is brain imaging showing that adolescents rely more on emotional areas of the brain in making decisions.³⁸

On the other hand, minors who are approaching adulthood vary considerably in their cognitive and reasoning ability. During the 1950s, Swiss psychologist Jean Piaget described the process by which adolescents reach a stage of formal operational thinking.³⁹ Piaget's work suggests that

³³ Lee v. Weisman, 505 U.S. 577, 593 (1992) [<http://perma.cc/QZA4-GZXL>]; Elizabeth S. Scott et al., *Evaluating Adolescent Decision Making in Legal Contexts*, 19 LAW & HUM. BEHAV. 221, 222 (1995).

³⁴ See generally Valerie F. Reyna & Frank Farley, *Risk and Rationality in Adolescent Decision Making: Implications for Theory, Practice, and Public Policy*, 7 PSYCHOL. SCI. PUB. INT. 1 (2006) [<http://perma.cc/P96L-43RY>]; Adriana Galvan et al., *Risk-Taking and the Adolescent Brain: Who is at Risk?*, 10 DEVELOPMENTAL SCI. F8 (2007); Valerie F. Reyna et al., *Risky Decision Making in Childhood and Adolescence: A Fuzzy-Trace Theory Approach*, in THE DEVELOPMENT OF JUDGMENT AND DECISION MAKING IN CHILDREN AND ADOLESCENTS, at 77 (Janis E. Jacobs & Paul A. Klaczynski eds., 2005).

³⁵ Scott, *supra* note 33, at 222; see also William Gardner & Janna Herman, *Adolescents' AIDS Risk Taking: A Rational Choice Perspective*, in ADOLESCENTS IN THE AIDS EPIDEMIC, 17–18 (William Gardner et al., eds., 1990).

³⁶ Jay N. Giedd et al., *Brain Development During Childhood and Adolescence: A Longitudinal MRI Study*, 2 NATURE NEUROSCIENCE 861, 861–62 (1999); Elizabeth R. Sowell et al., *In Vivo Evidence for Post-Adolescent Brain Maturation in Frontal and Striatal Regions*, 2 NATURE NEUROSCIENCE 859, 861 (1999).

³⁷ See Sara B. Johnson et al., *Adolescent Maturity and the Brain: The Promise and Pitfalls of Neuroscience Research in Adolescent Health Policy*, 45 J. ADOLESCENT HEALTH 216, 217 (2009) (“Although myelin cannot be measured directly, it is inferred from volumes of cerebral white matter. Evidence suggests that, in the prefrontal cortex, this does not occur until the early 20s or later.” (citations omitted)) [<http://perma.cc/9KS4-LN7Z>]. It is telling that this was the traditional age for recognizing a person as “of age,” as being a mature decisionmaker.

³⁸ Abigail A. Baird et al., *Functional Magnetic Resonance Imaging of Facial Affect Recognition in Children and Adolescents*, 38 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 195, 198 (1999) [<http://perma.cc/LE62-S79S>].

³⁹ See generally BÄRBEL INHELDER & JEAN PIAGET, THE GROWTH OF LOGICAL THINKING FROM CHILDHOOD TO ADOLESCENCE: AN ESSAY ON THE CONSTRUCTION OF FORMAL OPERATIONAL STRUCTURES (Anne Parsons & Stanley Milgrim trans., 1958); THE ESSENTIAL PIAGET (Howard E.

at least some minors between the ages of fourteen and eighteen may possess sufficient cognitive processing capacity and self-knowledge to make a fully informed choice. Professor Stephen Ellmann suggests that people can exercise free choice when: (1) they know there is a decision to be made, and that they have the right to make it; (2) they know the choices and the costs and benefits of these choices; and (3) they understand their values and emotional needs.⁴⁰

B. Flexibility and Minor Decisionmaking

Like researchers, courts also acknowledge that some adolescents may be able to make their own end-of-life choices. Under U.S. law, age eighteen, while presumptively the age of majority, is not always a bright line. This has long been the case; at common law, the rule of sevens carved out different presumptions, depending upon three age ranges.⁴¹ According to the rule of sevens, minors from birth to age seven had no capacity, minors between the ages of seven and fourteen had a rebuttable presumption of no capacity, and minors from age fourteen to twenty-one had a rebuttable presumption of capacity.⁴² Those over twenty-one were presumed to have full capacity.

More recently, the mature minor doctrine has created an avenue for minors who demonstrate the capacity to make informed decisions to exercise some authority over their own medical treatment. The mature minor doctrine theoretically can apply in any situation in which a minor is seeking to make a decision about medical treatment. In determining whether the minor is sufficiently mature to exercise control over treatment options, the minor's capacity is evaluated in order to determine whether the minor has:

- (1) an intellectual appreciation of the causal connections between one's choices and the consequences that will likely follow,
- (2) a realistic affective and evaluative capacity to appreciate the weight and significance of the risks and benefits, proximate and distant, associated with the consequences of one's choices, and
- (3) a self-determining capacity to choose or to decline to make a choice while not being unduly swayed by impulse.⁴³

Gruber & J. Jacques Vonèche eds., 1977); Jean Piaget, *Piaget's Theory*, in 1 HANDBOOK OF CHILD PSYCHOLOGY 103 (Paul H. Mussen ed., Guy Gellerier & Jonas Langer trans., 4th ed., 1983). While Piaget has been influential, his work is not without its detractors. One criticism of Piaget's stages theory is that it is too rigid; children do not necessarily move through the stages at the same ages and in discrete steps (a fact that he has acknowledged).

