

**DePaul Law Review** 

Volume 45 Issue 4 *Summer 1996: Symposium -Telecommunications Regulation in an Era of Convergence* 

Article 10

# The Potential Right of Chronically III Adolescents to Refuse Life-Saving Medical Treatment - Fatal Misuse of the Mature Minor Doctrine

Jessica A. Penkower

Follow this and additional works at: https://via.library.depaul.edu/law-review

## **Recommended Citation**

Jessica A. Penkower, *The Potential Right of Chronically III Adolescents to Refuse Life-Saving Medical Treatment - Fatal Misuse of the Mature Minor Doctrine*, 45 DePaul L. Rev. 1165 (1996) Available at: https://via.library.depaul.edu/law-review/vol45/iss4/10

This Comments is brought to you for free and open access by the College of Law at Via Sapientiae. It has been accepted for inclusion in DePaul Law Review by an authorized editor of Via Sapientiae. For more information, please contact digitalservices@depaul.edu.

# THE POTENTIAL RIGHT OF CHRONICALLY ILL ADOLESCENTS TO REFUSE LIFE-SAVING MEDICAL TREATMENT—FATAL MISUSE OF THE MATURE MINOR DOCTRINE

## INTRODUCTION

A court's consideration of whether to legally sanction an adolescent's<sup>1</sup> refusal of life-saving medical treatment<sup>2</sup> necessarily involves balancing significant ethical interests. On one side of the scale is the interest of the chronically ill adolescent who feels he or she cannot tolerate another day of illness and/or treatment.<sup>3</sup> On the other side is

2. This Comment primarily addresses the issues implicated when adolescents refuse "life-saving," not "life-sustaining," medical treatment. Refusal of life-saving treatment involves refusal of curative treatment, thus creating a "life or death" situation. Lisa Anne Hawkins, Note, *Living Will Statutes: A Minor Oversight*, 78 VA. L. REV. 1581, 1595 (1992). On the other hand, decisions regarding the discontinuation of life-sustaining treatment involve a "quality of life" inquiry. *Id.* at 1595-96. The term "necessary medical treatment" will be used interchangeably with "lifesaving medical treatment" throughout this Comment.

3. See infra notes 13-17 and accompanying text (discussing the case of Benny Agrelo, a twotime liver transplant patient who refused to continue his immunosuppressant regimen because of its debilitating side effects). Within the past several years, the media have reported stories similar to Benny's. One of the most publicized cases of adolescent noncompliance with life-saving medical treatment involved 16-year-old cancer patient Billy Best. Billy ran away from home for several weeks in October, 1994, with the intent of travelling from Massachusetts to California by bus, because he could not cope with the hair loss, nausea and weakness from twice-monthly chemotherapy. John Ritter, Mass. Teen on the Run—from Chemotherapy, USA TODAY, Nov. 11, 1994, at 8A. In a note he left in his bedroom before leaving town, Billy explained, "The reason I left is because I could not stand going to the hospital every week. . . . I feel like the medicine is killing me instead of helping me." Morose, Boy with Cancer Runs Away, CHI. TRIB.,

<sup>1.</sup> The term "adolescence" is defined as "[t]hat age which follows puberty and precedes the age of majority." BLACK'S LAW DICTIONARY 49 (6th ed. 1990). Taken at face value, the dictionary definition provides a certain and measurable upper boundary of adolescence-a legislative designation of a chronological age. This author suggests, however, that adolescence is not so simplistic a concept. For more than two decades, psychologists and sociologists have generally recognized adolescents as a unique group of persons in our society. See FRANKLIN E. ZIMRING, THE CHANGING LEGAL WORLD OF ADOLESCENCE at xi (1982). They have acknowledged that while "the beginning of adolescence can be set quite accurately (as it is defined by the specific physiological criterion of sexual maturity), the terminal point of adolescence can only be approximated, for there is no sharp differentiation between adolescence and adulthood." DAVID KRECH ET AL., ELEMENTS OF PSYCHOLOGY 70 (2d ed. 1969). Legal doctrine has not yet been aligned with scientific data. As one commentator explains, "law and social science have been talking past each other on issues relating to adolescence for quite some time . . . [and] legal doctrines relating to adolescence frequently appear strained and are susceptible to gross misinterpretation." ZIMRING, supra, at xiii. This Comment illustrates Professor Zimring's observations by exploring the law's response to adolescents who refuse life-saving medical treatment.

the interest of society in preserving the adolescent's life.<sup>4</sup> Regardless of how the scale of ethics may tip, courts have historically refused to indulge in any sort of balancing of interests and have uniformly forbidden minors from making such weighty decisions for themselves.<sup>5</sup> Common law holds that any person under the age of majority is a minor<sup>6</sup> and is legally incapable of rendering or withholding consent for medical treatment.<sup>7</sup> The minor's intolerance for his or her illness and/or treatment is not legally relevant.

Recently, however, courts have begun to deviate from the common law maxim in order to allow certain chronically ill minors to discontinue necessary medical treatment.<sup>8</sup> The tool utilized by courts is the "mature minor doctrine," which permits a minor who exhibits the "maturity" of an adult to make decisions that traditionally have been reserved for persons who have attained the age of majority.<sup>9</sup> One

4. This interest is best illustrated by the State's *parens patriae* power. "Parens patriae" is defined as "the principle that the state must care for those who cannot take care of themselves, such as minors who lack proper care and custody from their parents." BLACK'S LAW DICTIONARY at 1114. See In re Hamilton, 657 S.W.2d 425, 429 (Tenn. App. 1983) ("[I]t is well-settled that the State as *parens patriae* has a special duty to protect minors and, if necessary, make vital decisions as to whether to submit a minor to necessary treatment where the condition is life threatening, as wrenching and distasteful as such actions may be."). The Supreme Court of Illinois also has stated that "[w]here the health care issues are potentially life threatening, the State's *parens patriae* interest is greater than if the health care matter is less consequential." In re E.G., 549 N.E.2d 322, 327 (Ill. 1989).

5. See E.G., 549 N.E.2d at 328 (Ward, J., dissenting) (referring to "the ancient responsibility of the State as parens patriae to protect minors and to decide for them ... vital questions, including whether to consent to or refuse necessary medical treatment."); Dan W. Brock, *Children's Competence for Health Care Decisionmaking*, in CHILDREN AND HEALTH CARE: MORAL AND SO-CIAL ISSUES 181, 181 (Loretta M. Kopelman & John C. Moskop eds., 1989) ("The general presumption then in legal policy is that adults are entitled to decide about their medical care while children are not.").

6. A "minor" is "[a]n infant or person who is under the age of legal competence." BLACK'S LAW DICTIONARY at 997. The age of majority in all states is now 18. ANGELA R. HOLDER, LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE 129 (2d ed. 1985) [hereinafter HOLDER, LEGAL ISSUES].

7. See Brock, supra note 5, at 181 ("[T]he law presumes that minors ... are not competent to decide about their medical care .... [T]he law generally holds that others, usually parents or guardians, are to decide for them about their medical treatment."); Hawkins, supra note 2, at 1586 ("Traditional common law generally viewed minors as unable to make sound decisions about medical treatment; thus, it vested consensual authority in the parents ....").

8. See infra part I.C. (reviewing cases in which the mature minor doctrine has been invoked to allow adolescents to discontinue necessary medical treatment).

9. See JAMES M. MORRISSEY ET AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS 43 (1986) (explaining that the mature minor doctrine holds that "if a minor is of sufficient intelligence and maturity to understand and appreciate both the

Nov. 4, 1994, § 1, at 26. The news magazine television show Dateline, in a January, 1995 broadcast, reported the stories of several other chronically ill adolescents who have refused life-saving medical treatment because of intolerable side effects. *Dateline* (ABC television broadcast, Jan. 20, 1995).

may initially interpret this phenomenon as an expansion of the rights of minors, based upon judicial recognition that chronically ill adolescents are (or may be) as mature as adults.<sup>10</sup> However, as this Comment will demonstrate, "maturity" is not a well-defined legal term,<sup>11</sup> and the mature minor doctrine is more an instrument of paternalism than a conduit of liberty for adolescents.<sup>12</sup> The doctrine is nonetheless capable of effecting drastic consequences. This Comment will explore the anomaly of adolescents being afforded the right to refuse life-saving medical treatment purportedly on the basis of their "maturity." Such anomaly is aptly illustrated by the following case.

During the summer of 1994, fifteen-year-old Benny Agrelo, a twotime liver transplant recipient residing in Florida, was given permission by a Broward County Juvenile Court judge to stop taking immunosuppressant drugs necessary to sustain his life.<sup>13</sup> Benny had previously discontinued his anti-rejection regimen because it caused him to suffer debilitating headaches and severe irritability.<sup>14</sup> When Florida's Department of Health and Rehabilitative Services learned that Benny had stopped taking his medication, Benny was forcibly taken from his home on grounds of alleged medical neglect.<sup>15</sup> At the hospital, Benny refused to have a biopsy or blood tests performed or to take any medication.<sup>16</sup> After four days, the judge vacated the agency's detention order, and Benny was permitted to go home, discontinue treatment, and ultimately die.<sup>17</sup>

Benny's case, widely publicized in the popular press, has elicited responses varying from supportive to outraged to bewildered.<sup>18</sup> As

11. See infra part II.B. (analyzing the definitional shortcomings of the mature minor doctrine).

14. Id.

15. Tom Lassiter & Barbara Walsh, Liver Patient Urges Teen To Take Medicine, ORLANDO SENTINEL, June 15, 1994, at B6.

16. Christine Gorman, A Sick Boy Says "Enough!", TIME, June 27, 1994, at 65.

17. Id.

benefits and risks of the proposed medical or surgical treatment, then the minor may consent to that treatment without parental consent . . . . "); see also infra part I.B.4. (discussing the mature minor doctrine generally).

<sup>10.</sup> Such an interpretation is suggested by the Illinois Supreme Court. See, e.g., In re E.G., 549 N.E.2d 322, 327-28 (Ill. 1989) ("If the evidence is clear and convincing that the minor is mature enough to . . . exercise the judgment of an adult, then the mature minor doctrine affords her the common law right to consent to or refuse medical treatment.").

<sup>12.</sup> See infra part II.A. (positing that paternalism is a primary motivation for the mature minor doctrine).

<sup>13.</sup> Nancy San Martin, *Suffering Ends for Brave Teen-Ager*, ORLANDO SENTINEL, August 21, 1994, at B7.

<sup>18.</sup> See, e.g., Amy Driscoll, Ailing Teen Struggles with Crush of Publicity, MIAMI HERALD, June 16, 1994, at A1 (reporting that before his death, Benny Agrelo was overwhelmed by phone calls, letters, and gifts, and was being hounded to accept made-for-TV movie offers and magazine and television interviews); Gorman, supra note 16, at 65 (quoting Dr. Andrew Klein, a liver-

one author explains it, "Benny's story seems to be yet another case of a patient asserting his right to die when medicine can only prolong suffering. The twist is that Benny is still, in the eves of the law, a child who cannot make such weighty decisions on his own."<sup>19</sup> It is this "twist" that grabs the attention of the critical legal mind. Benny's case is not simply a quirk in the legal system; rather, it reflects a fusion of highly complex legal and ethical issues that have not been sufficiently. explored by the courts. Whether Benny was forced to remain alive and suffer the side effects of his medication or, as the case turned out, permitted to die, society is uncomfortable with both alternatives.<sup>20</sup> One cannot help but wonder whether Benny, as he matured into an adult, would have better tolerated his physical pain and "outgrown" his emotional anguish. It is this uncertainty, coupled with the novelty of legally sanctioning a fifteen-year-old's resolution to die, that commands the legal community to examine the soundness of this line of legal decisions.

Ultimately, there is neither a legal nor ethical "answer" to the question of whether a chronically ill minor—specifically an adolescent has the right to discontinue life-saving medical treatment. Nonetheless, Benny Agrelo's case, among others,<sup>21</sup> seems to have blurred the distinction between the rights of adults and minors to refuse life-saving medical treatment. Thus, it is imperative for the legal community not only to be well-informed of the judicial doctrines that determine the allocation of decision-making authority regarding adolescent

19. Gorman, supra note 16, at 65.

20. See, e.g., id. ("Benny... seems not only too young to die but also too young to want to."). In other "right to die" cases, however, courts have taken the position that it is not the place of the medical community to inflict upon a suffering individual the burden of remaining alive. See, e.g., Bouvia v. Super. Ct., 179 Cal. App. 3d 1127, 1143 (1986) ("It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure.").

21. See infra part I.C. (discussing cases in which courts have permitted adolescents to discontinue life-saving medical treatment).

transplant specialist at Johns Hopkins Medical School: "Considering the severe shortage of organ donors, I think there is a moral obligation to take care of the organ you receive as best you can."). Dr. Klein explained, however, that preserving an organ should not be at the expense of maintaining some "semblance of pleasure in life." *Id.*; Lassiter & Walsh, *supra* note 15 (quoting a 61-year-old liver transplant patient who wished to persuade Benny Agrelo to continue taking his medication and to tell him: "I know about the headaches you've had. It's not a good feeling. It's discouraging, I know that. To tell you the truth, sometimes I felt like throwing in the towel."); Melanie McFarland, *Fresh Starts; Transplant Patients Don't Prescribe Ever Giving Up*, CHI. TRIB., Aug. 23, 1994, at 1 (quoting a 14-year-old kidney transplant recipient who found it hard to understand why Benny Agrelo chose to die over taking his medication: "He had a whole life ahead of him, and he should have taken his medicine."). McFarland also quotes a registered nurse and clinical ethicist who maintained the opinion that "[i]f he was in that much pain and he felt he was going to die anyway, I can't blame him for that choice." *Id*.

health care, but also to develop a comprehensive understanding of how chronically ill minors, who experience a significant disruption of adolescence, cope and develop over the long term.

This Comment evaluates the legitimacy of what appears to be an evolving right of adolescents to refuse necessary medical treatment, in light of recent research on the psychological, social, and emotional experience of chronically ill adolescents. First, this Comment reviews the philosophical basis of the right to refuse medical treatment and explores how adults may practically invoke that right. It then examines the rights of minors in the health care context and details the evolution of the mature minor doctrine. Finally, it explores the psychosocial development of chronically ill adolescents in an attempt to explain why ill adolescents may refuse necessary medical treatment. In synthesizing this information, it will become apparent that the method of evaluating maturity under the mature minor doctrine is devoid of any substantive inquiry into the unique experience of the chronically ill adolescent and that there is a rather attenuated nexus between the right to refuse necessary medical treatment and the adolescent's ability to make an informed life or death decision. Therefore, the Comment concludes that it is inappropriate to legally sanction a minor's refusal of necessary medical treatment under the current formulation of the law.

## I. BACKGROUND

## A. The Right of Adults to Refuse Medical Treatment

The right of an adult to refuse medical treatment in present day America has its roots in this country's long-standing moral tradition of recognizing an individual's personal autonomy as inviolable.<sup>22</sup> The law continues to respect human dignity by granting individuals the freedom to make certain choices about their lives that comport with their own values.<sup>23</sup>

1169

<sup>22.</sup> See Union Pacific Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.").

<sup>23.</sup> See HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREAT-MENT AND THE CARE OF THE DYING 7 (1987) ("Our ethical framework draws on the value of patient autonomy or self-determination, which establishes the right of the patient to determine the nature of his or her own medical care."). "Self-determination" describes "people's interest in making important decisions about their life for themselves according to their own values and aims." Brock, *supra* note 5, at 193.

In the realm of health care, personal autonomy notions are manifest in the doctrine of informed consent.<sup>24</sup> Informed consent generally requires a physician to disclose to a patient prior to performing any medical procedure his or her "diagnosis, the general nature of the contemplated procedure, the risks involved, the prospects of success, the prognosis if the procedure is not performed, and alternative medical treatment."<sup>25</sup> The patient may then have enough data to intelligently weigh the probable risks and benefits before deciding whether or not to submit to the proposed treatment.<sup>26</sup> Under the common law, a physician must obtain his or her patient's consent prior to administering any kind of medical treatment.<sup>27</sup> Thus, a surgeon who operates without first securing consent commits a battery and is liable for damages.<sup>28</sup>

The logical corollary to the doctrine of informed consent is the right to informed refusal.<sup>29</sup> Every competent adult has the right to forego all forms of medical intervention, including life-saving or life-prolonging treatment.<sup>30</sup> However, when an individual refuses life-sustaining treatment, the court may order the treatment if it determines that the individual's interest in self-determination is outweighed by one or a combination of four countervailing state interests.<sup>31</sup> Courts have

26. ZeBarth v. Swedish Hosp. Medical Ctr., 499 P.2d 1, 10 (Wash. 1972).

27. In re Estate of Longeway, 549 N.E.2d 292, 297 (Ill. 1989).

28. Schloendorff v. Society of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).

29. Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 270 (1990); see also In re Conroy, 486 A.2d 1209, 1222 (N.J. 1985) ("[T]he patient's ability to control his bodily integrity through informed consent is significant only when one recognizes that this right also encompasses a right to informed refusal.").

Decisions allowing adults to refuse life-sustaining medical treatment have also been premised upon the constitutional rights to privacy and liberty, *see, e.g., In re* L.H.R., 321 S.E.2d 716 (Ga. 1984) (holding that an incompetent adult's constitutional right to refuse treatment may be asserted by the family of the adult or legal guardian), and upon state statute, *see, e.g.*, Conservatorship of Drabick, 245 Cal. Rptr. 840 (Cal. Ct. App. 1988) (recognizing that California Probate Code § 2355 gives persons the right to determine the scope of their own medical treatment). For an in-depth discussion of the federal right to privacy, see *Longeway*, 549 N.E.2d at 296-97 (tracing the development of the federal right to privacy through caselaw).

30. Longeway, 549 N.E.2d at 297. For a detailed examination of the law governing the right to die, see generally ALAN MEISEL, THE RIGHT TO DIE (1989) (analyzing comprehensively the reported legal cases on the right to die and the related statutory enactments).

