

Allowing Adolescents to Make Life-and-Death Decisions about Themselves:  
Rights and Responsibilities of Adolescents, Families, and the State

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**Abstract**

There is consensus among scholars writing in bioethics, medicine, and the law, that adolescents ought to participate in health care decision making about themselves. There is less agreement on what adolescent ‘participation’ means and about the range of health care decisions that adolescents can and should make, especially whether adolescents should be able to have ultimate authority over life-and-death decision making about themselves. This dissertation argues that adolescents should not be allowed to exercise such authority in the life-and-death decision making setting. A current, misconstrued ‘respect’ for adolescent autonomy is not justified by our inadequate understanding of decision making capacity, especially for adolescents who are in danger of making medical decisions that may greatly impact their future. Deliberation ought to be guided by a triadic approach that incorporates the interests, roles, and responsibilities of parents, health care providers, and the adolescent in a therapeutic alliance focused on beneficence to the adolescent patient.

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*Table of Contents*

<b>Chapter 1</b>	Considering Life-and-Death Decision Making by Adolescents:	
	Introduction and Overview	1
I.	Sketching the Contours of the Problem	5
II.	Best Interests and the Principle of Beneficence	14
III.	Participation in Decision Making – Respect for	
IV.	Developing Autonomy	17
IV.	Conclusion	24
 <b>Chapter 2</b>	 The “Capacity Problem” in Adolescent Life-and-Death Decision Making	 26
I.	Exceptions to the Minor’s Inability to Consent to or Refuse Treatment	30
II.	Informed Consent or Refusal of Medical Treatment	32
III.	The “Capacity Problem” – Generally	39
IV.	The “Capacity Problem” – Specifically	45
	Point One: The ambiguity of determining capacity	46
	Point Two: Adolescents’ Capacity Skills: Are they Based Only in Cognition?	54
	Point Three: What does Adolescent Decision Making Say about Autonomy and the Role of the Family?	80
	Point Four: The relationship between health care providers, family, and the adolescent facing life and death	82
 <b>Chapter 3</b>	 Adolescents’ Interests, Rights, and Responsibilities in Making Life-and-Death Decisions about their Medical Treatment	 84
I.	Interests of Adolescents with Serious Illness	87
II.	Adolescent ‘Rights’ to Make Serious Health Care Decisions	98
III.	Adolescent Refusal of Life-or-Death Treatment	109
IV.	Ethical Rights and Responsibilities of the Sick Adolescent and of Others	130
V.	Conclusion	139
 <b>Chapter 4</b>	 Parental Rights and Responsibilities when an Adolescent Refuses Life-or-Death Treatment	 141
I.	Describing the Context	141
II.	The Argument So Far: Rights and Responsibilities of the	

	Adolescent in Making Decisions about Treatment for Life-Threatening Illness	144
III.	Parental interests in decision making for their children: Buchanan and Brock	147
IV.	'Parental Autonomy'	164
V.	Adolescents Without Involved Parents in their Lives	168
VI.	Conclusion	170
<b>Chapter 5</b>	Health Care Provider and State Intervention in Adolescent Treatment Refusal: Roles and Responsibilities of the State	172
I.	A Brief Return to AJ and BJ	175
II.	Interests of the State in Intervening in Adolescent or Parental Refusals of Treatment	180
<b>Chapter 6</b>	Concluding Reflections	210
<b>References</b>		216

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## **CHAPTER 1**

### **Considering Life-and-Death Decision Making by Adolescents:**

#### **Introduction and Overview**

The purpose of this dissertation is to explore the ethical issues surrounding adolescent life-and-death decision making. The dissertation builds on and critiques work in bioethics, medicine, and the law, much of which shares a consensus that adolescents ought to be active participants in health care decision making about themselves.<sup>1</sup> There is, however, less agreement among these authors on what adolescent ‘participation’ means and about the range of health care decisions that adolescents can and should make. This uncertainty is most clearly reflected in advocates’ arguments for allowing adolescents to make all of their own health care decisions. Interestingly, their position becomes hesitant and tentative upon consideration of whether the adolescent facing life-and-death circumstances should be the final decision maker regarding medical treatment. The advocates’ equivocation about adolescents making such decisions about themselves highlights the problem of placing adolescents in positions of having ultimate autonomy over irreversible life-and-death medical decisions. My thesis is that adolescents should not be allowed to exercise such authority in the life-and-death setting. Rather, deliberation ought to incorporate the triad of parents, health care providers, and the adolescent in a therapeutic alliance focused on beneficence to the adolescent patient.