⁴⁰ See Stephen Ellmann, *Lawyers and Clients*, 34 UCLA L. REV. 717, 727–28 (1987).

⁴¹ *Cardwell v. Bechtol*, 724 S.W.2d 739, 745 (Tenn. 1987) [<https://perma.cc/S7VF-HX77>]. As a result of a movement in the late 1960s to link draft age and voting age, the voting age was lowered from twenty-one to eighteen.

⁴² *Id.*

⁴³ See generally COMPETENCY: A STUDY OF INFORMAL COMPETENCY DETERMINATIONS IN PRIMARY CARE (Mary Ann Gardell Cutter & Earl E. Shelp eds., 1991); BECKY WHITE, COMPETENCE TO CONSENT (1994). See also Mutcherson, *supra* note 7, at 314 (“The court’s goal should be to

The mature minor doctrine holds that where a minor is “of sufficient intelligence and maturity to understand and appreciate both the benefits and risks of the proposed medical or surgical treatment, then the minor may consent to that treatment without parental consent”⁴⁴ In *Bellotti v. Baird*, the Supreme Court held that if a state requires minors to obtain parental consent to obtain an abortion, it must also allow the minor “to show either: (1) that she is mature enough and well enough informed to make her abortion decision, in consultation with her physician, independently of her parents’ wishes; or (2) that even if she is not able to make this decision independently, the desired abortion would be in her best interests.”⁴⁵ In essence, *Bellotti* requires a state to apply the mature minor doctrine or to make a best-interest determination where abortion is concerned.

A number of state courts have applied the principle, at some points providing additional guidance, and at others orienting the doctrine within their own state’s legislative and common law framework.⁴⁶ In *Cardwell v. Bechtol*, for example, the Supreme Court of Tennessee wrote, “The mature minor exception is part of the common law of Tennessee. Its application is a question of fact for the jury to determine whether the minor has the capacity to consent to and appreciate the nature, the risks, and the consequences of the medical treatment involved.”⁴⁷ But the *Cardwell* court cautioned service providers and lower courts not to be overly expansive with the doctrine, noting that “[a]doption of the mature minor exceptions to the common law rule is by no means a general license to treat minors without parental consent and its application is dependent on the facts of

determine whether the adolescent has the capacity for mature and thoughtful decision-making and can therefore make a treatment decision that is informed, intelligent, and voluntary. An adolescent would need to show that she could articulate her health problem and its consequences as well as indicate an understanding of the available treatment options and why she has made a particular decision about that treatment.”). For a discussion of the mature minor doctrine, see Melinda T. Derish & Kathleen Vanden Heuvel *Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment*, 28 J.L. MED. & ETHICS 109 (2000) [<http://perma.cc/E4K7-F6E4>]; Jonathan F. Will, *My God My Choice: The Mature Minor Doctrine and Adolescent Refusal of Life-Saving or Sustaining Medical Treatment Based Upon Religious Beliefs*, 22 J. CONTEMP. HEALTH L. & POL’Y 233 (2006) [<http://perma.cc/69WR-UWG5>].

⁴⁴ JAMES MORRISSEY ET AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS: A LEGAL GUIDE 43 (1986); see also Joan-Margaret Kun, Comment, *Rejecting the Adage “Children Should Be Seen and Not Heard”—The Mature Minor Doctrine*, 16 PACE L. REV. 423 (1996) (discussing the rights of mature minors under state laws and suggesting new legislation and guidelines) [<http://perma.cc/QE7N-E5GY>].

⁴⁵ 443 U.S. 622, 643–44 (1979) (footnote omitted).

⁴⁶ See, e.g., *In re E.G.*, 549 N.E.2d 322, 327–28 (Ill. 1989) (finding that the mature minor doctrine was sufficient grounds for the trial court to hold a minor capable of refusing medical treatment, but that there are situations where the minor’s decision must be balanced with other concerns) [<http://perma.cc/TD3F-TH5R>]; *In re Green*, 307 A.2d 279 (Pa. 1973) (affirming the trial court’s order that respected the wishes of an adolescent to decline a spinal operation) [<http://perma.cc/9VZN-GY7L>]. But see *Niebla v. County of San Diego*, No. 90-56302, 1992 WL 140250, at *4 (9th Cir. June 23, 1992) (declining to reverse a dismissal based on the trial court’s refusal to apply the mature minor doctrine in a case compelling blood transfusions for a Jehovah’s Witness minor) [<http://perma.cc/2RLK-FHEY>].

⁴⁷ 724 S.W.2d 739, 745 (Tenn. 1987).

each case.”⁴⁸ In *Belcher v. Charleston Area Medical Center*, the Supreme Court of Appeals of West Virginia asserted that the national standard of care was that a mature minor must be involved in discussions that “affect their livelihood.”⁴⁹ Other courts apply a slight variation on these principles. In *In re Swan*, the Supreme Court of Maine deferred to the wishes of seventeen-year-old accident victim who was in a persistent vegetative state who had expressed a wish not to be kept alive under those circumstances prior to the accident.⁵⁰

Legislation has been slow to follow court decisions. For instance, when it comes to the formation of legally valid advanced directives, most state statutes indicate a “competent adult” or similar (over the age of seventeen) requirement.⁵¹ New Mexico, which permits capable unemancipated minors to make decisions about life-sustaining treatment in some circumstances, is a notable exception.⁵²

In contrast, other state statutes specifically exclude minors—unless they are emancipated—in granting the authority to make such choices. For example, a provision of South Carolina’s Death with Dignity (or Right to Die) Act permits a person to adopt a written declaration that life-sustaining procedures may be withheld, but only *if the person is eighteen years of age or older*.⁵³

C. Adolescent Autonomy and Importance of Control

Although adolescents vary in terms of their cognitive maturity, there are important reasons to give adolescents a broader voice in their healthcare decisionmaking, including recognition of the adolescent’s personal autonomy, freedom, and dignity. Gerald Dworkin has noted:

there is value connected with being self-determining that is not a matter either of bringing about good results or the pleasures of the process itself. This is the intrinsic desirability of exercising the capacity for self-determination. We desire to be recognized by

⁴⁸ *Id.*

⁴⁹ 422 S.E.2d 827, 835 (W. Va. 1992) [<http://perma.cc/WAG9-ABSC>].