31. In re Guardianship of Grant, 747 P.2d 445, 451 (Wash. 1987).

<sup>24.</sup> See Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 269 (1990) (plurality opinion) ("This notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment.").

<sup>25. 3</sup> DAVID W. LOUISELL & HAROLD WILLIAMS, MEDICAL MALPRACTICE § 22.04(3)(a) (1995). There are several limitations to the informed consent requirement. Disclosure is not necessary where: (1) a risk of a particular treatment is common knowledge; (2) the patient affirmatively represents that he or she does not want the risks disclosed; (3) an informed consent is not reasonably possible; or (4) disclosure of the risks would substantially and adversely affect the patient's health. MORRISSEY ET AL., *supra* note 9, at 14-15.

identified these interests as (1) the preservation of life, (2) the protection of innocent third parties, (3) the prevention of suicide,<sup>32</sup> and (4) the maintenance of the ethical integrity of the medical profession.<sup>33</sup>

Although adults may refuse all forms of medical treatment absent any overriding state interest, in recent years the issue of whether there exists a constitutional right to die has generated considerable controversy within the medical and legal communities.<sup>34</sup> With the development of medical technology capable of sustaining life well past the point where, decades ago, natural forces would have brought certain death, the number of cases involving the right to refuse life-sustaining treatment have multiplied.<sup>35</sup> Right to die advocates on one side of the debate espouse that the individual's right to self-determination is ab-

33. In re Colyer, 660 P.2d 738 (1983). Incompetent adults possess the same rights as competent adults regarding bodily integrity, including the right to refuse medical treatment. Parry, supra note 32, at 470. However, because incompetent adults lack the legal capacity to make decisions concerning their medical treatment, someone acting as a surrogate must exercise the right to refuse treatment on their behalf. Id.; see, e.g., Superintendent of Belchertown v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) (holding that a state institution was permitted to withhold chemotherapy from a profoundly retarded 67-year-old man suffering from leukemia, by adopting a "substituted judgment" standard, whereby courts are to determine what the incompetent individual would decide if he or she were competent under the prevailing circumstances).

The balance between an incompetent adult's right to self-determination and the four state interests is somewhat altered where an individual is in a persistent vegetative state and has no medical probability of substantial recovery. Under such circumstances, the state's interest in the preservation of life has been held insufficient to outweigh the individual right; the state interest in the prevention of suicide has been considered inapplicable where there was no intent to die and where death would be the result of natural processes; the state interest in the protection of third parties has been held to be inapplicable where third parties themselves supported termination of treatment; and the state's interest in maintaining the ethical integrity of the medical profession has been held not to be contravened where the prevailing standards of medical ethics have not condemned the termination of treatment. 48 A.L.R. 4th 67 (1989); see also In re Quinlan, 355 A.2d 647, 664 (N.J. 1976) ("We think that the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims.").

34. See Hawkins, supra note 2, at 1582 ("A relatively recent legal development, the right to refuse life-sustaining treatment has generated voluminous legal literature.").

35. See Cruzan v. Harmon, 760 S.W.2d 408, 412 n.4 (Mo. banc 1988) (collecting 54 reported decisions from 1976 through 1988); see also OFFICE OF TECHNOLOGY ASSESSMENT TASK FORCE, LIFE SUSTAINING TECHNOLOGIES AND THE ELDERLY 41 (1988) (stating that "the timing of death—once a matter of fate—is now a matter of human choice").

<sup>32.</sup> Foregoing life-sustaining or life-saving medical treatment is not legally equivalent to committing suicide. See John W. Parry, The Court's Role in Decisionmaking Involving Incompetent Refusals of Life-Sustaining Care and Psychiatric Medications, 14 MENTAL & PHYSICAL DISABIL-ITY L. REP. 468, 470 (1990) ("[T]he law recognizes that the right to die is a decision to forego an intrusion into one's body which is necessary to sustain life, while suicide is the taking of one's own life by initiating an action that harms the human organism."). Most states outlaw suicide. Id.

solute,<sup>36</sup> while those on the other side of the debate emphasize the State's interest in preserving life.<sup>37</sup>

The United States Supreme Court addressed the issue of whether an adult has a constitutional right to die in the seminal case *Cruzan v*. *Director, Missouri Department of Health*,<sup>38</sup> in which it upheld a Missouri state law which required clear and convincing evidence of an incompetent patient's desire to discontinue life-sustaining medical treatment before terminating such treatment.<sup>39</sup> *Cruzan* has been hailed as formally establishing a constitutional right to die;<sup>40</sup> however, a careful examination of the Court's opinion reveals that the Court never explicitly declared such a right. Rather, the Court merely stated that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."<sup>41</sup> Despite widespread assumptions to the contrary, this declaration falls short of formally articulating a constitutional right to die.<sup>42</sup>

Moreover, the Court, concerned with the finality of terminating lifesustaining treatment of an individual who is incapable of articulating his or her own desires, held that Missouri could "safeguard the personal element of this choice through the imposition of heightened evi-

37. This view was articulated in *Cruzan*: "[W]e think a State may ... simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual." *Id.* at 282.

38. 497 U.S. 261 (1990). Nancy Beth Cruzan was rendered incompetent as a result of severe injuries sustained during an automobile accident. Nancy's parents and coguardians sought a court order directing the withdrawal of their daughter's artificial feeding and hydration equipment after it became apparent that she had virtually no chance of recovering her cognitive faculties. *Id.* 

39. Id. at 282.

40. See HEALTH LAW 1079 (Barry R. Furrow et al., eds. 1991) (recognizing that the syllabus prepared for the Court's reported opinion stated that the opinion recognized a constitutionally protected liberty interest in a competent person to refuse unwanted medical treatment, and recalling that *Cruzan* was hailed by the *New York Times* as the first case to acknowledge a right to die).

41. Cruzan, 497 U.S. at 278.

42. This shortfall may have been a deliberate decision based on Court politics. See HEALTH LAW, supra note 40, at 1079-80 (positing that because Justice Scalia, who wrote a separate concurring opinion, did not believe that any constitutional right was implicated in the case, it is unlikely that Chief Justice Rehnquist, in writing the Court's plurality opinion, would formally recognize a right to die and risk losing Justice Scalia's vote to establish a majority).

<sup>36.</sup> See Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 303 (1990) (Brennan, J., dissenting) (explaining that a decision whether to undertake some medical procedure that could prolong the process of dying "must be made on the basis of individual values, informed by medical realities, yet within a framework governed by law," and that "[t]he role of the courts is confined to defining that framework, delineating ways in which government may and may not participate in such decisions").

dentiary requirements."<sup>43</sup> The Court's reasoning reflected profound apprehension over legally sanctioning any individual's decision to terminate life-sustaining treatment:

An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of lifesustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.<sup>44</sup>

Although *Cruzan* involved terminating life-sustaining treatment of an incompetent adult, the Court's logic is applicable to the situation in which life-saving medical treatment is being refused by a chronically ill adolescent, who is especially susceptible to forces that may alter his or her decision-making capabilities.<sup>45</sup>

# B. Minors in the Health Care System: Rights and Doctrines<sup>46</sup>

The competing interests of self-determination and the preservation of life, illustrated by *Cruzan*, are relevant to the case in which a mature adolescent refuses medical treatment. In light of the courts' historic stance towards minors' decision-making capacity, it seems that the balance between the two interests should tip in favor of preservation of life.<sup>47</sup>

Traditionally, children have not been afforded full rights to self-determination where their physical well-being is at issue.<sup>48</sup> Courts generally have adhered to the principle that minors are incapable of making legal decisions for themselves. It is well-settled that parents enjoy a substantive constitutional right to make decisions concerning

46. Much of the information in the following section was collected during the author's tenure as an assistant to Professor Michelle Oberman. The author thanks Professor Oberman for introducing these areas of the law and for helping to clarify the ideas presented herein.

47. Cf. Brock, supra note 5, at 192-93 ("Unlike adults, a child's good is more fully determined by the developmental needs of children generally at that age than by his or her current but predictably transient goals and preferences.... The value of self-determination too constitutes a weaker basis for children's involvement in decisionmaking than it does for adults.").

48. See Elizabeth J. Sher, Note, Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State, 58 N.Y.U. L. REV. 157, 169 (1983) (explaining that "although it is ostensibly the child whose 'best interest' is at stake, courts generally are called upon to balance two perceptions of the child's best interest, [those of the parents and those of the state], neither of which necessarily emanates from the individual child.").

<sup>43.</sup> Cruzan, 497 U.S. at 281.

<sup>44.</sup> Id. at 283.

<sup>45.</sup> See infra part I.D.1. (discussing how chronic illness affects adolescents' self-esteem and outlook on the future).

their children's care and welfare according to the dictates of their own consciences.<sup>49</sup> However, parental autonomy must yield to state intervention when parents fail to provide reasonably necessary medical care for their children.<sup>50</sup> The question whether, and under what circumstances, a state may order medical treatment for a child over parental objections places three sets of interests in contention: (1) The "natural rights" of parents; (2) the responsibilities of the state; and (3) the personal needs of the child.<sup>51</sup> Courts faced with the task of balancing these interests have uniformly decided that state intervention is appropriate where medical treatment is necessary to save a child's life.<sup>52</sup>

51. For a thorough exploration of the competing interests of parents, children, and the state that are implicated in medical decision-making for children, see Sher, *supra* note 48, at 166-84.

52. See, e.g., Jehovah's Witnesses in Washington v. King Cty. Hosp., 278 F. Supp. 488 (W.D. Wash. 1967) (upholding, in a class action brought on behalf of the 8,900 Jehovah's Witnesses in Washington state, the constitutionality of a state law which made children of Jehovah's Wit-

<sup>49.</sup> See, e.g., Wisconsin v. Yoder, 406 U.S. 205, 232-34 (1972) (upholding the right of Amish parents to remove their children from public school to alternatively provide them with religiously-based, community-sponsored vocational training); Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925) (according parents the right to educate their children in parochial schools); Meyer v. Nebraska, 262 U.S. 390, 400 (1923) (protecting the right of parents against state interference to have their children taught German in parochial school); see also Custody of a Minor, 379 N.E.2d 1053, 1062 (Mass. 1978) (explaining that caselaw has recognized that these "natural rights" of parents encompass an entire "private realm of family life" and must be protected from unwarranted state interference). But see Sher, supra note 48, at 175 (cautioning that none of the above-cited cases explicitly recognized a broad constitutional right of parental autonomy, but rather, they established a limited parental right to make choices involving education, religion, and morality).

<sup>50.</sup> See MORRISSEY ET AL., supra note 9, at 24-25 ("Under the doctrine of parens patriae, ... the state has assumed the role of all children's ultimate protector. Society has accorded the state the right to step in and take over from parents when the latter fail to meet certain standards."); see also Custody of a Minor, 379 N.E.2d at 1063 (citing Richards v. Forrest, 180 N.E. 508, 511 (1932)) ("[T]he parental right to control a child's nurture ... is akin to a trust, 'subject to ... [a] correlative duty to care for and protect the child, and ... [terminable] by [the parents'] failure to discharge their obligations.' ").

Refusals of medical care by parents on behalf of their children are commonly based upon, but not limited to, religious grounds. See, e.g., People ex. rel. D.L.E., 645 P.2d 271, 272-76 (Colo. 1982) (holding that a 14-year-old child with a life-endangering grand mal epileptic condition was dependent and neglected where parents failed to obtain treatment on religious grounds, despite a state statute which prohibited a finding of neglect if the child was in good faith "under treatment solely by spiritual means through prayer"); *In re* Willman, 493 N.E.2d 1380, 1390 (Ohio App. 1986) (holding that the religious beliefs of parents did not justify refusing an operation to remove a life-threatening tumor from the arm of their seven-year-old son); *In re* Hamilton, 657 S.W.2d 425, 429 (Tenn. App. 1983) (ordering a 12-year-old girl to undergo chemotherapy and radiation to treat Ewing's Sarcoma, over the religious-based objections of her father).

Refusals based on cultural beliefs also have been addressed by the courts. See, e.g., James Feron, Mother Apparently Wins Bid to Block Surgery, N.Y. TIMES, Dec. 13, 1990, at B5 (discussing a federal judge's decision to allow a woman to have her daughter treated with traditional Chinese remedies rather than undergo surgery, prescribed by physicians, for severe juvenile rheumatoid arthritis).

Notwithstanding the prevailing state interventionist policies regarding child welfare, a Florida state court judge gave fifteen-year-old Benny Agrelo his tacit blessing to discontinue medically necessary treatment and die.<sup>53</sup> If this case is indicative of a shift in the law toward expanding the rights of minors in the health care system, it is necessary not only to track the direction in which the law is moving, but also to trace how the law has developed over the past several decades and to identify the objectives that have steered it along its course of evolution.

#### 1. Minors' Capacity in Tort Law — Common Law Position

"Capacity" is a murky tort law concept. Although the law generally maintains its traditional protective posture toward minors, cases reflect that under limited circumstances, minors have the capacity to consent to certain kinds of invasions and conduct.<sup>54</sup> A minor is presumed to acquire the capacity to consent when he or she has the ability of the average person to understand and weigh the risks and benefits of a proposed course of action.<sup>55</sup>

In the realm of health care, the common law position was that until reaching the age of majority, a minor lacked legal authority to consent to his or her own health care treatment.<sup>56</sup> Authority to consent was

379 N.E.2d at 1065.

53. See supra notes 13-17 and accompanying text (discussing the case of Benny Agrelo, who was permitted by a Florida state judge to discontinue critical medical treatment).

54. W. PAGE KEETON ET AL., PROSSER & KEETON ON THE LAW OF TORTS § 18, at 115 (5th ed. 1984).

55. Gulf & S.I.R. Co. v. Sullivan, 119 So. 501, 502 (Miss. 1928). To reflect the minor's reasoning abilities as they evolve through different stages of his or her development, capacity sometimes has been determined by the "Rule of Sevens." Cardwell v. Bechtol, 724 S.W.2d 739, 745 (Tenn. 1987). The Rule of Sevens provides that under the age of seven, a child has no capacity; between the ages of seven and fourteen, there exists a rebuttable presumption that the minor has no capacity; and between the ages of fourteen and twenty-one, there exists a rebuttable presumption that the individual has capacity. *Id*.

56. Michelle Oberman, Turning Girls into Women: Re-evaluating Modern Statutory Rape Law, 85 J. CRIM. L. & CRIMINOLOGY 15, 47 (1994); Tania E. Wright, A Minor's Right To Consent to Medical Care, 25 How. L.J. 525, 525-26 (1982).

nesses wards of the court and authorized blood transfusions when their parents refused them on religious grounds). In *Custody of a Minor*, the Massachusetts Supreme Court invoked a balancing test and found:

<sup>[</sup>T]he parents' refusal to continue with chemotherapy amounted to an unwillingness to provide the type of medical care which was necessary and proper for the child's wellbeing. Where, as here, the child's very life was at stake, such a finding is sufficient to support an order removing legal custody from the parents, even though the parents are loving and devoted in all other respects.

delegated exclusively to parents and guardians.<sup>57</sup> This precept was defended on two grounds. First, the law presumed that a minor lacked the maturity and wisdom to correctly determine his or her medical needs.<sup>58</sup> Second, the law accorded parents (primarily fathers) absolute control over all aspects of their children's upbringing.<sup>59</sup> Health care providers risked being subject to an action for assault and battery for rendering treatment to a minor without first obtaining parental consent.<sup>60</sup> The practical result of the parental consent rule was that children in need of medical attention were left untreated.<sup>61</sup>

## 2. Early Exceptions to the Common Law Rule

Early exceptions to the common law rule emerged in order to address the needs of those minors who required emergency medical treatment<sup>62</sup> or were emancipated.<sup>63</sup> It is uncontroverted that in an emergency, a minor of any age may be treated without parental con-

61. As one commentator notes, "Besides hampering the minor's ability to obtain needed medical services in the absence of his or her parents' consent, the traditional concept of the parental right also led to extreme judicial reluctance to order medical care for a minor in opposition to a parent's express refusal to consent." Wright, *supra* note 56, at 527.

One may envision the Fourteenth Amendment equal protection implications of a situation in which the respective medical treatment of a minor and an adult, both afflicted with the same illness, differed insofar as the minor was sent away, and the adult was treated. HOLDER, LEGAL ISSUES, *supra* note 6, at 124. For further discussion of minors' constitutional right to medical care, see *id*.

62. See Hawkins, supra note 2, at 1586 ("[E]arly common law, recognizing that physicians' fear of liability might discourage prompt treatment, implied consent in emergency situations. This type of exception is 'situational,' because its applicability turns on the type of treatment decision involved.") (footnote omitted).

63. See MORRISSEY ET AL., supra note 9, at 32 ("We have been unable to discover a single instance of a physician's being found liable for providing care to an emancipated youth on his or her own consent and without the consent of parents."); see also Holder, Right To Decide, supra note 57, at 162 (explaining that the Anglo-American legal system has acknowledged the notion of an "emancipated minor" for at least 200 years).

<sup>57.</sup> See Angela R. Holder, Children and Adolescents: Their Right To Decide About Their Own Health Care, in CHILDREN AND HEALTH CARE: MORAL AND SOCIAL ISSUES 161, 161 (LORETTA M. Kopelman & John C. Moskop eds. 1989) [hereinafter Holder, Right To Decide].

<sup>58.</sup> Eve W. Paul, Legal Rights of Minors to Sex-Related Medical Care, 6 COLUM. HUM. RTS. L. REV. 357, 359-60 (1974).

<sup>59.</sup> Holder, Right To Decide, supra note 57, at 161; Comment, Counseling the Counselors: Legal Implications of Counseling Minors Without Parental Consent, 31 MD. L. REV. 332, 335-38 (1971).