⁵⁰ 569 A.2d 1202, 1202–03 (Me. 1990) [<http://perma.cc/Z4FT-UWDX>].

⁵¹ For example, the Florida legislature has determined that “every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment.” FLA. STAT. ANN. § 765.102(1) (West 2010) [<http://perma.cc/6PFY-4PFC>].

⁵² “Subject to the provisions of Subsection B of this section, if an unemancipated minor has capacity sufficient to understand the nature of that unemancipated minor’s medical condition, the risks and benefits of treatment and the contemplated decision to withhold or withdraw life-sustaining treatment, that unemancipated minor shall have the authority to withhold or withdraw life-sustaining treatment.” N.M. STAT. ANN. § 24–7A–6.1.C. (Supp. 2013).

⁵³ S.C. CODE ANN. § 44–77–30 (2002) [<http://perma.cc/JND3-FLCS>]; see also ALA. CODE § 22–8A–4 (LexisNexis 2006) (“competent adult”) [<http://perma.cc/4BCH-FEZ8>]; GA. CODE ANN. § 31–32–5 (West 2010) (“emancipated or 18 years of age or older”) [<http://perma.cc/BK7C-XPKA>]; N.H. REV. STAT. ANN. § 137–J:1 (LexisNexis 2012) (“competent person”) [<http://perma.cc/QGJ6-HKR3>]; N.D. CENT. CODE § 23–06.5–01 (2012) (“competent adult”) [<http://perma.cc/P2SY-FFRF>]; W. VA. CODE ANN. § 16–30–4(a) (LexisNexis 2011) (“competent adult”) [<http://perma.cc/EY44-FK72>].

others as the kind of creature capable of determining our own destiny.⁵⁴

The feeling of control is an important influence on human behavior.⁵⁵ When individuals perceive that they have control over events, they experience less fear.⁵⁶ Conversely, risks over which people perceive that they have little influence are likely to be viewed as more dangerous and less acceptable.⁵⁷ The ability to exercise some control over the course of serious illness arguably has particular import for the gravely injured or ill adolescent who often feels powerless and overwhelmed by her disease or injury.

As one commentator has noted, “[t]he law’s treatment of minors in the healthcare context has been scattered and contradictory.”⁵⁸ The current patchwork of court opinions, along with variability in how health care providers and hospitals handle this issue, counsel for a more unified approach.⁵⁹ Rhonda Gay Hartman calls for a “legal framework predicated on adolescent decisional ability” as a cure for inconsistent practices in the role adolescents have in choosing their own care.⁶⁰ Legal recognition of minors’ status as autonomous beings worthy of protection has been acknowledged by the Supreme Court. Recognizing the dignity and personhood of minors, the Court has extended Bill of Rights protections to persons under the age of eighteen, holding they are entitled to be free from oppressive state action.⁶¹ Several opinions suggest that the Court recognizes rights of citizens under the age of eighteen beyond the right to be nurtured, protected, and educated.⁶²

⁵⁴ GERALD DWORKIN, *THE THEORY AND PRACTICE OF AUTONOMY* 112 (1988)

⁵⁵ See George Loewenstein, *Out of Control: Visceral Influences on Behavior*, 65 *ORG. BEHAV. & HUM. DECISION PROCESSES* 272, 274 (1996) [<http://perma.cc/3Z7C-VYTC>].

⁵⁶ Paul Slovic, *Perception of Risk*, 236 *SCIENCE* 280, 283 (1987) (citation omitted) (“[E]xpressed preference studies have shown that other (perceived) characteristics such as familiarity, control, . . . and level of knowledge also seem to influence the relation between perceived risk, perceived benefit, and risk acceptance.”) [<http://perma.cc/6JJJ-ZMYJ>].

⁵⁷ *Id.* at 282–83 (example of psychometric data).

⁵⁸ Mutcherson, *supra* note 7, at 252.

⁵⁹ See *id.*; see also B. Jessie Hill, *Medical Decision Making by and on Behalf of Adolescents: Reconsidering First Principles*, 15 *J. HEALTH CARE L. & POL’Y* 37, 72–73 (2012) [<http://perma.cc/UXZ5-Z7F3>].

⁶⁰ Rhonda Gay Hartman, *Adolescent Autonomy: Clarifying an Ageless Conundrum*, 51 *HASTINGS L.J.* 1265, 1269 (2000).

⁶¹ *In re Gault*, 387 U.S. 1, 13 (1967) (“[N]either the Fourteenth Amendment nor the Bill of Rights is for adults alone.”) [<http://perma.cc/GJ4Z-AK2E>].

⁶² *Id.* The Court has also held that when persons under eighteen are prosecuted in the adult criminal justice system, they retain basic constitutional rights in those proceedings. See, e.g., *In re Winship* 397 U.S. 358, 368 (1970) (stating that minors are entitled to be found guilty “beyond a reasonable doubt”) [<http://perma.cc/Y8F2-H5MM>]; *Gallegos v. Colorado*, 370 U.S. 49, 54–55 (1962) (stating that a minor, without adult guidance, may not appreciate his constitutional rights before giving a confession) [<http://perma.cc/TC4U-TLXU>]; *Haley v. Ohio*, 332 U.S. 596, 601 (1948) (stating that “recitals which merely formalize constitutional requirements” do not sufficiently protect minors’ constitutional rights) [<http://perma.cc/BQ8P-9CEC>].

III. ADULTS AND BIASED DECISIONMAKING

Despite the strong justifications for parental control over an adolescent's decisionmaking, there may be some reason to reevaluate the current parental decisionmaking model in health care settings. A growing volume of scholarship on decisional biases suggests that adults fall prey to biases that distort their decisionmaking.⁶³ The term "bias" in psychology and decision theory refers to cognitive shortcuts that make storing, retrieving, and interpreting information faster and more efficient.⁶⁴ While these shortcuts are often adaptive,⁶⁵ they can lead to errors. Psychologists who study human behavior and judgment have identified numerous biases that could influence choice. The overoptimism bias, probability neglect, the availability heuristic, and the confirmation bias are several empirically demonstrated psychological phenomena that are particularly likely to be factors for parents and other adults who are faced with terminal illness in their child. These biases are robust, pervasive, and stubborn, and can lead to suboptimal decisionmaking.

A. Overoptimism Bias

Human beings are positive thinkers.⁶⁶ When individuals make predictions about their future career, their children's success, and the longevity of their own marriage, they vastly overestimate the likelihood of positive outcomes.⁶⁷ The bias is highly adaptive; a positive outlook on life

⁶³ Articles in law reviews and journals in psychology, political science, economics, communication, business, medicine, ethics, and other disciplines have discussed the role of biases in criminal behavior, investing, public panics, environmental degradation, negotiation, public health, political participation, charging decisions and plea bargaining, risk assessment, and many, many other areas. See generally Robert S. Adler, *Flawed Thinking: Addressing Decision Biases in Negotiation*, 20 OHIO ST. J. ON DISP. RESOL. 683 (2005); Shi-Ling Hsu, *The Identifiability Bias in Environmental Law*, 35 FLA. ST. U. L. REV. 433 (2008) [<http://perma.cc/D832-8MUA>]; M.V. Rajeev Gowda, *Heuristics, Biases, and the Regulation of Risk*, 32 POL'Y SCI. 59 (1999); Molly J. Walker Wilson, *Behavioral Decision Theory and Implications for the Supreme Court's Campaign Finance Jurisprudence*, 31 CARDOZO L. REV. 679 (2010) [<http://perma.cc/4SGK-CKSE>].

⁶⁴ See generally Amos Tversky & Daniel Kahneman, *Judgment Under Uncertainty: Heuristics and Biases*, in JUDGMENT UNDER UNCERTAINTY: HEURISTICS AND BIASES 3 (Daniel Kahneman et al., eds., 1982) (first defining biases as irrational patterns of human decisionmaking). See also Jon D. Hanson & Douglas A. Kysar, *Taking Behavioralism Seriously: The Problem of Market Manipulation*, 74 N.Y.U. L. REV. 630, 633 (1999) (defining biases as "cognitive illusions") [<http://perma.cc/4SGK-CKSE>].

⁶⁵ See generally Herbert A. Simon, *A Behavioral Model of Rational Choice*, 69 Q. J. ECON. 99 (1955) (proposing that decisionmakers use shortcuts) [<http://perma.cc/N6UY-2BT8>].

⁶⁶ See Neil D. Weinstein, *Unrealistic Optimism About Future Life Events*, 39 J. PERSONALITY & SOC. PSYCHOL. 806, 806 (1980) (describing this phenomenon as "unrealistic optimism") [<http://perma.cc/X5FG-YNEQ>].

⁶⁷ See Neil D. Weinstein & William M. Klein, *Unrealistic Optimism: Present and Future*, 15 J. SOC. & CLINICAL PSYCHOL. 1, 2 (1996) (emphasis omitted) (defining optimistic bias as the tendency to underestimate the "likelihood . . . of experiencing negative events"). For example, although estimated divorce rates hover between 35% and 50%, on their wedding day, couples tend to predict a zero chance of divorce. Lynn A. Baker & Robert E. Emery, *When Every Relationship Is Above Average: Perceptions and Expectations of Divorce at the Time of Marriage*, 17 L. & HUM. BEHAV. 439, 443 (1993).

increases the likelihood of success.⁶⁸ Optimism is also crucial for maintaining happiness.⁶⁹ In spite of the protective effect of positive predictions, overoptimism can interfere with rational decisionmaking.⁷⁰ Unrealistic hopefulness can cause parents to choose for their children drastic, painful, and costly treatment options that are unlikely to help and may decrease quality of life.

B. Probability Neglect

The term “probability neglect” refers to the tendency of people to ignore known probabilities when making a decision.⁷¹ For example, when asked initially about the practice of wearing a seatbelt, respondents overwhelmingly judge seatbelts to increase the safety of the passenger of a car.⁷² However, when asked to think about being trapped in a car in an emergency, respondents devalue seatbelts, in spite of contradictory probabilistic data.⁷³ Social scientists hypothesize that people fail to use probabilities in making decisions because statistics are abstract and seem disconnected from the real human problem that the decisionmaker confronts.⁷⁴ From an evolutionary perspective, this makes sense. When the ancestors of modern humans were confronted with a charging lion, they had to rely upon gut intuitions. Probabilistic information was not available and following instinct was the best choice.