<sup>60.</sup> HOLDER, LEGAL ISSUES, *supra* note 6, at 124-25; *see, e.g.*, Bonner v. Moran, 126 F.2d 121, 123 (CA DC 1941) (holding that a mother had a cause of action where her 15-year-old son donated skin for grafts for his cousin who had been badly burned, and the procedure was performed at the hospital without her knowledge or consent); Moss v. Rishworth, 222 S.W. 225, 226-27 (Tex. Comm'n App. 1920) (holding that parents had a cause of action where a doctor operated on their 11-year-old daughter to remove enlarged adenoids without obtaining their consent, and the daughter died post-operatively before coming out of anesthesia).

sent.<sup>64</sup> "Anything requiring relatively urgent attention or that is causing a child pain or fear" constitutes an emergency.<sup>65</sup> The emergency exception reflects that it is cruel to allow a child to suffer pain for an extended period of time because a health care professional refuses to render treatment for fear of being sued by the patient's parents.<sup>66</sup>

The second traditional exception to the common law rule allows emancipated minors to consent to their own medical care. Although jurisdictions vary in their definitions of "emancipation," generally an emancipated minor is "one whose parents have completely surrendered care, custody, and control of the child, have no involvement in the child's earnings, and have renounced parental duties."<sup>67</sup> For example, married minors are deemed emancipated and may consent to medical treatment for themselves or their own minor children.<sup>68</sup>

#### 3. Minor Treatment Statutes

The bulk of the modern exceptions to the common law rule have been codified in minor treatment statutes.<sup>69</sup> These statutes specify a particular age "at which a minor may be considered completely independent for health care purposes and treatment may be given as if he or she were an adult."<sup>70</sup> Like the traditional exceptions discussed above, minor treatment statutes were created to address the specific

65. HOLDER, LEGAL ISSUES, supra note 6, at 125-26; see also Holder, Right To Decide, supra note 57, at 161 (explaining that the emergency exception extends to minor conditions such as a sore throat or an earache).

66. HOLDER, LEGAL ISSUES, supra note 6, at 126.

67. Sher, *supra* note 48, at 158 n.5; *see also* Wright, *supra* note 56, at 529 ("The language of emancipation, however, places more emphasis on acts of release of the child by his parents and the actual independence, than on the child's judgment or appearance of maturity.").

68. Holder, *Right To Decide, supra* note 57, at 162; *see, e.g.*, Bach v. Long Island Jewish Hosp., 267 N.Y.S. 2d 289 (N.Y. 1966) (dismissing a married minor woman's assault action against the hospital where a biopsy was performed with her consent). Minors in the military also have been considered entirely emancipated. *See, e.g.*, Swenson v. Swenson, 227 S.W.2d 103, 106 (Mo. 1950) (holding that a minor's enlistment in military service "terminated" and "extinguished" the legal duty of his mother to maintain and support him). The scope of emancipated minors has expanded in some jurisdictions to include college students (even those who are still financially dependent on their parents), unmarried minor mothers, pregnant minors, and runaways. Holder, *Right To Decide, supra*, at 162.

69. See infra notes 73, 77, 78 (providing examples of minor treatment statutes).

70. Holder, Right To Decide, supra note 57, at 162.

<sup>64.</sup> See, e.g., Luka v. Lowrie, 136 N.W. 1106 (Mich. 1912) (holding that the defendant physician was justified in amputating a badly injured foot of a 15-year-old boy where the boy was unconscious and had no accessible friends or relatives); Sullivan v. Montgomery, 279 N.Y.S. 575 (N.Y. 1935) (finding the defendant physician not liable on a theory of assault for not obtaining parental consent where he administered ether to a 20-year-old boy before setting and casting the boy's swollen ankle). Where emergency treatment is negligent, the minor (through his or her parent or guardian) may sue the physician just as if parental consent had been given. HOLDER, LEGAL ISSUES, *supra* note 6, at 138.

health needs of minors and society. These statutes do not hinge on the maturity of the minor, nor were they created to further the rights of a minor who exhibits the maturity of an adult.<sup>71</sup> Rather, most of the statutory exceptions to the common law rule prohibiting minors from consenting to their own medical care focus on specific diseases, conditions, or treatments.<sup>72</sup>

Earlier statutes, drafted in the late 1960's, permitted unemancipated minors to consent to care for sexually transmitted diseases.<sup>73</sup> These laws were inspired by evidence of the growing prevalence of such diseases among adolescents and the fear that adolescents would not seek care if they first were required to inform their parents and obtain their consent.<sup>74</sup> Society's interest in halting the spread of sexually transmitted diseases was the true motivating force in promulgating these laws, not society's belief that some minors could be sufficiently mature to make medical decisions for themselves.<sup>75</sup> Minor treatment statutes may also be deemed an outgrowth of the emergency exception,<sup>76</sup> as evidenced by the fact that many states now have statutes that allow minors to obtain treatment without parental consent for alcohol and substance abuse<sup>77</sup> and psychiatric care.<sup>78</sup>

71. See infra notes 73-78 and accompanying text (analyzing the underlying motives for the enactment of minor treatment statutes).

73. Linda S. Ewald, *Medical Decisionmaking for Children: An Analysis of Competing Inter*ests, 25 ST. LOUIS U. L.J. 689, 701 (1982); Oberman, *supra* note 56, at 48. All jurisdictions have minor treatment statutes which permit unemancipated minors to consent to care for sexually transmitted diseases. Holder, *Right To Decide*, *supra* note 57, at 161.

For examples of modern statutes which allow minors to consent to treatment for sexually transmitted diseases, see Ala. Code § 22-8-6 (1990); ARIZ. REV. STAT. ANN. § 44-132.01 (1987); KAN. STAT. ANN. § 65-2892 (1985); MONT. CODE ANN. § 41-1-402 (1991); NEV. REV. STAT. ANN. § 129.060 (Michie Supp. 1991).

74. HOLDER, LEGAL ISSUES, supra note 6, at 130.

75. See ZIMRING, supra note 1, at 64 (" 'Privacy' legislation dealing with venereal disease and drug and alcohol abuse is really state guidance of adolescents rather than any recognition of autonomy. In public policy terms, there is only one right answer to the question of whether alcoholism, drug misuse, or venereal disease should be treated rather than ignored."). The Supreme Court of Tennessee also recently stated, "[T]hese statutes do no more than provide conditional immunities from certain types of liability in specific situations... or promote certain social purposes, such as treatment of drug abuse or venereal disease in minors." Cardwell v. Bechtol, 724 S.W.2d 739, 744 (Tenn. 1987).

76. Oberman, supra note 56, at 48.

77. For examples of modern statutes which allow minors to obtain treatment for alcohol and substance abuse, see ALA. CODE § 22-8-6 (1990); KAN. STAT. ANN. § 65-2892a (1985); MONT. CODE ANN. § 41-1-402 (1991); NEV. REV. STAT. ANN. § 129.050 (Michie Supp. 1991). One commentator explains that minor treatment statutes for substance abuse reflect "clear public policy interests in controlling and eradicating this serious and ubiquitous problem. States recognize that adolescent minors are particularly at risk and are unlikely to seek out help if not offered confidential care." MORRISSEY ET AL, supra note 9, at 74.

<sup>72.</sup> Wright, supra note 56, at 531.

## 4. Development of the Mature Minor Doctrine

Beyond the statutory exceptions to the common law rule, which are triggered by the type of treatment sought, there exists a gray area into which the common law has attempted to extend the rights of minors regarding their health care. These other principal exceptions to the common law rule may be best characterized as miscellaneous components of an amorphous "mature minor" doctrine, which has been a vehicle for allowing minors to consent to medical treatment in the absence of a minor treatment statute and without parental or guardian consent.<sup>79</sup> Most likely, it was the mature minor doctrine which enabled Benny Agrelo to discontinue his immunosuppressant regimen<sup>80</sup> and which will be utilized in future refusal of treatment and right to die cases involving adolescents. The mature minor doctrine has no formal definition; however, one commentator explains that the cases in which the rule has been applied have had the following factors in common:

1. The treatment was undertaken for the benefit of the minor rather than a third party.

2. The particular minor was near majority (or at least in the range of 15 years of age upward) and was considered to have sufficient mental capacity to understand fully the nature and importance of the medical steps proposed.

80. Cf. Teenager Allowed To Discontinue Liver Treatment (NPR radio broadcast, June 15, 1994) (discussing the case of Benny Agrelo, a reporter explained, "Health care officials generally believe minors are too young to make life and death decisions, so, in Florida, it was left to a judge to determine if Benito Agrelo, at age 15, was mature enough to refuse treatment."). The actual legal basis for the judge's decision in the Benny Agrelo case is uncertain because judicial opinions in juvenile cases are sealed.

<sup>78.</sup> E.g., ALA. CODE § 22-8-4 (1975) (permitting a minor who is 14 years or older, or who has graduated from high school, or who is married or divorced, or is pregnant, to consent to mental health service); COLO. REV. STAT. § 27-10-103 (1989) (permitting minors aged 15 years or older to consent to mental health services from a state-licensed hospital or physician); FLA. STAT. ANN. §§ 394.56(1) (1985) (providing that minors 12 years old and older may consent to outpatient mental health services, provided there is a hearing to determine the voluntariness of the application); GA. CODE ANN. § 37-3-20 (1985) (providing that a minor who is at least 12 years old may consent to admission for psychiatric care).

<sup>79.</sup> See Hawkins, supra note 2, at 1586-87 (explaining that "the mature minor doctrine enables a minor to consent to treatment unilaterally based upon his or her ability to understand and weigh the risks and benefits involved in the decision"). The mature minor doctrine tends to fill in the gaps left by minor treatment statutes. See Oberman, supra note 56, at 48 ("Minor treatment laws enhance a minor's power to consent in only a narrow set of statutorily specified situations. As a result, minors are frequently seeking non-emergency medical treatment to which they are not statutorily permitted to consent."). Moreover, maturity-based exceptions differ from statutory and emancipation-based exceptions in that the former depend on the minor's competence in relation to a specific decision, whereas the latter rely upon "objective proxies to afford general consent rights." Hawkins, supra, at 1587.

3. The medical procedures could be characterized by the court as less than "major" or "serious."<sup>81</sup>

Although under the aforementioned criteria the mature minor doctrine conceivably could apply in almost all cases involving an adolescent's consent to health care, courts are generally unwilling to give the mature minor exception a broad interpretation.<sup>82</sup>

One of the first reported cases involving the mature minor exception to the common law rule requiring parental consent for the medical treatment of a minor was *Bakker v. Welsh.*<sup>83</sup> In *Bakker*, the Supreme Court of Michigan held that a surgeon was not liable to a father for performing an operation to remove an ear tumor on a seventeen-year-old boy, where the boy's father had not given consent and the boy died during the administration of anesthesia.<sup>84</sup> The court reasoned that although it was not clear exactly who gave the consent for surgery, the boy was accompanied by an aunt and a sister, and all three of them understood that an operation was going to be performed on the boy.<sup>85</sup> Interestingly, the opinion did not discuss the boy's maturity.

More recently, in *Cardwell v. Bechtol*,<sup>86</sup> the Supreme Court of Tennessee explicitly adopted the mature minor exception to the parental consent rule.<sup>87</sup> In *Cardwell*, a young woman, seventeen years and

The American Bar Association has declared that "a minor of [sixteen] or older who has sufficient capacity to understand the nature and consequences of a proposed medical treatment for his or her benefit may consent to that treatment on the same terms as an adult." *Standards Relating to Rights of Minors*, 1980 I.J.A./A.B.A. JUVENILE JUSTICE STANDARDS PROJECT § 4.6 A. The brackets around sixteen are intended to minimize the significance of the age of the minor, thereby placing the emphasis on the minor's capacity to understand the nature and consequences of the proposed treatment as the essential prerequisite to informed consent to the treatment. *Id.* 

These definitions indicate that the mature minor doctrine contemplates that a minor attempting to invoke it is seeking beneficial or minor treatment. Thus, in the case of Benny Agrelo, if the mature minor doctrine was the basis of the judge's decision to let Benny discontinue lifesaving medical treatment, the doctrine was utilized incorrectly.

82. See Cardwell v. Bechtol, 724 S.W.2d 739, 745 (Tenn. 1987) ("Adoption of the mature minor exception 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 each case. It must be seen in the context of the tort in question.").

- 86. 724 S.W.2d 739 (Tenn. 1987).
- 87. Id. at 749.

<sup>81.</sup> Walter Wadlington, Minors and Health Care: The Age of Consent, 11 OSGOOD HALL L.J. 115 (1973); see also Holder, Right To Decide, supra note 57, at 163 ("[A] young person (of 14 or 15 or over) [who] understands the nature of proposed treatment and its risks and can give the same degree of informed consent as an adult patient, and the treatment does not involve very serious risks, ... may validly consent to receiving it.").

<sup>83. 108</sup> N.W. 94 (Mich. 1906).

<sup>84.</sup> Id. at 96.

<sup>85.</sup> Id.

seven months old, went to see the defendant doctor on her own initiative and without her parents' knowledge, seeking relief from back pain.<sup>88</sup> The defendant did not inquire about parental consent prior to rendering manipulative therapy because he believed, based upon the young woman's demeanor, that she was of age.<sup>89</sup> The parents of the young woman brought an action for battery after complications from the treatment arose.<sup>90</sup> The Supreme Court of Tennessee held that the defendant could not be held liable on a theory of battery for failing to obtain the consent of the minor's parents, reasoning that the young woman had "the judgment, ability, education, and training at her seventeen years, seven months to have the capacity to consent and did in fact consent to the Defendant's treatment."<sup>91</sup>

In 1992, in *Belcher v. Charleston Area Medical Center*,<sup>92</sup> the Supreme Court of West Virginia followed the *Cardwell* court's lead and formally recognized the existence of a mature minor exception to the common law rule of parental consent.<sup>93</sup> The court clarified that where a child is a "mature minor," the physician must obtain the child's consent before performing a procedure upon the child or administering or withholding treatment from him or her.<sup>94</sup> The court further explained that whether a minor has the capacity to consent depends upon the following:

[The] age, ability, experience, education, training, and degree of maturity or judgment obtained by the child, as well as upon the conduct and demeanor of the child at the time of the procedure or treatment . . . [and] whether the minor has the capacity to appreciate the nature, risks, and consequences of the medical procedure to be performed, or the treatment to be administered or withheld.<sup>95</sup>

Regarding physician liability, the *Belcher* court concluded that "[w]here there is a conflict between the intentions of one or both parents and the minor, the physician's good faith assessment of the minor's maturity level would immunize him or her from liability for the failure to obtain parental consent."<sup>96</sup>

The most common and arguably the most instructive applications of the mature minor doctrine arise in the context of minors seeking con-

88. Id. at 741.
89. Id. at 743.
90. Id. at 742.
91. Id. at 755.
92. 422 S.E.2d 827 (W. Va. 1992).
93. Id. at 838.
94. Id.
95. Id.
96. Id.

traceptives or abortions.<sup>97</sup> However, as Professor Michelle Oberman has observed through her research on statutory rape, "[A]t no point in the line of cases permitting minors' access to reproductive health care is there any substantive discussion of what constitutes maturity . . . .<sup>"98</sup> In fact, "the Supreme Court's decisions *ignore* the issue of how minors are supposed to demonstrate their maturity."<sup>99</sup>

Contraceptive freedom for both adults and minors is based on constitutionally-guarded privacy interests.<sup>100</sup> More than thirty years ago, in *Griswold v. Connecticut*,<sup>101</sup> the United States Supreme Court held unconstitutional a state statute prohibiting the distribution of contraceptives to married adults.<sup>102</sup> Twelve years later, in *Carey v. Population Services International*,<sup>103</sup> the Court extended its holding in *Griswold* to minors<sup>104</sup> and struck down a state statute which prohibited distribution of contraceptives to persons under sixteen years of age.<sup>105</sup> At first glance it may seem that the Court afforded minors access to contraceptives because it had been positively demonstrated that minors have the capacity to exercise mature judgment in making adult-like decisions. However, a closer examination of the *Carey* opinion reveals a more paternalistic motivation—that it was in adolescents' best interests to have access to contraceptives in light of the pervasive problems of sexually transmitted diseases, pregnancy, and

(These decisions [applying the constitutional right of sexual privacy to minors] have created the "mature minor" standard, declaring that a minor of sufficient maturity to make reproductive health care decisions enjoys the same constitutional privileges as an adult, including access to contraceptives and the ability to make a decision whether or not to undergo an abortion without undue interference from the state.);

see also Hawkins, supra note 2, at 1601-02 ("[J]udicial 'answers' to some of the legal questions in this context [of reproductive freedom] . . . represent attempts to define the boundaries of state and parental authority over minors' decisionmaking autonomy.").

100. See Carey v. Population Serv. Int'l, 431 U.S. 678, 684-85 (1977) ("While the outer limits of this aspect of privacy have not been marked by the Court, it is clear that among the decisions that an individual may make without unjustified government interference are personal decisions 'relating to marriage, procreation, contraception, family relationships, and child rearing and education.' ") (citations omitted).

101. 381 U.S. 479 (1965).

102. Id. at 483-86. In 1972, the United States Supreme Court held that states cannot bar contraceptive access to unmarried adults. Eisenstadt v. Baird, 405 U.S. 438, 454-55 (1972).

103. 431 U.S. 678 (1977).

104. Id. at 687 ("Griswold may no longer be read as holding only that a State may not prohibit a married couple's use of contraceptives.... [T]he teaching of Griswold is that the Constitution protects individual decisions in matters of childbearing from unjustified intrusion by the State.").

105. Id. at 682.

<sup>97.</sup> See Planned Parenthood Affiliates of Cal. v. Van de Kamp, 181 Cal. App. 3d 245, 278 (1st Dist. 1986)

<sup>98.</sup> Oberman, supra note 56, at 50.