For the parent with a critically ill child, maximizing good for the child may be eschewing the most aggressive treatment, or it may be not treating at all. The tendency of parents of an ill child to ignore or misinterpret a low probability of treatment success—particularly in tandem with the optimism bias—might lead a parent to reject the notion that a cure is unlikely. The parent, relying on an instinct to save his child, would then opt for the more aggressive form of treatment.

C. Availability Heuristic

When an event is cognitively available, people readily bring it to

⁶⁸ Tali Sharot, *The Optimism Bias*, 21 CURRENT BIOLOGY R941, R944 (2011) [<http://perma.cc/W6UD-RRST>].

⁶⁹ See generally Robert A. Cummins & Helen Nistico, *Maintaining Life Satisfaction: The Role of Positive Cognitive Bias*, 3 J. HAPPINESS STUD. 37 (2002). The group that is least likely to exhibit the overoptimism bias is the clinically depressed. See SHELLEY E. TAYLOR, POSITIVE ILLUSIONS: CREATIVE SELF-DECEPTION AND THE HEALTHY MIND 212–14 (1989).

⁷⁰ Cf. Robert A. Prentice, *The Case of the Irrational Auditor: A Behavioral Insight into Securities Fraud Litigation*, 95 NW. U. L. REV. 133, 152–56 (2000) (reviewing the negative effects of “undue optimism” on the rationality of auditors).

⁷¹ Cass R. Sunstein, *Probability Neglect: Emotions, Worst Cases, and Law*, 112 YALE L.J. 61, 62–63 (2002) [<http://perma.cc/6Q73-WXAE>].

⁷² *Id.* at 71.

⁷³ *Id.*

⁷⁴ Cf. Paul Slovic et al., *The Affect Heuristic*, in HEURISTICS AND BIASES, THE PSYCHOLOGY OF INTUITIVE JUDGMENT 401–03 (Thomas Gilovich et al. eds., 2002) (describing experiments in which subjects acted irrationally despite knowing probabilities of the possible outcomes).

mind, and as a result, judge it to be more common. Events become cognitively available when examples appear repeatedly, when the event or account is recent, or when the event is described using vivid language or images.⁷⁵ A commonly cited example occurs when a commercial jet crashes.⁷⁶ Because a large plane crash is considered newsworthy, it gets media attention. News accounts, along with photographs and descriptions of the event are broadcast and rebroadcast. Media outlets most often favor and choose images that are dramatic, vivid, and therefore particularly memorable. As a result, individuals overestimate the frequency of such crashes. This over-estimation translates to unreasonable attitudes about the risks posed by air travel.

Tragedies are not the only stories that get reported widely. Miracle cures are also likely to get press. In 1989, a survey of medical reporters found that recently hired medical reporters overwhelmingly favored stories about new treatments and drugs over stories on issues related to access, ethics, or health care policy.⁷⁷ As is true with all reporting, decisions about what to report and how to report it are made with the public's interest (but not necessarily the public's best interest) in mind.⁷⁸ According to Dr. Arthur Caplan, director of the Center for Biomedical Ethics at the University of Minnesota, "You can stack up a mountain of tapes of stories on the recent Pittsburgh baboon-liver transplant."⁷⁹ Such stories are overrepresented in media outlets, and they focus on very rare events.⁸⁰ Miracles are newsworthy precisely because they are so unexpected.

Parents of very ill children are highly motivated to find cures, and they often seek them out. For parents searching for treatments, these miracle stories are what is cognitively available. As a result, parents making decisions about a terminally ill child may have an unrealistic view of the likelihood of benefiting from novel or rare therapies.

⁷⁵ Molly J. Walker Wilson, *The Expansion of Criminal Registries and the Illusion of Control*, 73 LA. L. REV. 509, 552 (2013) ("Research demonstrates that recent or frequent events, and events or depictions that are vivid or emotionally loaded, are particularly likely to become cognitively available.") [<http://perma.cc/368K-VPMR>].

⁷⁶ See, e.g., Molly J. Walker Wilson, *A Behavioral Critique of Command-and-Control Environmental Regulation*, 16 FORDHAM ENVTL. L. REV. 223, 242 (2005) (citing Tversky & Kahneman, *supra* note 64, at 11).

⁷⁷ Gary J. Schwitzer, *Doctoring the News: Miracle Cures, Video Press Releases and TV Medical Reporting*, QUILL, Nov.–Dec., at 19, 20 (1992) [<http://perma.cc/7YMR-W5PJ>].

⁷⁸ A study of the top newspapers and top medical journals concluded that carefully controlled studies were "too boring or incremental to get press coverage" and that "mainstream media prefer weak observational studies" with splashy headlines. Hank Campbell, *Scare Journalism and Miracle Cures: American Media Prefer Weak Observational Studies*, SCI. 2.0 (Jan. 24, 2014, 9:26 AM), http://www.science20.com/science_20/scare_journalism_and_miracle_cures_american_media_prefer_weak_observational_studies-128393 (reporting on Senthil Selvaraj et al., *Media Coverage of Medical Journals: Do the Best Articles Make the News?*, 9 PLOS ONE 1 (2014) [<http://perma.cc/FYD2-2JQP>]) [<http://perma.cc/52VA-ZDPJ>].

⁷⁹ Schwitzer, *supra* note 77, at 20. As Caplan notes, this story originally impacted one patient. *Id.*

⁸⁰ *Id.*

D. Confirmation Bias

For parents caring for a critically ill child, the confirmation bias can work in tandem with both probability neglect and the availability heuristic to skew judgment and distort choice formation. The confirmation bias relates to the tendency of individuals to selectively look for information that supports a favored view.⁸¹ A commonly cited context in which this bias operates is in prosecutors' charging decisions.⁸² When a prosecutor adopts a theory of how a crime occurred or focuses on a person of interest, he or she will often selectively look for evidence that confirms that theory. The related concept of "tunnel vision" explains how individuals often focus only on data that falls within the scope of the theory, both "seeing" that which supports the theory and *not* perceiving that which would tend to discredit it.⁸³

The confirmation bias has been demonstrated in empirical investigations of judgment and choice.⁸⁴ One popular study format involves researchers testing the attitude of participants on various issues prior to exposing them to ambiguous or conflicting information. Following the presentation of the information, the researchers re-question the participants. Results of this study reveal that attitudes tend to be stronger after exposure to the information; participants appear to interpret the information in a way that is consistent with their prior beliefs—regardless of what those beliefs were.⁸⁵ Findings supporting the existence of the confirmation bias are robust, and the bias is found in a wide range of decisionmaking contexts.⁸⁶ In medical settings, for example, patients have been shown to perceive a physician's actions through the lens of this bias.⁸⁷

Other cognitive patterns likely interact with confirmation bias. For

⁸¹ Alafair Burke, *Neutralizing Cognitive Bias: An Invitation to Prosecutors*, 2 N.Y.U. J.L. & LIBERTY 512, 516–17 (2007) [<http://perma.cc/TCM6-9ZMQ>].

⁸² See, e.g., *id.*

⁸³ *Id.* at 517.

⁸⁴ Raymond S. Nickerson, *Confirmation Bias: A Ubiquitous Phenomenon in Many Guises*, 2 REV. GEN. PSYCHOL. 175, 177 (1998) [<http://perma.cc/Q4PG-695P>].

⁸⁵ In the late 1970s, researchers studied supporters and opponents of the death penalty. Pro- and anti-death penalty participants read a balanced essay that presented both evidence that capital punishment deters crime and evidence that it does not deter crime. The researchers then re-questioned the participants about their views. They found that participants in each group held their views even more strongly than they had prior to reading the essay. Apparently, they had interpreted the information they read in a way that was consistent with their preferred view. DANIEL GARDNER, *THE SCIENCE OF FEAR: WHY WE FEAR THE THINGS WE SHOULDN'T—AND PUT OURSELVES IN GREATER DANGER* 111 (2008).

⁸⁶ See generally Stephanie Eckman & Frauke Kreuter, *Confirmation Bias in Housing Unit Listing*, 75 PUB. OPINION Q. 139 (2011); Anna Harvey & Michael J. Woodruff, *Confirmation Bias in the United States Supreme Court Judicial Database*, 29 J.L. ECON. & ORG. 414 (2011) [<http://perma.cc/K2QZ-TPPJ>]; Carole Hill et al., *The Role of Confirmation Bias in Suspect Interviews: A Systematic Evaluation*, 13 LEGAL & CRIMINOLOGICAL PSYCHOL. 357 (2008); Franziska Tschan et al., *Explicit Reasoning, Confirmation Bias, and Illusory Transactive Memory: A Simulation Study of Group Medical Decision Making*, 40 SMALL GROUP RES. 271 (2009).

⁸⁷ Daniel Young, *Curing What Ails Us: How the Lessons of Behavioral Economics Can Improve Health Care Markets*, 30 YALE L. & POL'Y REV. 461, 486 (2012) [<http://perma.cc/K37C-BGX3>].

example, discounting negative probabilistic evidence is one form of tunnel vision. An actor who is motivated not to attend to disheartening statistical data is particularly likely to under-weigh this information when making a decision. The confirmation bias also influences behavior in ways that impact on cognitive availability. Searching for treatment options—and resulting success stories—increases exposure to this type of information, intensifying the cognitive availability and hence perceived efficacy of these options. In sum, the more cognitively available treatment success stories are, the easier it is to believe them to be common—or at least possible—a judgment that is bolstered by the motivation an individual has to believe that a cure could be a reality.

E. Effects of Bias on Parental Decisionmaking

The aforementioned biases can work together in the medical treatment context. Consider the following scenario. A parent has a child with a malignant brain stem glioma—an inoperable, invasive brain tumor. The sixteen-year-old child has resisted the recommended combination of chemo- and radiotherapies. As a result of the toxicity of the treatment, these therapies are quite difficult to endure. Without the therapies, the child will die. Even with the full range of possible therapies, the prognosis is quite poor. Oncologists have explained that the five-year survival rate hovers around fifteen percent. The parent's preference is to try anything and everything to save the child. The child has repeatedly and forcefully opposed any treatment and has asked to return home to spend the brief time she has remaining with family.

The parent starts with an overly optimistic outlook on her child's prognosis. She has unrealistic expectations, even in the face of sobering information about the aggressiveness of the cancer. The treating oncologists have explained the prognosis in probabilistic terms. The parent understands the data as it was presented to her, but she does not give that information the weight it deserves when considering the options. In an effort to stay actively informed, and hoping that she might turn up novel therapies, the parent has spent many hours researching cures. Although much of her search has resulted in pessimistic accounts, through sheer effort and creative searches she has turned up several stories of patients with similar diagnoses miraculously recovering. She has bookmarked the Internet sites with miracle stories and has returned to them repeatedly. With each visit back to the sites, her sense of hope and her estimates of the chance of a cure increase.