<sup>99.</sup> Id. at 51 (emphasis added).

illegitimate births.<sup>106</sup> As one commentator explains, "*Carey* is a classic case of deregulation—in this instance given constitutional recognition—to avoid harming kids in the name of helping them."<sup>107</sup>

The Carey opinion is a telling commentary on minors' rights in general. The Court cautioned that state restrictions inhibiting privacy rights of minors are valid if they serve a "significant" state interest beyond what would be relevant to an adult.<sup>108</sup> The Court noted that this standard, while less demanding than the "compelling" state interest test applied to restrictions on the privacy rights of adults, was appropriate because states have greater latitude to regulate the conduct of children and because "the law has generally regarded minors as having a lesser capability for making important decisions."<sup>109</sup>

The court's goal of bestowing upon an adolescent girl the lesser of two evils is also apparent in the context of abortion. In 1976, the United States Supreme Court declared in *Planned Parenthood v. Danforth*<sup>110</sup> that states were expressly prohibited from requiring parental consent for an unmarried minor's abortion.<sup>111</sup> However, the Court implied that it would be constitutional for a state to require a judicial determination that a minor is mature enough to give informed consent.<sup>112</sup> Within the *Danforth* opinion, Justice Blackmun recognized that states traditionally have had broader authority to regulate the activities of minors than the activities of adults, based on the states' interest in child protection.<sup>113</sup> Justice Stevens, concurring in part and dissenting in part, asserted that the state's interest in protecting minors from the consequences of incorrect decisions was valid<sup>114</sup> and therefore, requiring parental consent for a minor's abortion was "surely not irrational."<sup>115</sup>

112. Katherine M. Waters, Note, Judicial Consent To Abort: Assessing a Minor's Maturity, 54 GEO. WASH. L. REV. 90, 90 n.5 (1985).

<sup>106.</sup> In the *Carey* opinion, the Court cites statistics regarding the incidence of teenage pregnancy and abortion, and discusses social problems associated with teenage pregnancy, including forced marriages and impairment of educational opportunities. *Id.* at 696 n.21. For a detailed discussion of the debate over whether to provide minors access to contraceptives, see HOLDER, LEGAL ISSUES, *supra* note 6, at 267-75.

<sup>107.</sup> ZIMRING, supra note 1, at 62.

<sup>108.</sup> Carey v. Population Serv. Int'l, 431 U.S. 678, 693 (1977).

<sup>109.</sup> Id. at 693 n.15; see also supra notes 7, 54-59 and accompanying text (discussing the law's traditional presumption that minor's are incapable of making legal decisions for themselves).

<sup>110. 428</sup> U.S. 52 (1976).

<sup>111.</sup> Id. at 74.

<sup>113.</sup> Danforth, 428 U.S. at 74 (citing Ginsberg v. New York, 390 U.S. 629 (1968) (upholding a state law that prohibited the sale of sex-related magazines to minors) and Prince v. Massachusetts, 321 U.S. 158, 170 (1944) (upholding child labor laws)).

<sup>114.</sup> Id. at 102 (Stevens, J., concurring in part, dissenting in part).

<sup>115.</sup> Id. at 103 (Stevens, J., concurring in part, dissenting in part).

Since Danforth was decided, a plethora of decisions have attempted to clarify the myriad of competing interests in a minor's decision to have an abortion.<sup>116</sup> To this end, in *Bellotti v. Baird* (*Bellotti II*),<sup>117</sup> the United States Supreme Court, in a plurality opinion, concluded that a state could require a minor to consult with a parent before obtaining an abortion only if it also provided the minor with the alternative of seeking a judicial bypass of the parental consent requirement.<sup>118</sup> Thus, if a minor so wishes, she may go directly to a court or designated administrative agency where "[i]f she satisfies the court that she is mature and well enough informed to make intelligently the abortion decision on her own, the court must authorize her to act without parental consultation or consent."<sup>119</sup> However, if the minor is not found to exhibit the requisite maturity to make the decision independently, she may still be authorized to have the abortion if the court or agency finds that it would be in her best interests.<sup>120</sup>

Although *Bellotti II* granted a pregnant minor the alternative of proving that she is sufficiently mature to consent to an abortion independently of her parents, the Court failed to provide a set of objective criteria for measuring her maturity.<sup>121</sup> The Court's only guidance lies in two phrases inconspicuously woven into its opinion which state that a mature minor is one who is "well enough informed to make intelligently the abortion decision on her own"<sup>122</sup> and "fully competent to assess the implications of the choice she has made."<sup>123</sup> A determination of maturity that depends merely on the minor knowing and appreciating the possible effects and consequences of a given procedure has been criticized by commentators since the *Bellotti II* decision was handed down.<sup>124</sup> In the context of an adolescent refusing necessary

122. Bellotti v. Baird, 443 U.S. 622, 647 (1979).

123. Id. at 650.

124. See, e.g., Elizabeth Buchanan, The Constitution and the Anomaly of the Pregnant Teenager, 24 ARIZ. L. REV. 553, 566-74 (1982) (criticizing Bellotti IPs failure to provide any substan-

<sup>116.</sup> See Waters, supra note 112, at 90 ("The evolution of the 'mature-minor' standard reflects the Court's effort to balance a minor's privacy rights with the legitimate interests of her parents and the state.").

<sup>117. 443</sup> U.S. 622 (1979) (plurality opinion).

<sup>118.</sup> Id. at 643, 647.

<sup>119.</sup> Id. at 647.

<sup>120.</sup> Id. at 647-48.

<sup>121.</sup> See Steven F. Stuhlbarg, Note, When Is a Pregnant Minor Mature? When Is an Abortion in Her Best Interests? The Ohio Supreme Court Applies Ohio's Abortion Parental Notification Law: In re Jane Doe 1, 566 N.E.2d 1181 (Ohio 1991), 60 U. CIN. L. REV. 907, 916 (1992) (noting that "Justice Powell wrote virtually nothing about how to determine best interests, and only briefly noted how difficult it was to determine maturity"); Waters, *supra* note 112, at 101 ("Fundamental rights of mature minors are effectively dependent on a concept that the Court has failed to delimit with adequate specificity.").

medical treatment, where the stakes are arguably higher than in the abortion context,<sup>125</sup> the broad *Bellotti II* framework is unsuitable for assessing maturity. A fuller inquiry is warranted.

#### C. Refusal of Medical Treatment and the Mature Minor Doctrine

Only recently has the mature minor doctrine been invoked in the context of a minor refusing life-saving medical treatment.<sup>126</sup> However, the few cases in which courts have been faced with a minor who will almost certainly die if the refused medical treatment is not administered suggest that courts have taken a leap in the direction of extending to adolescents whatever "right" to die exists for adults.<sup>127</sup> A review of the relevant caselaw reveals that although it is unlikely that any judge would ever explicitly hold that a minor has a constitutional "right" to die,<sup>128</sup> opinions suggest that the right does implicitly exist under certain circumstances, namely where the minor is found to be "mature."<sup>129</sup> If this is so, it is crucial that courts develop a rational definition of "maturity" and apply it consistently. In an effort to delimit the boundaries of the mature minor doctrine, this section traces the circumstances in which the mature minor doctrine has been ap-

125. By this statement, the author simply points out that an adolescent who refuses life-saving medical treatment will meet an imminent and often immediate death, whereas a pregnant adolescent will not certainly die as an imminent and immediate consequence of being refused an abortion.

126. See infra notes 130-77 and accompanying text (discussing three cases involving minors refusing life-saving medical treatment decided since 1989 in which a mature minor standard was considered).

127. Although no court has articulated a "right" to die on behalf of minors, the right seems to exist under certain circumstances by virtue of the fact that in at least one case in which the mature minor standard was employed to allow a minor to refuse or discontinue life-saving medical treatment, the minor's death was the inevitable consequence of the court's decision. See In re E.G., 549 N.E.2d 322 (III. 1989); see infra notes 130-47 and accompanying text (discussing E.G. in detail). This is a gross deviation from the common law position, which prohibited minors of any age or maturity level from even consenting to beneficial medical treatment.

128. Cf. Holder, Right To Decide, supra note 57, at 164 (opining, "[W]here treatment is necessary, even if not life-saving, I doubt seriously that a minor has the right to refuse it.").

129. See infra notes 130-77 and accompanying text (discussing three cases involving minors refusing life-saving medical treatment decided since 1989 in which a mature minor standard was contemplated).

tive standard for future maturity determinations); Gene Lindsey, Comment, The Viability of Parental Abortion Notification and Consent Statutes: Assessing Fact and Fiction, 38 AM. U. L. REV. 881, 892 n.66 (1989) ("The difficulty with the Court's approach is that maturity and best interests have not been adequately defined, and as a consequence, the judicial bypass mechanism remains highly subjective."). One commentator has suggested that the Court require judges to assess "qualities recognized by educational and psychological disciplines as useful maturational standards indicative of an individual's ability to understand and bear the consequences of a serious decision." Waters, supra note 112, at 98-102.

plied either to allow or to prohibit an adolescent from refusing necessary medical treatment.

A pivotal case in which a court invoked the mature minor doctrine to allow a minor to refuse medically necessary treatment is *In re*  $E.G.^{130}$  In that case, seventeen-year-old E.G. needed blood transfusions for the treatment of leukemia.<sup>131</sup> She and her mother refused to consent to the transfusions, contending that "acceptance of blood would violate personal religious convictions rooted in their membership in the Jehovah's Witness faith."<sup>132</sup> Without the transfusions, E.G. was likely to die within one month, whereas with the treatment, which included blood transfusions and chemotherapy, there was an eighty percent chance that the disease would go into remission.<sup>133</sup> Although during two juvenile court hearings several doctors testified as to E.G.'s maturity, both courts declined to sanction E.G.'s refusal of the blood transfusions.<sup>134</sup>

However, on appeal, the Illinois Court of Appeals extended to "mature minors" the holding of *In re Estate of Brooks*,<sup>135</sup> which guaranteed adult Jehovah's Witnesses a First Amendment right to refuse

133. E.G., 549 N.E.2d at 323. The long-term survival rate for treated patients with E.G.'s type of medical condition was 20-25%. *Id.* 

134. The Illinois Supreme Court noted that at the first juvenile court hearing, E.G.'s treating physician, Dr. Yachnin, testified that "he discussed the proposed course of treatment with E.G., that E.G. was competent to understand the consequences of accepting or rejecting treatment, and he was impressed with her maturity and the sincerity of her beliefs." *Id.* Dr. Yachnin's evaluation of E.G.'s competency was corroborated by the testimony of Jane McAtee, the associate general counsel for the University of Chicago Hospital. *Id.* The juvenile trial court appointed McAtee temporary guardian and authorized her to consent to blood transfusions on E.G.'s behalf. *Id.* at 324. E.G. received several transfusions. *Id.* 

At E.G.'s second juvenile court hearing, Dr. Littner, a psychiatrist regarded as having special expertise in evaluating the maturity and competency of minors, expressed the opinion that E.G. had the maturity level of an 18- to 21-year-old. *Id.* However, the court concluded that "the State's interest in this case was greater than the interest E.G. and her mother had in refusing to consent to treatment." *Id.* at 324.

135. 205 N.E.2d 435 (III. 1965).

<sup>130. 549</sup> N.E.2d 322 (III. 1989).

<sup>131.</sup> Id. at 323.

<sup>132.</sup> Id. The First Amendment right of adult Jehovah's Witnesses to refuse blood transfusions was first recognized in In re Estate of Brooks, 205 N.E.2d 435 (III. 1965). The foundation for Jehovah's Witnesses' belief regarding the acceptance of blood is found in quotes from the Acts of the Apostles 15:20 ("Hence my decision is not to trouble those from the nations who are turning to God, but to write to them to abstain from things polluted by idols and from fornication and from what is strangled and from blood."); and from Leviticus 17:10 ("As for any man of the house of Israel or some alien resident who is residing as an alien in your midst, who eats any sort of blood, I shall certainly set my face against the soul that is eating the blood, and I shall indeed cut him off from among his people."). For an interesting case discussing the rights of Jehovah's Witnesses to refuse blood transfusions, see Jehovah's Witnesses in Washington v. King Cty. Hosp., 278 F. Supp. 488 (W.D. Wash. 1967).

blood transfusions.<sup>136</sup> The appellate court reasoned that because the United States Supreme Court allowed mature minors, through the exercise of constitutional privacy rights, to consent to abortions without parental approval, the extension of other rights guaranteed to adults was "inevitable."<sup>137</sup> The court also found that since E.G. was merely six months shy of her eighteenth birthday, she was "partially emancipated" and therefore had the right to refuse blood transfusions.<sup>138</sup>

The Illinois Supreme Court affirmed that part of the decision by the Illinois Court of Appeals holding that E.G. was a mature minor and therefore could refuse blood transfusions.<sup>139</sup> However, instead of basing its decision on federal constitutional grounds, the Illinois Supreme Court held that minors may possess and exercise rights regarding medical care as a function of Illinois common law.<sup>140</sup> After explaining that the age eighteen "is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood,"141 the court declared that the mature minor doctrine affords a minor the common law right to consent to or refuse medical treatment if the evidence is clear and convincing that he or she is mature enough to exercise the judgment of an adult.<sup>142</sup> Just as courts employ an "equation" to determine whether an adult may refuse life-saving medical treatment,<sup>143</sup> the E.G. court evaluated the strength of the minor's right to refuse treatment against four state interests: (1) Preserving life; (2) protecting third parties; (3) preventing suicide; and (4) maintaining the ethical integrity of the medical profession.144

142. Id. at 327-28. The court explained that "[a] minor may have a long and fruitful life ahead that an immature, foolish decision could jeopardize," and that the clear and convincing evidence standard furthered the state's public policy of placing high value on the sanctity of life. Id. at 327.

143. See supra notes 30-33 and accompanying text (explaining the method by which courts determine an adult's legal ability to refuse life-sustaining medical treatment).

144. E.G., 549 N.E.2d at 328. The court noted that protection of third parties is the interest that weighs most heavily against the minor's right to refuse treatment where parents object to the refusal. *Id.* The court also cautioned that "[w]here the health care issues are potentially life

<sup>136.</sup> E.G., 549 N.E.2d at 324.

<sup>137.</sup> Id. For relevant abortion cases, see City of Akron v. Akron Ctr. for Reproductive Health, Inc., 462 U.S. 416 (1983); Bellotti v. Baird, 443 U.S. 622 (1979).

<sup>138.</sup> E.G., 549 N.E.2d at 324.

<sup>139.</sup> Id. at 328.

<sup>140.</sup> Id. at 326.

<sup>141.</sup> Id. at 325. The court pointed out that, in many jurisdictions, minors are treated as adults under circumstances such as the following: Under minor treatment statutes and the criminal Juvenile Court Act; in the context of abortion; and pursuant to other constitutional rights, including freedom of expression, freedom from unreasonable searches and seizures, and the right to privacy. Id. at 325-26.

Justice Ward, one of two dissenting justices, challenged the court's decision on several grounds.<sup>145</sup> Justice Ward first questioned the court's skewed logic in allowing a minor to make a life and death decision:

I am sure that in a host of matters of far lesser importance it would not be held that a minor however mature could satisfy a requirement of being of legal age. It would not be held that a minor was eligible to vote, to obtain a driver's or pilot's license, or to enlist in one of the armed services before attaining enlistment age.<sup>146</sup>

Justice Ward also criticized the court for failing to state a standard by which a minor's maturity should be measured in future cases.<sup>147</sup> Although Justice Ward's dissenting opinion identified obvious inconsistencies in the law's treatment of minors and observed that the majority's opinion lacked guidance for future cases, these issues have not been addressed in subsequent refusal of treatment cases involving adolescents.

In Belcher v. Charleston Area Medical Center,<sup>148</sup> Larry Belcher, Jr., who was confined to a wheelchair as a result of muscular dystrophy, was seventeen years and eight months old when he suffered respiratory arrest.<sup>149</sup> At the hospital, doctors told Larry's parents that if Larry suffered another such attack, he would likely become respirator-dependent and have to be tube-fed.<sup>150</sup> One of the defendants, Dr. Ayoubi, asked Larry's parents whether they would want Larry subjected to resuscitative measures if he suffered another respiratory failure.<sup>151</sup> Larry's parents told Dr. Ayoubi that they did not want Larry resuscitated unless Larry requested it.<sup>152</sup> Although Larry was not involved in the decision,<sup>153</sup> a "Do Not Resuscitate" (DNR) order was nonetheless prepared.<sup>154</sup>

Subsequently, Larry suffered another respiratory arrest and cardiac failure, and because the hospital staff complied with the DNR order,

- 147. Id. (Ward, J., dissenting).
- 148. 422 S.E.2d 827 (W. Va. 1992).

- 151. Id.
- 152. Id.

154. Id.

threatening, the State's *parens patriae* interest is greater than if the health care matter is less consequential." *Id.* at 327.

<sup>145.</sup> Id. at 328-29 (Ward, J., dissenting).

<sup>146.</sup> Id. at 329 (Ward, J., dissenting).

<sup>149.</sup> Id. at 829-30.

<sup>150.</sup> Id. at 830.

<sup>153.</sup> Larry did not participate in the decision because Dr. Ayoubi felt that Larry was emotionally immature, that his medication diminished his capacity, and that the decision would have increased his anxiety. Id.

he died.<sup>155</sup> Larry's parents sued the hospital and Dr. Ayoubi for wrongful death, alleging medical malpractice and claiming that Larry should have been consulted prior to the issuance of the DNR order, in light of the "mature minor" exception to the common law rule of parental consent.<sup>156</sup>

The Supreme Court of Appeals of West Virginia held that informed consent by a mature minor is required *before* issuing a DNR order for that minor.<sup>157</sup> The court explicitly recognized the existence of a mature minor exception to the common law rule of parental consent in the state of West Virginia<sup>158</sup> and commented that "[i]t is difficult to imagine that a young person who is under the age of majority, yet, who has undergone medical treatment for a permanent or recurring illness over the course of a long period of time, may not be capable of taking part in decisions concerning that treatment."<sup>159</sup> The court further held that in determining whether a particular minor is "mature," the trier of fact should take into consideration the minor's age, ability, experience, education, training, and degree of maturity or judgment, and demeanor at the time of treatment.<sup>160</sup>

The mature minor doctrine also has been used to deny an adolescent the right to refuse medical treatment. In *In re Long Island Jewish Medical Center*,<sup>161</sup> Phillip Malcolm, several weeks shy of turning eighteen, needed blood transfusions as part of treatment for a malignant form of pediatric cancer.<sup>162</sup> With treatment, Phillip had a twenty to twenty-five percent chance for survival, whereas without treatment, he was certain to die within one month.<sup>163</sup>

Phillip and his mother and step-father adamantly opposed the transfusions on the ground that their religion, the Jehovah's Witness faith, did not permit the acceptance of blood.<sup>164</sup> Although the family had joined Jehovah's Witnesses in 1987, Phillip testified that when he orig-

159. Id. at 837.

163. Id. at 241.

1189

<sup>155.</sup> Id.

<sup>156.</sup> Id. at 830-31.

<sup>157.</sup> Id. at 838. The court stated that "except in very extreme cases, a physician has no legal right to perform a procedure upon, or administer or withhold treatment from a ... child without the consent of the child's parents or guardian, unless the child is a mature minor, in which case the child's consent would be required." Id.

<sup>158.</sup> Id.

<sup>160.</sup> Id. at 836. In this particular case, the issue was remanded to determine whether Larry came within the mature minor exception so as to have been entitled to consent to the treatment involved. Id. at 838.

<sup>161. 557</sup> N.Y.S.2d 239 (N.Y. App. Div. 1990).

<sup>162.</sup> Id. at 240-41.

<sup>164.</sup> Id.; see also supra note 132 (discussing the bases for Jehovah's Witnesses' refusal of blood transfusions).

inally began to study the teachings of this religion, he lost interest.<sup>165</sup> Phillip did not know the books of the Bible, but he did understand the basic tenet of the religion's prohibition regarding blood transfusions, and he stated that if the court ordered the transfusions it would not be his responsibility or sin.<sup>166</sup> Phillip also indicated that he consulted his parents before making decisions and considered himself a "child."<sup>167</sup>

The court held that while there was "much merit" to the mature minor doctrine, Phillip's lack of understanding of his religion and his medical condition mitigated against any finding of maturity under the doctrine.<sup>168</sup> The court authorized Phillip's doctors to administer blood transfusions whenever medically necessary during treatment until Phillip turned eighteen.<sup>169</sup>

The mature minor doctrine was also rejected in O.G. v. Baum.<sup>170</sup> In that case, a sixteen-year-old Jehovah's Witness was severely injured in a train accident. Surgery, which would have required blood transfusions, was necessary to save O.G.'s right arm.<sup>171</sup> If the arm was amputated, however, O.G. may or may not have needed transfusions.<sup>172</sup> Although both a County Child Protective Services caseworker and O.G.'s father stated that O.G. understood that refusing blood transfusions could be fatal, the Texas court declined to adopt the mature minor standard.<sup>173</sup>

The court rejected In re  $E.G.^{174}$  as a basis for allowing O.G. to refuse the blood transfusions.<sup>175</sup> In its discussion of E.G., the Texas court identified three distinguishing characteristics from the case at bar: (1) The court in E.G. did not apply federal constitutional law; (2) the record before the Illinois court contained testimony establishing E.G.'s competency; and (3) E.G. testified in court.<sup>176</sup> Dismissing E.G.as inapplicable, and finding both Texas state law and federal law unsettled regarding the right of a sixteen-year-old to refuse blood transfusions, the O.G. court authorized the hospital to administer the transfusions to O.G. as needed during surgery.<sup>177</sup>

165. Long Island Jewish Medical Ctr., 557 N.Y.S.2d at 241-42.
166. Id.
167. Id. at 242.
168. Id. at 243.
169. Id. at 243 n.15.
170. 790 S.W.2d 839 (Tex. Ct. App. 1990).
171. Id. at 840.
172. Id.
173. Id.
174. 549 N.E.2d 322 (Ill. 1989).
175. O.G., 790 S.W.2d at 842.
176. Id.
177. Id.

Read together, these cases highlight the problems that result from using the mature minor doctrine in the context of an adolescent refusing life-saving medical treatment. The disparity among jurisdictions in their use of the doctrine, the inherent vagueness of the concept of maturity, and the complexity of the medical and legal matters involved in treatment refusal cases effectively undermine the doctrine's efficacy. When an adolescent who refuses necessary medical treatment is brought to court, such as in the case of In re E.G. or Benny Agrelo, the sitting judge is faced with a task, the repercussions of which likely transcend anything he or she contemplated upon taking the oath of office-the judge is wholly responsible for deciding the fate of a person who is neither a child, nor an adult. Under the present construction of the mature minor doctrine, the judge is guided in his or her determination of maturity only by the requirement that the minor refusing treatment understand and appreciate the consequences of refusing treatment and that the minor exhibit the judgment of an adult.<sup>178</sup> This weak framework cannot support the weight of a decision that bears such grave consequences. It overlooks essential questions.

On an abstract level, why would a person, who has lived less than eighteen years, affirmatively choose to die? Practically, how should a court assess the validity of an adolescent's reason(s) for refusing treatment? How does the experience of living with chronic illness affect an adolescent, psychologically and emotionally? Do adolescents respond differently than adults to chronic illness? Is there a chance that a particular minor will outgrow his or her intolerance of illness and/or treatment? This is but an abbreviated list of inquiries that the mature minor doctrine does not currently provide for, but which must be considered before legally sanctioning an adolescent's refusal of life-saving medical treatment. The answers to these questions require courts to venture beyond the realm of legal doctrine, into the unfamiliar territory of the medical and psychological disciplines. Specifically, because a minor's illness touches every part of his or her life, the mature minor doctrine must take into account the unique psychological, emotional, and social experience of the chronically ill adolescent.<sup>179</sup>

<sup>178.</sup> See supra text accompanying notes 95, 122-23, 142, 160.

<sup>179.</sup> See Jan van Eys, The Normally Sick Child, in THE NORMALLY SICK CHILD 11, 11 (Jan van Eys ed., 1979) ("A child who is ill is not simply the sum of well child plus disease. The sick child is a total entity that must be approached as such.").

## D. The Unique Experience of the Chronically Ill Adolescent

Chronic illness may be defined as "any condition, congenital or acquired, that alters expected physical growth and development and requires extended or sequential services."<sup>180</sup> While one in four youths may have a chronic health condition,<sup>181</sup> the condition of a majority of these youths will not cause great dysfunction or require extraordinary medical care.<sup>182</sup> However, there are many conditions that are not only onerous, but destructive of the health and welfare of the youths they afflict.<sup>183</sup> The effects of chronic illness on adolescent development are numerous.<sup>184</sup> Moreover, chronic illness generates psychological repercussions distinguishable from other childhood traumas because of the constancy of the illness, the demands of treatment, and the likelihood of an early death.<sup>185</sup>

181. Nelson, supra note 180, at 2.

182. Id. Allergic disease, for example, is a relatively minor chronic health condition. Id.

183. Id.; see also Christine Harrison, Caring for the Chronically Ill Child, 3 CALYX 1, 1 (1993) (stating that illness can have terrible and long-lasting effects on the developing minor since his or her self-image is influenced by the way others view the illness, and the minor may feel uncertainty about the future and doubt over whether he or she will ever be happy); cf. Mario Cappelli et al., Chronic Disease and Its Impact: The Adolescent's Perspective, 10 J. ADOLESCENT HEALTH CARE 283, 283 (1989) (noting that according to epidemiological studies, chronically ill children and adolescents are more likely than their healthy counterparts to develop major psychosocial problems). But see Robert N. Jamison et al., Cooperation with Treatment in Adolescent Cancer Patients, 7 J. ADOLESCENT HEALTH CARE 162, 165 (1986) (finding, in a comparative study of older and younger adolescent cancer patients, that although older adolescent cancer patients were less cooperative with regard to their health care, their lack of cooperation was manifest by avoiding interaction with staff and other patients rather than missing clinic appointments or resisting procedures).

184. Researchers have found that chronic illness (and organ transplantation in particular) may potentially impact the achievement of developmental tasks during adolescence in the following ways: The task of independence may be expressed in risk-taking behavior; physical abnormalities which lower self-esteem and increase emotional difficulties may compromise the task of establishing a sense of personal identity; differentness may impair the task of identification with peers; and the task of preparation for sexual roles may be delayed or alternatively acted out in life-threatening ways. S. Sexson & J. Rubenow, *Transplants in Children and Adolescents, in* PSYCHIATRIC ASPECTS OF ORGAN TRANSPLANTATION 33, 35 table 4.1 (J. Craven & G.M. Rodin eds., 1992).

185. NICHOLAS HOBBS ET AL., CHRONICALLY ILL CHILDREN AND THEIR FAMILIES 73 (1985). Whether a child has hemophilia, diabetes, sickle cell anemia, or any of the other chronic illnesses, the relentlessness of the disease and the continuing need for treat-

<sup>180.</sup> Richard P. Nelson, Political and Financial Issues that Affect the Chronically III Adolescent, in CHRONIC ILLNESS AND DISABILITIES IN CHILDHOOD AND ADOLESCENCE 1, 1 (Robert Wm. Blum ed., 1984). Chronic conditions are typically not curable by short-interval treatment. Id. at 4.

This Comment addresses the experience of the chronically ill adolescent, and not that of the terminally ill adolescent. Terminal illness is "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time." 1989 UNIFORM RIGHTS OF THE TERMINALLY ILL ACT.

It should be noted that the psychosocial ramifications of chronic illness for adolescent patients is a relatively new area of study.<sup>186</sup> The rapid progress in the treatment of childhood diseases that were fatal in yesteryear has enabled very ill children to remain alive.<sup>187</sup> One example of this phenomenon is in the area of pediatric cancer:

The concerns of oncologists have increasingly shifted from palliation and terminal care as was the case in the 1950's, to an increased focus on the child and the family's psychological needs, including such issues as long-term pain and anxiety control, compliance with treatment regimens, chronic depressive reactions, and family system problems. The chronicity of childhood cancer and its treatment course have been intensified and the ultimate outcome has become more ambiguous. In some instances the course of treatment regimen itself has become more noxious or life-threatening.<sup>188</sup>

The psychological costs of this prolongation of life require the attention of the health care community and can no longer be ignored by the legal community.<sup>189</sup>

It is the aim of this section to explore the adolescent's experience with chronic illness as it relates to psychological, social and emotional development and well-being, and to hypothesize as to how that information might bear on an adolescent's refusal of life-saving medical treatment. First, this section discusses some of the general developmental problems that chronically ill adolescents face. Next, it examines how adolescents suffer differently than other age groups from the limitations imposed by chronic illness, as illustrated by studies of non-

187. Gerald P. Koocher, Psychosocial Issues During the Acute Treatment of Pediatric Cancer, 58 CANCER 468, 468 (1986).

188. Id. (citations omitted); see also Michael J. Dolgin et al., Caregivers' Perceptions of Medical Compliance in Adolescents with Cancer, 7 J. ADOLESCENT HEALTH CARE 22, 22 (1986) ("[A]dvances in the medical management of childhood and adolescent cancer have led to a shift in psychosocial emphasis from death and bereavement to living with a chronic disease and its treatment.").

189. See Koocher, supra note 187, at 472 ("As we strive for technical mastery over the diseases that are cancer, we should be intensely concerned about the emotional welfare of our patients and assure that human needs are fully addressed.").

ment necessarily limit activities, impose rigid routines of care, challenge a child's sense of self-worth, and force entry into a frightening world of emergency rooms, hospital corridors, and medical machines.

Id.

<sup>186.</sup> See Capelli et al., supra note 183, at 283 ("Although the literature is replete with studies examining the effects of chronic disease on children, only recently has attention been turned to the adolescent. Few studies have systematically investigated how adolescents view the impact of their illness on their family, social, and personal well-being.") (citations omitted); see generally Tracy R. Shaben, *Psychosocial Issues in Kidney-Transplanted Children and Adolescents: Literature Review*, 20 ANNA J. 663 (1993) (reviewing the literature from the 1960's to the present on psychosocial issues in kidney-transplanted children and adolescents).

<sup>1193</sup> 

compliance with prescribed medical regimens by transplant and cancer patients.

# 1. Illness in the Teenage Years: Desperately Seeking Normalcy

Adolescence is a time of life unmatched by any other in terms of emotional, psychological, and physical growth.<sup>190</sup> Adolescent development is often accompanied by feelings of self-doubt and inadequacy even for the healthiest individuals,<sup>191</sup> and chronic illness only exacerbates the adolescent's vulnerability in that he or she desperately wants to look, feel and act "normal."<sup>192</sup> Compromising the child's course of development into a "normal" teenager, chronic illness often forces those it afflicts into an indefinite "sick role" by "the continuing need to see physicians, take medication, receive treatment, and be aware of any change in symptoms."<sup>193</sup> Thus, chronically ill adolescents can have skewed perceptions of themselves and their place in the world.<sup>194</sup>

191. See HOBBS ET AL., supra note 185, at 72 ("Even with an intact, well-functioning body, it is hard enough to negotiate the currents and challenges of adolescence.").

192. See Patrick Alvin, Adolescents with Long-Term Illness and Compliance: A Clinician's Perspective, 13 J. Adolescent HEALTH 372, 373 (1992) ("[A]dolescence, itself, tends to amplify handicaps and differences from the 'norms.' For the child becoming an adolescent, the tolerance to any disease, its stigmas and limitations, decreases.").

193. Nelson, supra note 180, at 4.

194. Numerous studies have isolated particular psychological, social, and emotional problems experienced by adolescents living with chronic illness. See, e.g., Daniel Offer et al., Body Image, Self-Perception, and Chronic Illness in Adolescence, in CHRONIC ILLNESS AND DISABILITIES IN CHILDHOOD AND ADOLESCENCE 59 (Robert Wm. Blum ed., 1984) (documenting the self-images of groups of physically ill adolescents and comparing them with the self-images of nonpatient teenagers); Warren M. Seigel et al., Depression, Self-Esteem, and Life Events in Adolescents with Chronic Diseases, 11 J. ADOLESCENT HEALTH CARE 501 (1990) (finding that adolescents with chronic illness had higher depression scores and lower self-esteem than their healthy counterparts); Clara Wolman et al., Emotional Well-Being Among Adolescents with and Without Chronic Conditions, 15 J. ADOLESCENT HEALTH 199 (1994) (comparing healthy adolescents with chronic cally ill adolescents and finding that the ill adolescents worried more about dying soon and about

<sup>190.</sup> See Robert Wm. Blum, The Dying Adolescent, in CHRONIC ILLNESS AND DISABILITIES IN CHILDHOOD AND ADOLESCENCE 159, 159 (Robert Wm. Blum ed., 1984) [hereinafter Blum, Dying Adolescent] ("Adolescence is a time measured by firsts-new experiences that bring the developing teenager into contact with his or her emerging potential."); Jeanne Brooks-Gunn, Why Do Adolescents Have Difficulty Adhering to Health Regimes?, in DEVELOPMENTAL AS-PECTS OF HEALTH COMPLIANCE BEHAVIOR 125, 125 (Norman A. Krasnegor et al. eds., 1993) ("Adolescence is a challenging time in that adolescents begin engaging in so-called adult behaviors and are confronted with a plethora of interwoven and complex issues, such as autonomy, intimacy, and achievement."). Developmental tasks facing the adolescent include "adaptation to sudden physical changes and preoccupation with physical appearance, the emergence of sexuality, establishing a sense of personal identity and identification with a peer group, increasing independence and separation from family, developing abstract reasoning skills and formal operational thought." WILLIAM T. GARRISON & SUSAN MCQUISTON, CHRONIC ILLNESS DURING CHILDHOOD AND ADOLESCENCE: PSYCHOLOGICAL ASPECTS 67 (1989); see also supra note 184 (describing the ways in which the adolescent's achievement of four specific developmental tasks may be compromised by chronic illness).

Despite the numerous forces conspiring to limit their options, chronically ill teenagers have the same developmental needs as all other youths.<sup>195</sup> One important aspect of adolescent development contemplates the formation of social and peer relations. Chronic illness hinders the successful achievement of such relations. Studies reveal that chronically ill adolescents "have fewer close friends, are less likely to date, and are less likely to obtain their driver's license, even when not precluded by their disability,"<sup>196</sup> and that their illness "disrupts their freedom and popularity... and [they] are twice as likely to report being unhappy."<sup>197</sup>

Adolescents are also particularly concerned with how their peers perceive them, and adolescents suffering from a chronic illness are often faced with the anxiety-provoking situation of having to reintegrate into peer groups after a prolonged hospitalization.<sup>198</sup> As one child has explained, justifying absence from school necessarily requires disclosure of the illness, which can be an alienating experience.<sup>199</sup>

I don't try to tell them [friends] anymore. I'd have to get into what it [cystic fibrosis] is doing to my body; they couldn't handle it. It happened a lot before when I told people what was going on with me; then they couldn't look or talk to me anymore.<sup>200</sup>

At the time when peer relationships are extremely important, friends of chronically ill youths are constantly unsure of how close to become.<sup>201</sup> It is not unusual for chronically ill adolescents to experience extreme feelings of loneliness and isolation,<sup>202</sup> which, in turn, can

196. Cappelli et al., supra note 183, at 284 (citations omitted).

198. Blum, Dying Adolescent, supra note 190, at 172.

199. Id.

- 200. Id. (alteration in original).
- 201. Id. at 167.

school or future work, had poorer body image, and scored lower on tests of emotional wellbeing). But see Capelli et al., supra note 183 (finding no differences between the responses of chronically ill adolescents and healthy adolescents on standardized measures of coping strategies, mastery, self-efficacy, social support, and depression).