In a situation like the one described here, there is no single correct decision. For that matter, it is difficult to know what “most” people would choose. The parent's instinct to save her child is understandable, even noble. The child's desire not to suffer through painful, and likely ineffective, treatments is reasonable. On the one hand, it is the child's body and life. She is the one who will suffer, either way. On the other hand, over

the years, the parent has made many choices about the child's body—what she puts in it in terms of food, what activities she engages in, how she is dressed on a cold day, and how she stays hydrated on a hot one. Few in our society would question the wisdom of giving the parent control over these decisions for her children—even when the child occasionally opposes a parental decision. When a fit, loving parent makes an informed decision about her minor child, it seems presumptively correct. But there are features of the terminally ill child context that suggest that this presumption at least be questioned.

IV. A PROPOSAL FOR FAMILY DECISIONMAKING

Hospitals and health care providers routinely include parent preferences in decisions about the appropriate treatment.⁸⁸ Studies of parent–physician interactions reveal that parents often influence treatment proposals, even when a provider is not conscious of the extent to which the parent is exerting influence.⁸⁹ Frequently, the assumption is that, for an older child, the parent's decision is informed at least in part by the wishes of the child. In cases where the wishes of the parent and the child diverge, the question is whether there is a viable alternative to traditional deference to the parent. For a variety of reasons discussed in Parts I and II of this Essay and articulated by the Supreme Court on several occasions,⁹⁰ parents should retain some measure of control over treatment choices. However, respect for the parent can coexist with involvement of the child in the decisionmaking process, and, as discussed earlier, there are important reasons why an older minor should have a significant voice in the course of treatment.

A better model can be found by looking at recent hospital innovations in dealing with the ethical issues that arise from difficult healthcare decisions. Ethical considerations have become increasingly salient in the acute care context, both because new technologies have increased the potential for prolonging life, and also because of cases like *Cruzan v.*

⁸⁸ For example, the Children's Hospital of Wisconsin has a website explaining that: Specific treatment for brain tumors will be determined by your child's physician based on:

- Your child's age, overall health and medical history.
- Type, location, and size of the tumor.
- Extent of the disease.
- Your child's tolerance for specific medications, procedures or therapies.
- Expectations for the course of the disease.
- **Your opinion or preference.**

Brain Tumors, CHILD. HOSP. OF WIS. (emphasis added), <http://www.chw.org/medical-care/macc-fund-center/conditions/oncology/brain-tumors> (last visited Mar. 16, 2015) [<http://perma.cc/7PVD-GTU7>]. Note that there is no mention of the child's opinion or preference. In light of the current state of the law, this is altogether typical and proper.

⁸⁹ Tanya Stivers, *Parent Resistance to Physicians' Treatment Recommendations: One Resource for Initiating a Negotiation of the Treatment Decision*, 18 HEALTH COMM., 41, 67–68 (2005) [<http://perma.cc/6W5Y-F32Z>].

⁹⁰ See *supra* Part I.

*Director, Missouri Department of Health.*⁹¹ Faced with complex legal and ethical situations involving terminal patients in a variety of situations, hospitals have instituted ethics committees to consult in difficult cases. Nancy Dubler and Leonard Marcus write: “[The] recognition that thorny ethical issues are sometimes best tackled from within has left hospitals, long-term care facilities, and some home care agencies to create ethics committees or hire ethics consultants.”⁹² Committees, however, spend a significant amount of time not in case consultation, but in developing and evaluating hospital policy.⁹³ As a result, they may not be ideally situated to meet the needs of the individual patients and families.

In lieu of a committee, a bioethical mediator, whether operating under the nomenclature “ethical consultant” or “clinical ethicist,”⁹⁴ can provide a bridge between parties who disagree and can help individuals to recognize the exogenous factors that might be affecting their preferences.⁹⁵ When an adolescent has a preference that is different from her parents, a bioethical mediator can help the child and the parents reach a compromise that is acceptable for all parties. Alternatively, a mediator can provide an objective perspective and, properly trained, can assess the biases that are influencing preferences.

When a child is facing life-threatening illness or injury, a bioethical mediator can help to manage a number of competing considerations. One is to keep parents comforted and engaged. Parents contemplating the end of their child’s life are already in a state of emotional turmoil. Heavy-handed interference by medical professionals or state actors who threaten to further strip them of control where their child is concerned will do more harm than good. Without parental support, a child is less likely to thrive under optimal circumstances, to say nothing about when the child’s health is seriously compromised.⁹⁶ Moreover, the child who is at the center of conflict will

⁹¹ *Cruzan v. Dir., Mo. Dep’t of Health* 497 U.S. 261 (1990) [<http://perma.cc/5TVT-WBEN>]. In *Cruzan*, the Court held that competent persons have a Fourteenth Amendment liberty interest in refusing any and all medical treatments. *Id.* at 278. However, the Court also indicated that an “incompetent” patient may not have the same right to refuse treatment because of the lack of informed consent, but surrogates may be empowered to make such decisions for patients. *Id.* at 280. The Court ruled that particular family members need not automatically become authorized surrogates; instead, states can impose their own requirements for surrogacy. *Id.* at 285–87. Another well-known case that preceded *Cruzan* was *In re Quinlan*, 355 A.2d 647 (N.J. 1976) [<https://perma.cc/LG3E-VTL2>], in which the parents of Karen Quinlan, a young woman who was in a persistent vegetative state, went to court to be permitted to remove artificial life-sustaining treatment. In 1976, the New Jersey Supreme Court ruled in the family’s favor.

⁹² NANCY NEVELOFF DUBLER & LEONARD J. MARCUS, *MEDIATING BIOETHICAL DISPUTES: A PRACTICAL GUIDE* 4 (1994).