<sup>195.</sup> All adolescents "need opportunities to develop peer relationships and to experiment with different personalities and styles." Blum, *Dying Adolescent, supra* note 190, at 173. Normal developmental needs are rarely acknowledged by physicians who work with seriously ill youths, leaving youths ill-informed and frustrated. *Id.* Areas of particular concern include life planning and future goals, sexuality, the relationship between stress and illness, limits and risks of physical exertion, and modification of medical regimens based on life style. *Id.* 

<sup>197.</sup> Id. (citations omitted).

<sup>202.</sup> Id. at 166; see also HOBBS ET AL., supra note 185, at 79 ("The urge to cloister oneself can be powerful, especially during adolescence. The presence of a chronic illness, regardless of its degree of visibility, can deter socializing with friends and acquaintances."). Maturational discrepancies (for example, those associated with Crohn's disease, end-stage renal failure or cystic

hamper normal development and growth and even cause a physical condition to deteriorate.<sup>203</sup>

Researchers find that the isolation felt by chronically ill adolescents correlates to difficulty with what should be a natural shift of attention from parents to peers.<sup>204</sup> At the time when their peers are all experimenting with independence, ill adolescents experience a prolonged dependence on their parents, who have been, and most likely still are, responsible for making sure their children adhere to their treatment regimens.<sup>205</sup> It is not unusual for conflict to arise between chronically ill adolescents and their parents over the "ownership" of the illness as the adolescent begins to manage his or her own treatment regimen.<sup>206</sup> One researcher has found that "parent-adolescent conflicts frequently center on issues of parental infantilization of their teenage children that disallows the new competencies of adolescence that the chronically ill teenager is striving to realize."207 This parent-child "tug-ofwar" is just one facet of the chronically ill adolescent's struggle for dominion over his or her world. Hospitalization or reliance on medical staff and the treatments they provide add to the adolescent's bat-

fibrosis) and frequent hospitalizations may magnify the adolescent's sad feelings. Blum, Dying Adolescent, supra, at 165-66.

203. Adolescents are typically reluctant consumers of care. Nelson, *supra* note 180, at 7. Health care professionals may approach their work assuming that they are providing to an eager patient or client something that that person really wants, when in reality that person does not want anything that professionals have to provide. Adolescents prefer to use their time, energy, and resources for other pursuits. The need to pass, or to be inconspicuous, often results in practices detrimental to health, such as eating inappropriate foods, suppressing a cough, or taking unwarranted risks.

Blum, Dying Adolescent, supra note 190, at 172.

204. See Blum, Dying Adolescent, supra note 190, at 167.

205. See id. (explaining that during childhood, "parents closely supervise drug regimens, special diets, and physical therapy as if the disease were their own," and that "[t]he relationship between parent and child during the first decade of life, coupled with the parents' feelings of responsibility, makes the adolescent's transition from dependence through independence to interdependence most difficult").

206. Id. at 172; cf. Robert L. Holmes, Children and Health Care Decisionmaking, in Children and Health Care: Moral and Social Issues 173, 174 (Loretta M. Kopelman & John C. Moskop eds., 1989).

The child . . . during the teen years . . . usually wants as much freedom as it can get. And the common measure of its success in getting it is the extent to which it can chart a different course from that wished for it by its parents. Thus responsible parents find themselves caught in the middle, between guiding and supervising their children, on the one hand, and letting them enjoy more freedom of choice, on the other.

Holmes, supra at 174.

207. Blum, *Dying Adolescent, supra* note 190, at 172; see also Dolgin et al., supra note 188, at 22 ("Parents may complicate matters by becoming over-protective—often as a means of combating their own feelings of fear and helplessness.").

tle.<sup>208</sup> In an attempt to regain control, some adolescents fail to comply with their prescribed courses of therapy, which can result in acute relapses or recurrent illnesses.<sup>209</sup>

Related to issues of control are the chronically ill adolescent's feelings about, and responses to, the uncertainty of outcome inherent in chronic illness.<sup>210</sup> While most healthy teens are enthusiastic about future prospects of independence, self-sufficiency and the experience of forming new relationships, seriously ill adolescents may perceive their future options as dependent on the status of their health condition.<sup>211</sup> One researcher suggests that uncertainty about the future poses more of an obstacle for the pediatric patient "whose developmental changes are progressing at a more rapid pace, than for the adult patient who has established basic life activity patterns."212 Many chronically ill adolescents have a distorted picture of the future, which may be attributable to their arrested cognitive growth.<sup>213</sup> Psychologists posit that during adolescence there is a cognitive shift from concrete to abstract reasoning,<sup>214</sup> a component of which is the development of the ability to draw upon old experiences to solve new problems.<sup>215</sup> This developing capacity is predicated upon the individual being exposed to multiple new experiences.<sup>216</sup> Because adolescents with chronic illness have less opportunity to experiment than do their healthy peers, they "lack the experiential substrate for healthy cognitive growth."217

211. See Nelson, supra note 180, at 4 ("The arduous adolescent process of exploring limits, reality testing, and self-image development may be severely delayed or compromised.").

<sup>208.</sup> See Dolgin et al., supra note 188, at 22 ("The adolescent's sense of personal autonomy is compromised by hospitalization and frequent clinic visits, which shift control over the adolescent's life to the institution and its staff."); see also Jamison et al., supra note 183, at 166 (finding adolescent cancer patients who believed that health professionals were not wholly responsible for treatment and outcome to be more cooperative with treatment regimens).

<sup>209.</sup> Blum, *Dying Adolescent, supra* note 190, at 172-73. Blum posits that where adolescents use their illness as a "weapon" by failing to comply with a prescribed therapeutic regimen, they must view their illness as belonging more to others, such as their parents, than themselves. *Id.* 

<sup>210.</sup> See Koocher, supra note 187, at 471 ("Uncertainty regarding the duration of the illness or its ultimate outcome probably remains the greatest single psychological stressor facing the patient with a life-threatening illness.").

<sup>212.</sup> Id.

<sup>213.</sup> Blum, Dying Adolescent, supra note 190, at 167-69.

<sup>214.</sup> Thinking abstractly awakens adolescents to their own ability to affect symptoms and results and allows them to understand the permanence of their illnesses and to think about the future, early death, or increased incapacitation. Joan M. Patterson, *Chronic Illness in Children* and the Impact on Families, in CHRONIC ILLNESS AND DISABILITY 90 (Catherine S. Chilman et al. eds., 1988).

<sup>215.</sup> Blum, Dying Adolescent, supra note 190, at 167.

<sup>216.</sup> Id.

<sup>217.</sup> Id.

The behavioral patterns that emerge in response to uncertainty about the future are varied. For example, adolescents may "excessively structure every present moment to meet preconceived notions of the future,"<sup>218</sup> or alternatively, they may completely reject the possibility of experiencing future events,<sup>219</sup> a form of denial which can translate into present-moment gratification behavior.<sup>220</sup> In one study, it was found that chronically ill adolescents uniformly rejected discussion of future events and exhibited hostility when the interviewer asked about future goals.<sup>221</sup> Some chronically ill adolescents begin to write their wills during periods of hospitalization.<sup>222</sup> This perhaps indicates passive acceptance of a future marred by the realistic possibility of an early death. Other adolescents deal with the possibility of early death more aggressively, possibly in an attempt to circumvent what must feel like an eternal waiting game. One physician has reported that nearly ten percent of the chronically ill adolescents seen in the clinical program with which he is affiliated have attempted suicide.223

The emotional experience of chronically ill adolescents—that they may feel isolated, out of control, frustrated, depressed about the future, and just plain "different"—may prompt some to refuse medical treatment.<sup>224</sup> To illustrate how these feelings translate into life-threatening behavior, the following section focuses on recent research on compliance patterns in adolescents.<sup>225</sup>

220. Patterson, *supra* note 214, at 88. Patterson explains that denial is closely related to an adolescent's noncompliance with prescribed treatment and that such risk-taking represents a way for adolescents to challenge their own mortality. *Id.* 

221. See R. Kastenbaum, *Time and Death in Adolescence, in* THE MEANING OF DEATH (H. Feifel ed., 1959) (finding that "[r]eferences to future events provoked resentment and anger in adolescents who sense that theirs is not the future of their able-bodied peers.").

222. See HOBBS ET AL., supra note 185, at 75 (considering a chronically ill adolescent's writing of his or her will "a reasonable, adultlike way of dealing with the fear of an impending death").

223. Alvin, supra note 192, at 373.

224. See infra part I.D.2. (exploring noncompliant behavior in chronically ill adolescents).

225. Again, research on compliance behavior that focuses specifically on adolescents is scant. See Brooks-Gunn, supra note 190, at 129 ("It is believed that young adolescents exhibit less health-promoting behaviors than do older individuals. Although literature from several sources supports this contention, surprisingly little frank developmental research exists, in the sense of making direct comparisons among children, younger adolescents, older adolescents, and young adults.") (footnote omitted); Jamison et al., supra note 183, at 162 ("Although adolescents have often been stereotyped as noncompliant, few studies have examined this issue."). Moreover, it should be noted that many of the studies that have been published have been inconclusive and

<sup>218.</sup> Id. at 168.

<sup>219.</sup> Patterson, *supra* note 214, at 88. Parents often contribute to their chronically ill adolescent's denial of future events. *See* Alvin, *supra* note 192, at 373 ("[M]any parents have lived under post-traumatic stress, having raised their sick child as 'different' from others. Some parents have even never allowed themselves to think about any viable future project for their child, including that of adolescence.").

#### 2. Compliance Behavior Among Chronically Ill Adolescents

Research on compliance behavior is an important resource to draw upon for analyzing *why* an adolescent might refuse life-saving medical treatment. It is not uncommon for well-informed adolescents to refuse treatment recommended by their physicians.<sup>226</sup> The term "noncompliance" describes "nonadherance (or partial nonadherance) to a prescribed therapeutic or disease preventing regimen."<sup>227</sup> One researcher has observed, "While twenty-five to fifty percent of the general population fail to comply with one or another aspect of a prescribed medical regimen . . . , compliance remains one of the most poorly understood of health behaviors."<sup>228</sup>

Generally, causes for noncompliance include lack of understanding of the diagnosis and treatment plan, denial of illness and consequences, life style, desire to remain ill and dependent on others, and low self-esteem.<sup>229</sup> Not every impetus behind noncompliant behavior is easy to detect or define. Consider the observation of one physician, practicing in adolescent medicine:

Another thing I have come to know is that some adolescents with non- or hardly visible handicaps could experience much more emotional pain than those with obvious physical signs or impairments....[T]he emotional aspects and the personal representations of an illness can have little or nothing to do with its particular type or clinical severity. In fact, they seem to heavily depend upon multiple factors most of which do not belong to the rational and logical biomedical domain. Most of the adolescent's behaviors are condi-

sometimes conflicting. Id. The following section presents some of the studies which suggest that compliance behavior among adolescents differs from that among older patients.

228. Robert Wm. Blum, Compliance with Therapeutic Regimens Among Children and Youths, in Chronic Illness and Disabilities in Childhood and Adolescence, 143, 143 (Robert Wm. Blum ed., 1984).

<sup>226.</sup> Tomas J. Silber, Ethical Considerations in the Care of the Chronically III Adolescent, in Chronic Illness and Disabilities in Childhood and Adolescence 17, 22 (Robert Wm. Blum ed., 1984).

<sup>227.</sup> Andre N. Minuth, *The Economic Load of the Noncompliant Patient: Must Society Pay for the Shrew*?, 16 ARTIFICIAL ORGANS 98, 98 (1992). The term "gross noncompliance" refers to patient conduct such as missed appointments, treatment resistance or refusal, discontinuation of treatment against medical advice, or failure to comply with follow-up requirements. Dolgin et al., *supra* note 188, at 23.

<sup>229.</sup> Minuth, *supra* note 227, at 98. An adolescent's refusal may also be a response to unbearable side effects of certain treatments. See GARRISON & McQUISTON, supra note 190, at 69 (discussing cancer treatments and stating that "the immediate effects of . . . radiation therapy, chemotherapy, and surgery, may be increased pain, nausea, and disfigurement, and it is understandable that many children and adolescents would have difficulty seeing beyond these effects to their potential long-term benefits"). Socio-economic status is another variable relevant to predicting noncompliance. See Dolgin et al., supra note 188, at 25-26 (discussing possible explanations for differing results between two studies of noncompliance among cancer patients).

tioned by these factors, the understanding of which may be complex.  $^{230}$ 

In short, adolescent compliance behavior is unpredictable. Therefore, accurately assessing the maturity of a chronically ill adolescent who has refused life-saving medical treatment seems to be a futile task. To illustrate the phenomenon of noncompliance among adolescents and how it may bear on the issue of maturity, the following discussion focuses on published studies of adolescent transplant recipients<sup>231</sup> and cancer patients<sup>232</sup> conducted during the past two decades.<sup>233</sup>

In a 1978 study,<sup>234</sup> Barbara M. Korsch et al. found that of eighty child renal transplant patients, fourteen were noncompliant with their immunosuppressant regimen.<sup>235</sup> Thirteen of the noncompliant patients were adolescents.<sup>236</sup> All of the patients understood the importance and action of the immunosuppressant medications and had been warned that failure to take their medications regularly might cause rejection and allograft loss.<sup>237</sup> The researchers identified two dominant motivations for noncompliance: Adolescent girls resented the cosmetic side effects of the steroid medication;<sup>238</sup> "[o]ther patients appeared to resent their dependence on the treatment and the medical

232. Refusal of medical treatment by cancer patients will necessarily result in death. Chemotherapy, radiation therapy, and other aggressive treatments provide the patient's only path to survival. Alan D. Blotcky et al., *Psychosocial Characteristics of Adolescents Who Refuse Cancer Treatment*, 53 J. CONSULTING & CLINICAL PSYCHOL. 729, 729 (1985).

233. Compliance by adolescents with other chronic illnesses, such as epilepsy, diabetes, and cystic fibrosis, also has been the subject of recent research. See, e.g., Cappelli et al., supra note 183; E. Chigier, Compliance in Adolescents with Epilepsy or Diabetes, 13 J. ADOLESCENT HEALTH 375 (1992); Ira M. Friedman et al., Compliance with Anticonvulsant Therapy by Epileptic Youth, 7 J. Adolescent Health Care 12 (1986).

234. Barbara M. Korsch et al., Noncompliance in Children with Renal Transplants, 61 PEDIAT-RICS 872 (1978).

235. Id. at 873.

236. Id. at 872. The patients who were over the age of 12 were deemed adolescents for purposes of this study. Id. at 873.

237. Id. at 874.

238. Id. Steroids and immunosuppressive drugs, both medications continually needed to prevent kidney rejection, sometimes cause a cushingoid appearance, characterized by "an abnor-

<sup>230.</sup> Alvin, supra note 192, at 373.

<sup>231.</sup> A kidney transplant recipient who is noncompliant with his or her immunosuppressant regimen risks rejection of the organ, in which case, hemodialysis must be administered until another kidney is transplanted. Susan D. Klein et al., *Chronic Kidney Disease and Transplantation in Childhood and Adolescence, in* CHRONIC ILLNESS AND DISABILITIES IN CHILDHOOD AND ADOLESCENCE 429, 438 (1984). Noncompliance, therefore, does not necessarily precipitate death in kidney transplant recipients. As Klein et al. explain, "Kidney transplantation is a therapeutic intervention designed both to save the individual's life and to enable him or her to experience a higher quality of life than with alternative therapies for end-stage renal disease." *Id.* at 439. Nonetheless, the patterns of behavior among these patients are instructive in delineating the reasons why adolescents, as a distinct population of transplant recipients, may become noncompliant with their prescribed therapeutic regimens.

establishment and were in effect experimenting and testing to see whether they could 'fool' the physicians, their parents, and the system."<sup>239</sup> Korsch and her colleagues concluded that the experiences related to the treatment of end-stage renal disease are particularly stressful to adolescent patients, especially adolescent girls, and that the combination of a vulnerable personality and renal failure occurring during the critical period of adolescence leads to severe maladaption and noncompliance.<sup>240</sup>

In another study of transplant recipients,<sup>241</sup> Susan D. Klein et al. similarly found adolescent patients to be particularly vulnerable to emotional stress as compared with patients of other ages.<sup>242</sup> In a study of fifty-two chronically ill patients in a pediatric renal clinic, ranging in age from eight to twenty,<sup>243</sup> the adolescents in the study accounted for forty-nine percent of the incidents of major emotional problems among the sample.<sup>244</sup> Significantly, suicidal thinking, the most severe reaction that was reported, occurred only among adolescents.<sup>245</sup>

The study revealed a discrepancy in emotional stability between adolescent transplant recipients and recipients belonging to other age groups. While subjective dissatisfaction with appearance was identified as a factor critical to the general adjustment of the adolescents, appearance did not seem as important to older patients.<sup>246</sup> Furthermore, the study showed that transplanted adolescent females experienced less control over destiny, lower stability of identity, less independence, greater preoccupation, less happiness, and lower selfesteem.<sup>247</sup> Older recipients did not exhibit these characteristics.<sup>248</sup>

The Klein study also revealed compliance behavior by adolescents to be markedly different from that by adults.<sup>249</sup> For example, adult transplant recipients with adverse symptoms were more likely to com-

241. Klein et al., supra note 231, at 429.

242. Id. at 440.

243. Fourteen of the subjects were age 16 or over, and 38 of the subjects were between the ages of 8 and 15. *Id.* at 430.

244. Id. at 440.

245. Id.

246. Id. at 446. The researchers observed that a disease had greater significance for the adolescent's overall adjustment once it had become visible. Id.

247. Id.

248. Id. "In fact, older women seem to fare better psychologically than do older men over the short term after transplantation." Id.

249. Id. at 449-52.

mally round, or moon-shaped, face and a protruding abdomen." Klein et al., *supra* note 231, at 438.

<sup>239.</sup> Korsch et al., supra note 234, at 875.