⁹³ Cf. Gail J. Povar, *Evaluating Ethics Committees: What Do We Mean by Success?*, 50 MD. L. REV. 904, 908 (1991) (“Numerous authors have envisioned policy generation as one of the more important tasks of institutional ethics committees.”) [<http://perma.cc/WCJ4-ERBK>].

⁹⁴ Dubler & Marcus, *supra* note 92, at 7.

⁹⁵ *Id.*

⁹⁶ Cf. Jianghong Li et al., *Parents’ Nonstandard Work Schedules and Child Well-Being: A Critical Review of the Literature*, 35 J. PRIMARY PREVENTION 53, 57 (2003) (“Attachment, psychoanalytic, and family theorists have emphasized the importance of the parent–child relationship in developing children’s trust and a sense of identity. . .”).

experience psychic distress, and this can further exacerbate her medical condition. If the child's wish to forego particular treatments is at the heart of the conflict, intervening between the parent and the child might damage the relationship and result in feelings of resentment in the parents and guilt in the child. Furthermore, parents who are losing their child to illness may exhibit predictable patterns of bias discussed previously that cloud their judgment. Irrational thinking can be particularly strong for individuals who are facing devastating outcomes. The prevalence of these biases is more pronounced when considered along with the stages-of-grief model developed in 1969 by clinical psychologist Elisabeth Kübler-Ross.⁹⁷ The first state of grief experienced by parents facing the death of a child is *denial*.⁹⁸ Overly optimistic expectations about the potential for improvement and selective searches for information that confirms a hopeful prognosis are fundamental aspects of the denial stage. For parents who are making decisions while in this stage of coping, a genuine desire to make the best decision for the child is often not sufficient to overcome the cognitive and emotional roadblocks. Bioethical mediators are well-situated to track and address each of these potential dilemmas.

Ultimately, the best decisions will be made in a cooperative environment, where biases and irrationalities can be kept in check by countervailing perspectives. Where there is conflict between the wishes of the two parents or between the wishes of the parents and those of the child, a trained bioethical mediator can help guide the parties toward a resolution.⁹⁹ Bioethical mediators can, in many instances, help the parties to avoid conflict altogether by maintaining open communication and helping the patient and family members to suspend judgment while the perspectives of each individual are explored.¹⁰⁰ As one commentator has put it, "Mediation can help clarify: the interests and rights of the parties; the issues on which the parties disagree; and a resolution that respects the best interest of the patient and the integrity of the provider."¹⁰¹ A successful mediator is neutral and trained to recognize the biases mentioned in this

⁹⁷ See D. Christian Addicott, *Regulating Research on the Terminally Ill: A Proposal for Heightened Safeguards*, 15 J. CONTEMP. HEALTH L. & POL'Y 479, 497-99 (1999) [<http://perma.cc/4JF7-LSWE>]. Elisabeth Kübler-Ross argued in her seminal work, *On Death and Dying*, that patients progress through a series of six set stages: first shock, then denial, anger, bargaining, depression, and finally acceptance. See generally ELISABETH KÜBLER-ROSS, *ON DEATH AND DYING* (1969).

⁹⁸ Cf. Kübler-Ross, *supra* note 97, at 34-43.

⁹⁹ Bioethics mediators are trained to understand the issue that face patients and to help the patient and family members communicate clearly desires and concerns.

¹⁰⁰ One lawyer who has represented patients remarked, "If we had been better communicators, or if a bioethics mediator had been called in instead of the hospital lawyer and then a judge . . . [we] . . . would have explored what Mrs. P's true interests were and what she was trying to communicate when she took the no-injection position." Carol B. Liebman, *Introduction to the Symposium Issue on Alternative Dispute Resolution Strategies in End-of-Life Decisions*, 23 OHIO ST. J. ON DISP. RESOL. 1, 3 (2007).

¹⁰¹ *Using Mediation for Bioethical Dilemmas*, 13 ALTERNATIVES TO THE HIGH COST OF LITIG. 159, 159 (1995).

Essay as well as other biases that might be influencing the parties. By gently probing the bases for parents' and adolescents' attitudes and preferences, the mediator can encourage recognition of unrealistic assumptions that may be the sources of disagreement. When all parties have a clearer sense for the costs and benefits of various treatment options, there is greater opportunity for the parents and child to engage in an informed and productive discussion.

CONCLUSION

When it comes to treatment options for critically ill adolescents, the wishes of the mature minor may or may not be respected. Until a child reaches the age of eighteen, her parents are the presumptive decisionmakers. There are good reasons for parental deference. Some of these reasons are historical, some are based upon Supreme Court precedent and parental rights, and some relate to incomplete cognitive development of older minors. Nevertheless, if the goal is to promote good decisionmaking, an adolescent patient should have a role in deciding on treatment. This Essay has argued that the existing singular focus on the limits of adolescents' capacity is misplaced; it has also suggested that biases can influence parents' choices. Several biases described in the Essay suggest in particular that parents may push for aggressive therapies that are unlikely to be efficacious in light of medical evidence. Particularly in situations where the child prefers to forego these treatments, this choice may ultimately be optimal for the child.

Where the wishes of the parents and child diverge, a bioethical mediator can serve an important role, helping the family reach a decision that is comfortable for everyone. A successful mediator will identify the limitations of each individual involved, while also acknowledging the important roles of both adolescent and parents. When it comes to selecting among treatment options for a critically ill adolescent, there is often no single, obviously correct choice. Including parents' *and* adolescents' perspectives regarding treatment improves the decisionmaking process, while simultaneously legitimizing the vital role that each individual has in the ultimate outcome.