<sup>240.</sup> Id. at 875-76.

ply with their prescribed medication regimen than those with no symptoms.<sup>250</sup> Conversely, adolescents who were symptomatic missed their medications more often,<sup>251</sup> despite the fact that the possible consequences of such behavior could be devastating.<sup>252</sup> It was posited that such behavior "may reflect denial, acting out, or self-destructive motivations."<sup>253</sup> Klein and her colleagues concluded that adolescents may be particularly vulnerable to what they termed the "vicious circle":

[T]he late adolescent-young adult patients who are not taking their medications appear at risk both psychologically and physically. They are not feeling well, they are generally unhappy and specifically unhappy with their appearance, they seem to think less highly of themselves, and they tend to be female. This problem of non-compliance may be particularly difficult to solve because of interdependence of these factors; i.e., the medications tend to create appearance problems and unhappiness, but without them the patient will not be able to maintain health.<sup>254</sup>

Studies of adolescent cancer patients also provide insight into the compliance behavior of chronically ill adolescents.<sup>255</sup> In a study of ten adolescents who refused cancer treatment over a two-year period,<sup>256</sup> Alan D. Blotcky et al. found discrete personality factors which seemed to contribute to the refusal.<sup>257</sup> These included anxiety levels, sense of external control (i.e. belief that one's life is controlled by luck, God, etc.), hopelessness, family satisfaction, religiosity, and physician satisfaction.<sup>258</sup> Blotcky and his colleagues also found that the adolescents' primary reasons for refusing treatment included the fear of how they would look, fear of friends' reactions, side effects of treatment, and painful medical procedures.<sup>259</sup> The refusers reported that their illness was beyond the control of themselves or their physician,

254. Id. at 452.

255. See, e.g., Dolgin et al., supra note 188 (conducting two studies to assess the scope and determinants of gross noncompliance in adolescent cancer patients); Jamison et al., supra note 183 (identifying factors that relate to an adolescent's cooperation with cancer treatment, using a nurse-rated cooperation scale).

256. Blotcky et al., supra note 232.

257. Id. at 730.

258. Id.

259. Id.; see also Dolgin et al., supra note 188, at 25 (finding, in one of two studies of gross noncompliance in adolescent cancer patients, that "[p]rognosis at diagnosis, severity of side effects, and obvious physical residua were significantly related to noncompliance").

<sup>250.</sup> Id. at 450.

<sup>251.</sup> Id.

<sup>252.</sup> See id. ("Although we cannot untangle the direction of causal relationships here, it appears that the noncompliant patients within this age cohort may actually be making themselves sicker.").

<sup>253.</sup> Id.

and that their lives were determined by luck, fate, or religious convictions.<sup>260</sup> Furthermore, by discontinuing the treatment, the refusers ceased suffering the side effects of chemotherapy and thus, tended to believe that their disease was "getting better" or "not changing," and that their chances of cure were still "excellent" or "good."<sup>261</sup>

In addition to "feeling better" or asymptomatic, refusers of chemotherapy may believe that they are successfully avoiding unpleasant long-term physical effects that some radiation treatments may produce. Certain types of cancer treatment can cause sterility, growth retardation or cognitive disabilities, which may have long-enduring psychological ramifications.<sup>262</sup> One researcher has identified several specific psychological disorders related to cancer treatment. First, a chronically suppressed immune system may result in anxiety over potential infections or "germ phobias."<sup>263</sup> Second, chemotherapy-related delayed puberty in adolescent female patients can cause poor self-esteem.<sup>264</sup> Third, adolescent concern over sterility can lead to depression.<sup>265</sup>

In sum, there exist numerous factors unique to adolescents that contribute to noncompliance with treatment regimens. In light of the research suggesting that adolescents may respond differently than adults to chronic illness, the question thus becomes, is it a legitimate exercise of judicial authority to sanction an adolescent's refusal of life-saving medical treatment pursuant to the mature minor doctrine?

### II. ANALYSIS

The mature minor doctrine has skewed the bright-line rule that adults may legally refuse medical treatment and minors may not. For all practical purposes, the doctrine allows some minors to make deci-

265. Id.

1203

<sup>260.</sup> Blotcky et al., *supra* note 232, at 731. This belief may protect patients from experiencing severe anxiety. Koocher, *supra* note 187, at 471. Other studies show that most adolescent cancer patients cope with the stress of their illness through adaptive denial or intellectual defense mechanisms. See, e.g., GERALD P. KOOCHER & J.E. O'MALLEY, THE DAMOCLES SYNDROME: PSYCHOSOCIAL CONSEQUENCES OF SURVIVING CHILDHOOD CANCER (1981); S.B. Lansky et al., *Refusal of Treatment: A New Dilemma for Oncologists*, 1 AM. J. PEDIATRIC HEMATOLOGY/ ONCOLOGY 277 (1979).

<sup>261.</sup> Blotcky et al., *supra* note 232, at 730. Nausea and vomiting are the most common side effects of chemotherapy. Koocher, *supra* note 187, at 469.

<sup>262.</sup> Koocher, *supra* note 187, at 469; *see also* Dolgin et al., *supra* note 188, at 22-23 (explaining that diagnosis and treatment of serious illness during adolescence may cause physical weakness, dependence on others, and disruption of peer relations; it may inhibit psychosocial and psychosexual development; and it may compromise the adolescent's sense of personal autonomy).

<sup>263.</sup> Koocher, supra note 187, at 469.

<sup>264.</sup> Id.

sions for themselves when they engage in adult-like activities that would ordinarily be reserved to their parents.<sup>266</sup> In recent years, the law has gone so far as to allow mature minors to refuse medical treatment without which they were destined to meet an imminent death.<sup>267</sup> While the age eighteen does not necessarily accurately reflect the time when all adolescents achieve the mental and emotional aptitude to make adult-like decisions, there is something disconcerting about placing a life or death decision into the hands of a fifteen-year-old such as Benny Agrelo,<sup>268</sup> even if it is his own life at stake.

The logical justification for employing the mature minor doctrine would seem to be judicial recognition that it is possible for some adolescents to attain the faculty for adult-like decision-making, in conjunction with psychosocial documentation that those adolescents do, in fact, exercise adult-like judgment regarding their health care. In other words, the mature minor doctrine should be the legal system's way of expressing that anyone who exhibits the maturity of an adult ought to enjoy the same substantive rights that an adult enjoys while engaging in adult-like activity. Once a determination of maturity is made, the adolescent ought to be free to make whatever decisions he or she deems appropriate, without parental or state interference, and indifferent to judicial notions of what is in the adolescent's "best interests."

A close examination of the mature minor doctrine's evolution reveals that the purposes sought to be served by removing the parental consent barrier to certain forms of medical treatment for adolescents reflect a more paternalistic objective by the courts. Instead of affording adolescents a right to access for the sake of expanding their rights in the health care context, courts have extended the right to access where it is in adolescents' best interests to do so. The minor is never free from an inquiry as to what is in his or her best interests. Courts will not even embark on a maturity evaluation unless a finding of maturity will in some way serve the best interests of the minor.<sup>269</sup> Thus, the initial inquiry must be whether it is *ever* in the best interests of an adolescent to refuse necessary medical treatment. If the answer

<sup>266.</sup> See supra part I.B.4. (tracing the development of the mature minor doctrine).

<sup>267.</sup> See supra text accompanying notes 13-17 (discussing the case of Benny Agrelo, in which a trial court judge most likely invoked the mature minor doctrine to allow a 15-year-old liver transplant pattient to discontinue anti-rejection medication); supra notes 130-47 and accompanying text (discussing In re E.G., in which a minor suffering from leukemia was permitted to refuse blood transfusions that were part of treatment to save her life).

<sup>268.</sup> See supra text accompanying notes 13-17 (discussing the case of Benny Agrelo).

<sup>269.</sup> See infra notes 274-85 and accompanying text (discussing the emergency exception to the common law rule requiring parental consent, minor treatment statutes, and abortion laws).

is "no," then courts would never even have to assess maturity. If, however, it is determined that under certain circumstances it is in the best interests of adolescents to forego necessary medical treatment, then courts would need to indulge in a maturity evaluation when presented with adolescents who refuse medical treatment.

As the following discussion will show, both levels of evaluation are problematic. First, determining whether allowing adolescents to refuse life-saving medical treatment is in their best interests necessarily requires that there exist a mode of analysis for defining what those interests are in such a situation. Although the mature minor doctrine recognizes that minors' personal interests warrant respect, courts have ordinarily analyzed those interests in an "unsystematic and unfocused fashion."<sup>270</sup> Moreover, an ancillary consequence of inquiring into adolescents' best interests is that such inquiry effectively undermines adolescents' interest in personal autonomy.<sup>271</sup> Second, the vagueness and malleability of the current formulation of the mature minor doctrine make judicial assessments of maturity suspect.<sup>272</sup>

To better understand the complexities of the interrelationship between maturity inquiries and best interest determinations, the first section of the Analysis traces the development of minors' limited rights to consent to and refuse medical care as a manifestation of paternalism. Particularly noteworthy are judicial reluctance to extend to minors any consensual authority where proposed medical treatment is not beneficial and the persistence of the notion that parents are appropriate adjudicators of their children's best interests. The second section of the Analysis focuses on the validity of the mature minor doctrine in light of its potential for misapplication.

#### A. The Paternalism Concept

Paternalism is at the heart of all legal policies governing allocation of consensual rights in the health care context.<sup>273</sup> The common law

<sup>270.</sup> Stuart J. Baskin, Note, State Intrusion into Family Affairs: Justifications and Limitations, 26 STAN. L. REV. 1383, 1392 (1974).

<sup>271.</sup> See Hawkins, supra note 2, at 1592 ("If paternalism is the prevailing policy in this context, the argument for minors' increased autonomy becomes weaker when the decision involves refusal of, rather than consent to, medical treatment."). However, assessing the best interests of a chronically ill adolescent must take into consideration the individual's personal suffering that would result by being forced to endure unbearable side effects of treatment until turning eighteen.

<sup>272.</sup> See infra part II.B.

<sup>273.</sup> See Hawkins, supra note 2, at 1587 ("A single policy emerges from both the requirement for parental consent and the associated situational and status exceptions: paternalism.").

rules requiring parental consent for the treatment of minors,<sup>274</sup> and their exceptions,<sup>275</sup> further paternalistic goals by allocating decisionmaking capacity in a way that yields maximum benefit not only to the specific minor whose treatment is at issue, but to the general public as well. For example, exceptions to the common law rule under emergency circumstances were premised on the idea that it is always in the best interests of a child to receive prompt medical attention when his or her health or life is endangered.<sup>276</sup> Similarly, minor treatment statutes were enacted in response to society's fear that minors would rather suffer from sexually transmitted diseases, alcohol and substance abuse, and mental disorders than risk the consequences of consulting their parents, who may be angry, accusative, or unsupportive.<sup>277</sup> Finally, in the abortion context, it was feared that if minors were denied access to legal abortions.<sup>278</sup> One commentator has observed:

Despite a plethora of cases which purport to turn on minors' maturity, the case law granting reproductive rights to minors, like the mature minor doctrine generally, rests not on an assessment of maturity, but rather, on a calculus which permits minors autonomy only when the treatment is relatively low risk, or when denying access may cause the minor to suffer permanent harm.<sup>279</sup>

As another commentator has posited that affording minors access to abortions and contraceptives fulfills the government's obligation "to do less harm than good."<sup>280</sup>

That the state's interests in preservation of life and protection of minors' health are the paramount objectives in allocating to adolescents any degree of consensual authority over their health care is supported by the fact that mature minors traditionally have been permitted to consent to their own medical treatment only where the

<sup>274.</sup> See supra part I.B.1. (discussing the common law position that until reaching the age of majority, a minor lacks legal authority to consent to his or her own medical care).

<sup>275.</sup> See supra parts I.B.2.-3. (discussing the common law emergency and emancipation exceptions and minor treatment statutes).

<sup>276.</sup> See supra text accompanying note 66 (explaining the law's recognition that it is cruel to allow a child to suffer in an emergency merely because he is unaccompanied by his or her parents).

<sup>277.</sup> See supra part I.B.3. (discussing the development of minor treatment statutes); see also ZIMRING, supra note 1, at 65 (explaining that "[t]o seek parental approval for treatment of these conditions is to inform parents of underlying patterns of behavior that are not likely to inspire parental approval.").

<sup>278.</sup> See Hawkins, supra note 2, at 1607-08 (observing that the "'best interests' rationale applies . . . in the context of abortion, where requiring parental consent might prompt minors to seek unsafe, illegal abortions out of fear (however ill-founded) and desperation").

<sup>279.</sup> Oberman, supra note 56, at 52.

<sup>280.</sup> ZIMRING, supra note 1, at 66.

treatment was for their benefit.<sup>281</sup> "Benefit" translates to curative or therapeutic treatment.<sup>282</sup> State intervention policies similarly exemplify society's interest in affording minors beneficial treatment.<sup>283</sup> In the case of a young minor, for example, the state is not entitled to interfere with parents' decisions to refuse medical treatment on behalf of their child.<sup>284</sup> However, the state has full discretion to intervene when the refused treatment is necessary to save the minor's life.<sup>285</sup>

Parents are the traditional adjudicators of their children's best interests. The mature minor doctrine should, in theory, effectively usurp parents' authority over health care decisions affecting their children. However, it is often difficult to divorce the minors' interests from the parents' interests. In the context of abortion, the Court in Danforth held that the rights of parents must yield to the fundamental rights of their children.<sup>286</sup> However, this is not an absolute right of minors to be free from the intrusion of their parents into their decision to have an abortion. Rather, the United States Court of Appeals for the Seventh Circuit has noted that "even though a parent has an interest in the decision whether the minor is to have an abortion, the state has the power and duty to exclude the parent from the decision-making process if it is determined that exclusion would better serve the minor's The pregnant adolescent must still go to court and welfare."<sup>287</sup> demonstrate either that she is mature or that it is in her best interests

282. See MORRISSEY ET AL., supra note 9, at 17 ("[I]t is clear that where the courts have viewed minors as mature enough to consent to medical treatment, the procedures involved have been relatively uncomplicated and have been recommended for the minor's own benefit.").

283. See supra text accompanying notes 50-52 (discussing state intervention policies).

284. See, e.g., Newmark v. Williams, 588 A.2d 1108, 1115-20 (Del. 1991) (sustaining parental objection to chemotherapy where the treatment was "more likely to fail than succeed" and could be fatal in itself).

285. See MORRISSEY ET AL., supra note 9, at 96 (noting that all states consider "the withholding of necessary medical treatment from a child to constitute abuse and/or neglect").

286. Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. 52, 71-76 (1976). In Wynn v. Carey, 582 F.2d 1375 (7th Cir. 1978), the Court of Appeals for the Seventh Circuit interpreted *Danforth* as standing for the following proposition:

Because it is the minor, not the parents, who physically bears the child and faces the physiological and emotional risks attendant to childbirth, and because it is the minor, not the parents, who is responsible for the child once it is born, the Court held that parents do not have the right to stop an abortion if their mature daughter, with the consent of her physician, decides to terminate the pregnancy.

Id. at 1386.

287. Wynn, 582 F.2d at 1386 (emphasis added).

1207

<sup>281.</sup> See supra note 81 and accompanying text (defining the mature minor doctrine). It has been observed that in most consent to treatment cases in which the mature minor doctrine has been invoked, the medical procedures involved have been less than "serious." ZIMRING, supra note 1, at 66.

to refrain from involving her parents in her decision to have an abortion.

In the context of an adolescent refusing necessary medical treatment, courts have yet to honor a minor's refusal over the objections of his or her parents. For example, in *In re E.G.*,<sup>288</sup> although the court framed its decision to accept E.G.'s refusal of blood transfusions in terms of the minor's interest in self-determination and not her parents' interest in autonomy from the state, E.G.'s parents did not object to her refusal.<sup>289</sup> In one commentator's opinion, "where the child's life is at stake, a conflict between the parents and the child should be resolved in favor of preservation of the child's life, even if treatment is given over the child's objection."<sup>290</sup>

Considering the development of minor abortion law,<sup>291</sup> the alignment of parent and child interests in *In re E.G.*,<sup>292</sup> and the Supreme Court's consistent reiteration of the "natural rights" of parents to raise their children in the manner they see fit,<sup>293</sup> one is inclined to believe that only where parents concur with their minor child's refusal of life-saving medical treatment will a court consider giving legal effect to the minor's wishes. Thus, in addition to conducting a best interests inquiry—which lacks any substantive guidelines—courts must at some point take into account the alignment between the parents' and the minor's desires. This clearly undermines the utility of declaring a particular minor to be mature enough to make a personal choice regarding his or her health care.

Finally, the psychosocial experience of the chronically ill adolescent should not be overlooked as a significant variable in the best interests analysis. Research indicates that adolescents manifest an intolerance for both illness and its treatment that markedly exceeds that of similarly ill adults.<sup>294</sup> When the physical and emotional turmoil felt by a chronically ill adolescent translates into noncompliant behavior, certain questions must be addressed: Will the adolescent feel better, physically and/or emotionally, in a few months or few years? What if,

<sup>288. 549</sup> N.E.2d 322 (III. 1989); see supra notes 130-47 and accompanying text (discussing E.G. in detail).

<sup>289.</sup> E.G., 549 N.E. 2d at 326-28.

<sup>290.</sup> HOLDER, LEGAL ISSUES, supra note 6, at 122.

<sup>291.</sup> See supra notes 110-24 and accompanying text (discussing the evolution of minor abortion law).

<sup>292.</sup> See supra text accompanying note 132 (noting that E.G.'s mother concurred with E.G.'s refusal of medically necessary blood transfusions).

<sup>293.</sup> See supra notes 49, 57-59 and accompanying text (discussing the right of parents to make decisions regarding the care of their children).

<sup>294.</sup> See supra part I.D. (discussing psychosocial research concerning chronically ill adolescents).

in time, there is a less invasive, more tolerable treatment developed? Most importantly, is it ever in the best interests of an adolescent to forego the opportunity to grow up? Although there are no correct or concrete answers to these questions, merely positing them highlights that there are inherent problems with legally sanctioning an adolescent's refusal of life-saving medical treatment, especially in light of the courts' traditional protective posture towards minors.

Since serving the best interests of a minor is the primary goal in making any decision regarding a minor's health, and because parents maintain a judicially recognized interest in the care of their adolescent children, invocation of the mature minor doctrine to allow an adolescent to refuse life-saving medical treatment runs contrary to the traditional policies governing allocation of consensual authority in the health care context.<sup>295</sup> This undermines the legitimacy of using the mature minor doctrine to afford adolescents the right to refuse lifesaving medical treatment. Nonetheless, assuming that such theoretical considerations are overlooked, there still exists the practical problem of creating an appropriate standard for determining maturity.

## B. Definitional Shortcomings of the Mature Minor Doctrine

As a matter of analytical process, a minor who is found by a court to be mature may legally refuse medical treatment by invoking a right that is normally reserved for adults.<sup>296</sup> The minor's refusal will be honored so long as his or her interest in self-determination is not outweighed by one or a combination of four state interests.<sup>297</sup> Thus, the method by which a court assesses a minor's maturity will be outcomedeterminative of whether he or she may refuse life-saving treatment.<sup>298</sup> To illustrate the significance of the term "maturity," this section first delineates how courts currently define "mature minor." It then addresses the problems inherent in making a subjective assess-

<sup>295.</sup> See In re E.G., 549 N.E.2d 322, 329 (Ill. 1989) (Ward, J., dissenting) (explaining that E.G. "is not a holding where consent to treatment is the question but rather a unique one where a minor's injury or very self-destruction may be involved").

<sup>296.</sup> If a minor is found to be mature, the court is effectively declaring the minor to be an adult for purposes of making a particular decision.

<sup>297.</sup> See supra text accompanying notes 143-44 (discussing the "equation" the court used to determine whether the adolescent in *In re* E.G. could legally refuse necessary blood transfusions); see also supra text accompanying notes 31-33 (explaining that where an adult refuses life-sustaining treatment, the court will balance the individual's interest in self-determination against four countervailing state interests).

<sup>298.</sup> If a minor is found to be mature, his or her interest in self-determination will equal that of an adult. It is rare that a court will find that a state interest outweighs an *adult*'s interest in self-determination, and thus, it logically follows that no state interest should outweigh a *mature minor*'s interest in self-determination.

ment of a minor's maturity. Finally, it explores the necessity of incorporating information regarding the psychosocial development and compliance behavior of chronically ill adolescents into a working definition of "maturity."

## 1. Present Interpretation of the Mature Minor Doctrine

Caselaw yields little guidance as to what constitutes maturity for purposes of declaring an adolescent a mature minor. In the caselaw to date, the issue of a minor's maturity receives little more than a brief reference, and often, the court will simply cite several factors that it or another court considered relevant in previous cases, without actually applying the factors to the facts of the instant case. Although a synthesis of the courts' analyses of maturity in the cases discussed in the Background section provides a laundry list of what may be "recommended" factors to consider in assessing maturity,<sup>299</sup> the traits and circumstances they appraise are not dispositive of maturity. At present, it is recommended that courts consider the following to determine whether a minor is mature: the minor's age,<sup>300</sup> judgment,<sup>301</sup> education,<sup>302</sup> training,<sup>303</sup> ability,<sup>304</sup> and experience;<sup>305</sup> the minor's conduct and demeanor at the time of treatment:<sup>306</sup> whether the minor exhibits the maturity of an eighteen to twenty-one-year-old;<sup>307</sup> whether the minor understands the basic tenets of his or her religion if religion is the basis of the refusal;<sup>308</sup> whether the minor is well enough informed to make an intelligent decision;<sup>309</sup> whether the minor has the capacity to appreciate the risks of the medical procedure administered or withheld;<sup>310</sup> and whether the minor can assess the implications of his or her choice.311

While these factors may provide some insight into whether or not a minor understands the nature of his or her ailment and the possible

- 309. Bellotti v. Baird, 443 U.S. 622, 647 (1979).
- 310. Belcher v. Charleston Area Medical Ctr., 422 S.E.2d 827, 838 (W. Va. 1992).
- 311. Bellotti, 443 U.S. at 650.

<sup>299.</sup> See supra parts I.B.4., I.C. (discussing cases in which the mature minor doctrine has been invoked in the health care context).

<sup>300.</sup> Belcher v. Charleston Area Medical Ctr., 422 S.E.2d 827, 838 (W. Va. 1992).

<sup>301.</sup> Id.; In re E.G., 549 N.E.2d 322, 328 (Ill. 1989); Cardwell v. Bechtol, 724 S.W.2d 739, 755 (Tenn. 1987).

<sup>302.</sup> Cardwell, 724 S.W.2d at 755; Belcher, 422 S.E.2d at 838.

<sup>303.</sup> Cardwell, 724 S.W.2d at 755; Belcher, 422 S.E.2d at 838.

<sup>304.</sup> Cardwell, 724 S.W.2d at 755; Belcher, 422 S.E.2d at 838.

<sup>305.</sup> Belcher, 422 S.E.2d at 838.

<sup>306.</sup> Id.

<sup>307.</sup> E.G., 549 N.E.2d at 324.

<sup>308.</sup> In re Long Island Jewish Medical Ctr., 557 N.Y.S.2d 239, 243 (N.Y. App. Div. 1990).

consequences of refusing treatment, they are vague and incapable of vielding an accurate assessment of maturity where the minor under consideration is a chronically ill adolescent. For example, a chronically ill sixteen-year-old can certainly explain to a judge that she knows she will die if she stops her chemotherapy, but that death is preferable to the dreadful side effects of treatment. She may be welleducated and maintain adult-like composure throughout her treatment. Under the current standards for assessing maturity, this particular adolescent may qualify as "mature," which means the law will treat her as having the capacity of a similarly situated adult to make a life or death decision. The problem is that although she may look, talk, and act like an adult, she is an adolescent, and adolescents respond differently to chronic illness than adults.<sup>312</sup> Chronically ill adolescents and chronically ill adults are not similarly situated in terms of their emotional and psychological development and coping.<sup>313</sup> Under the current standards for determining maturity, this concept is ignored. Thus, the minor's life is left entirely to the discretion of a single judge.

#### 2. Judicial Discretion

The lack of any meaningful guidance by way of legislation or legal precedent as to how a judge might go about assessing a minor's maturity creates the potential for unchecked judicial discretion and inconsistent application of an ill-defined standard. The standards by which a judge will decide the fate of a minor are ultimately the judge's own values.<sup>314</sup> Furthermore, it is unlikely that a judge will have the time necessary to fully evaluate every component of the minor's specific situation.<sup>315</sup> It is unclear the amount and types of information about

314. Waters, *supra* note 112, at 92. Waters argues that "the Court must elaborate upon the mature-minor standard to ensure that a minor's right to an abortion is not obscured by a veil of judicial discretion." *Id.* 

315. See id. at 98 n.55

<sup>312.</sup> See supra parts I.D.1.-2. (discussing research on adolescents' response to chronic illness).

<sup>313.</sup> Id. Perhaps the differences in coping ability between adolescents and adults are not significant enough to justify disparate treatment of them. Although comparative research of the two age groups is not yet well-developed and the extent of these differences is unclear, there is no conclusive evidence that chronically ill adolescents and adults respond to their illnesses in the *same* way. Therefore, it is not appropriate for the law to presume that because a minor exhibits characteristics of "maturity" unrelated to his or her illness that he or she is as mature as an adult in all relevant respects.

For the judge to have intimate knowledge of the person before the court, he must review files and reports, consult with relevant medical and counseling professionals, and spend time with the teenager. . . . [I]t is likely unfeasible for a judge to acquire the needed familiarity with the teenager and her situation.

the minor a judge is required to collect before he or she is able to make an informed assessment of maturity.

Vague standards for assessing maturity also invite determinations based upon characteristics that may be the "fortuitous product of educational opportunity and socioeconomic advantage,"<sup>316</sup> and thus create the potential for discrimination. For example, two sixteen-yearolds, each experiencing the same acute treatment for the identical form of cancer, may be dealt with quite differently depending upon their respective physical appearances, their dispositions while talking to the judge, and their abilities to articulate their feelings.<sup>317</sup>

This is not to suggest that an objective test for maturity, such as an age-based standard which would allow a seventeen-year-old to refuse treatment, but would bar a fifteen-year-old from even petitioning the court for an assessment of his or her maturity, is preferable to a subjective evaluation.<sup>318</sup> Age-based standards of maturity are no less arbitrary than the standards that are presently in place.<sup>319</sup> Rather, the primary problem with the current method of evaluation of maturity is that it is devoid of any substantive inquiry into the psychosocial ramifications of chronic illness during adolescence that may precipitate an adolescent's refusal of life-saving medical treatment.

# 3. The Experience of the Chronically Ill Adolescent as a Factor in Assessing Maturity

Incorporating available information regarding the impact of chronic illness on the emotional stability of an adolescent is an integral part of creating a working definition of "mature minor" in the health care context, especially where an adolescent is refusing medical care necessary to sustain his or her life. Moreover, because the mature minor doctrine is a vehicle through which to promote the "best interests" of

<sup>316.</sup> Id. at 99.

<sup>317.</sup> See id. (explaining that "[e]qual and consistent treatment of similarly situated minors may be impossible if the general procedures or inquiries for determining maturity are left to ad hoc decision making and excessive judicial discretion").

<sup>318.</sup> See id. at 100 (observing the following in the context of abortion:

Objective standards, such as age or physical attributes, reveal only the most general aspects of a teenager's status and are too dependent on the superficial aspects of chronology or physiology to assess adequately an individual's capacity to rationally consider and comprehend the short- and long-term consequences of aborting or continuing a pregnancy.).

For a discussion of proposed objective diagnosis-based standards for assessing maturity, see generally Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645 (1977).

<sup>319.</sup> See supra text accompanying notes 300-11 (reciting the factors that currently guide courts in assessing maturity).

minors,<sup>320</sup> it does not seem possible to make a sound life or death decision without considering whether there are specific characteristics that distinguish a seriously ill adolescent from a similarly ill adult, and which may influence an adolescent's compliance behavior.

An adolescent's apparent ability to comprehend that death will be the inevitable consequence of discontinuing life-saving medical treatment should not be the most weighty factor in determining that a minor is mature. Explicit acceptance of death as an alternative to continuing medical treatment should likewise not be considered dispositive of a minor's maturity. Current literature regarding the psychosocial ramifications of chronic illness suggests that adolescents are particularly susceptible to "intolerance."<sup>321</sup> This intolerance encompasses the physical, emotional, and psychological suffering caused by the adolescent's illness and treatments.<sup>322</sup> Because certain manifestations of intolerance are unique to the adolescent age group,<sup>323</sup> they may be considered temporary, in which case the risk of making an erroneous decision to discontinue or refuse necessary medical treatment greatly increases.

In Cruzan v. Director, Missouri Department of Health,<sup>324</sup> the Court was clearly bothered by the risk of error that is inherent in choosing to terminate life-sustaining treatment on behalf of an incompetent adult.<sup>325</sup> In light of the traditional protective posture of courts regarding the medical care of minors<sup>326</sup> and the possibility that a minor will outgrow the intolerance for his or her illness and/or treatment, it would seem that the courts would be equally, if not more, reluctant to allow a mentally competent minor to refuse medical treatment necessary to sustain his or her life.

Intolerance bears on maturity in a variety of ways. Educational psychologists measure the components of an adolescent's maturity, which include his or her relative emotional, psychological, and social growth, through "developmental tasks."<sup>327</sup> One commentator has noted the following:

1213

<sup>320.</sup> See supra part II.A. (discussing the paternalistic objectives of mature minor law).

<sup>321.</sup> See supra parts I.D.1.-2. (discussing ways in which the emotional effects of chronic illness and its treatment translate into behavior patterns among adolescents).

<sup>322.</sup> See supra parts I.D.1.-2.

<sup>323.</sup> See supra parts I.D.1.-2.

<sup>324. 497</sup> U.S. 261 (1989).

<sup>325.</sup> See supra text accompanying notes 43-44.

<sup>326.</sup> See supra part I.B.1. (discussing common law rules which allocate to parents the authority to consent to health care for their children).

<sup>327.</sup> Waters, supra note 112, at 101 n.62.

The developmental tasks of adolescents include achieving more mature relationships with age-mates of both sexes, achieving emotional independence from parents and other adults, selecting and preparing for an occupation, developing intellectual skills and concepts necessary for civic competence, achieving socially responsible behavior, and acquiring a set of values and an ethical system as a guide to behavior.<sup>328</sup>

Against this criteria, arguably, chronically ill adolescents develop at a slower rate than their healthy contemporaries.<sup>329</sup> Chronically ill adolescents often isolate themselves from their peers, either because they feel that their physical condition scares people away, or because they spend too much time out of school, thus preventing them from building any significant relationships.<sup>330</sup> At the same time, chronically ill adolescents are more likely than healthy adolescents to remain dependent on their parents.<sup>331</sup> The combination of continued dependence on parents and isolation from peers (even if it is self-imposed) creates a rebellious effect in some adolescents, which may lead to self-destructive behavior, including noncompliance with medication or other forms of treatment.<sup>332</sup>

The data on compliance behavior by chronically ill patients clearly identify adolescents as the group most likely to become noncompliant.<sup>333</sup> While researchers cite dissatisfaction with appearance, side effects of treatment, and fear of friends' reactions as some of the most significant factors leading to noncompliance,<sup>334</sup> these feelings may be well-disguised by the adolescent.

Studies of compliance behavior in chronically ill adolescents are relevant to legal analysis on two interrelated levels: First, the data identifies adolescents as a discreet subset of chronically ill patients<sup>335</sup> that requires particular attention by the medical, psychological, and legal communities. Second, because the true underlying motivations for refusing treatment could be difficult for a judge to identify (especially by the current method of assessing maturity), it is imperative that the

<sup>328.</sup> Id.

<sup>329.</sup> See supra part I.D.1. (discussing the aberrant social development of chronically ill adolescents).

<sup>330.</sup> Blum, Dying Adolescent, supra note 190, at 167.

<sup>331.</sup> See supra notes 205-07 and accompanying text (describing the relationship between chronically ill adolescents and their parents).

<sup>332.</sup> See supra part I.D.2. (discussing noncompliance with prescribed medical treatment among chronically ill adolescents).

<sup>333.</sup> See supra part I.D.2.

<sup>334.</sup> See supra note 259 and accompanying text (discussing the results of several studies of adolescent patients refusing treatment for cancer) and notes 238, 246, 251, 254 (discussing the results of two studies of adolescent patients refusing treatment for kidney disease).

<sup>335.</sup> See supra parts I.D.1.-2.

legal system construct a mode of analysis for determining maturity that accounts for the unique response by adolescents to the experience of chronic illness, as illustrated by their compliance behavior.

#### III. CONCLUSION

As medical technology continues to progress at unprecedented rates, it is likely that state agencies will, in the future, present to the various courts throughout the nation situations akin to that of Benny Agrelo. The courts must prepare themselves to make such life or death decisions and must base their decisions on rational legal doctrine. In theory, the mature minor doctrine provides a court with the greatest ability to take account of all factors relevant to deciding whether to legally sanction an adolescent's decision to forego life-saving medical treatment.<sup>336</sup> Despite its apparent flexibility, the doctrine, as applied in this context, suffers from two fundamental flaws: Its vagueness invites inconsistency in application,<sup>337</sup> and it fails to recognize the uniqueness of the population affected.<sup>338</sup> Furthermore, a review of the evolution of minors' legal ability to consent to certain forms of health care reveals an underlying paternalistic objective, which is significant in that it requires courts to evaluate and identify what course of action would be in the best interests of the refusing adolescent. Not only does such an inquiry involve unjustified subjectivity, but it effectively undermines the premise upon which the doctrine is based-that some minors are mature enough to make their own decisions, regardless of whether their parents, their doctors, or the courts concur.

That courts have deviated from the common law position regarding minors as incapable of making reasoned, adult-like decisions, to allow them to refuse life-saving medical treatment, merits scrutiny. The ambiguity in prohibiting minors from purchasing alcoholic beverages, cigarettes or pornographic magazines, but allowing them to refuse lifesaving medical treatment speaks for itself. Perhaps there exists some justification for the dichotomy, but the courts have yet to articulate it.

<sup>336.</sup> See supra notes 79-81 and accompanying text (introducing the mature minor doctrine as a loosely defined and malleable legal tool).

<sup>337.</sup> See supra part II.B.2. (explaining that the lack of uniform standards by which to assess a minor's maturity inevitably invites judicial discretion, which leads to inconsistent outcomes among cases).

<sup>338.</sup> See supra part II.B.3. (arguing that in the context of adolescents who refuse life-saving medical treatment, the mature minor doctrine, as currently interpreted, is an incomplete method of determining maturity, as it does not take into account differences between adolescents and adults in terms of their ability to cope with chronic illness).

It is unacceptable that these issues are yet unaddressed by the legal community, for one must remember that relatively young lives are at stake. The medical, psychological, sociological, as well as legal complexities involved in cases of adolescents refusing life-saving medical treatment cannot easily be untangled. Nonetheless, the gravity of the consequences of continuing to apply the mature minor standard, despite its shortcomings, demands that courts tackle this area of the law. Acknowledging the adolescent's atypical experience with chronic illness represents the first, and most essential, step.

Jessica A. Penkower\*

<sup>\*</sup> The author wishes to acknowledge Professor Michelle Oberman for her inspiration, ideas, and thought-provoking conversations on the issues presented herein, and to thank Lili Penkower and Alan Penkower for their helpful assistance throughout the drafting of this Comment.