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<sup>1</sup> Examples of notable scholars writing from a bioethics perspective of adolescent decision making capacity include Dan Brock and Allen Buchanan (see extensive discussion in Chapter 2), Lainie Friedman Ross, who is also a pediatrician, and Richard B. Miller (see discussion in Chapter 4, especially). Legal scholars include Elizabeth Scott, Rhonda Gay Hartman, and Jennifer Rosato (discussion of these commentators appears throughout subsequent chapters).

This dissertation will develop a patient-centered beneficence-based triadic approach for decision making about adolescents in life-and-death circumstances. Specifically, the approach supports my contention that we should not ‘abandon’ the adolescent to his or her developing autonomy when the adolescent refuses life-or-death medical treatment. This position is likely to be criticized by those who consider most adolescents as capable decisions makers and thereby autonomous. I agree that the developing decision making capacity of the adolescent is, and ought to be, acknowledged, and even respected in the context of many health care decisions. However, I argue that an adolescent’s refusal of life-or-death medical intervention should not be respected, except where not treating better serves beneficence to the ill adolescent. At such times, agreeing with an adolescent’s refusal of life-and-death medical intervention is not justified from the standpoint of respecting autonomy, since decisional capacity is, as yet, incomplete and autonomy is not present. Rather the ‘refusal’ is permitted from the vantage of patient beneficence, wherein the possible benefit of life-or-death treatment for the adolescent is disproportionate to probable burdens, such as unrelenting pain and suffering. The deliberative triadic approach develops three categories for considering the interests, roles, and responsibilities of the adolescent, the parents and family, and the health care providers and the state. Such interests, roles, and responsibilities on the part of individuals with a stake in the decision about an adolescent’s life-or-death treatment will be shown to be rooted in the bioethical principle of beneficence as it impacts the

adolescent.<sup>2</sup>

For the purpose of this analysis, the "adolescent" is a young person, usually of teenage years,<sup>3</sup> within an age group whose level of maturity is individually variable, and arguably fluid. "Adolescent life-and-death decision making" refers to a scenario in which the teenage patient, parents, and care providers are involved in considering whether to withhold or withdraw, initiate or continue medical treatment that will impact whether the adolescent lives or dies. The 'developing' autonomy and decision making capacity of an adolescent describe the teenager's increasing ability to evaluate her circumstances and make meaningful decisions about herself. Such evaluation depends on her comprehension of communicated information in a context of understanding her own personal values and goals. Because such skills are still 'developing,' health care providers are correct in not authorizing what appear to be autonomous refusals of life saving treatment. The deliberative approach presented in this dissertation will show that the presumed respect of an adolescent's refusal of life-and-death treatment is more coherently rooted in the principle of beneficence than in the principle of respect for autonomy.

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<sup>2</sup> Beneficence is one of a cluster of 4 principles – along with respect for persons and their autonomy, nonmaleficence and justice – which James Childress and Tom Beauchamp conclude are central to biomedical ethics. Beneficence refers to a group of norms for providing benefits and balancing benefits against risks and costs. Beauchamp, T.L. & Childress, J.F. (2001). *Principles of Biomedical Ethics*, 5<sup>th</sup> ed. New York: Oxford University Press, 12.

<sup>3</sup> For age levels, see Holder, A.R. (1985). *Legal Issues in Pediatric and Adolescent Medicine*, 2nd ed. New Haven, CT: Yale University Press. Very mature twelve year olds may, for example, not be considered adolescents if designation is achieved by having attained teenage years. However, "pre-adolescents", defined as 10 to 12 or 13 will not be categorically excluded from this analysis, nor will "late-adolescents" who can be up to 21 years of age.



In this chapter I present concepts that will be greatly expanded as they later arise within the three components of this approach. For example, the concept of best interests has significant relevance to decision making about young pediatric patients because they usually neither appreciate their medical situation nor contribute to a discussion about it. In contrast, older children and adolescents may be inappropriately dismissed from such discussion because of their decision making ‘category’ as a legal minor. I will argue that the category of minor child allows parents, health care providers and the state to appropriately protect adolescents from irreversible treatment decisions about their life or death. The fact of legal minority allows us greater ethical discretion in protecting an adolescent from the harm of her “bad decision.”

In Chapter 2, I proceed to identify difficulties in the determination of decision making capacity among adults generally, and among adolescents specifically. These shortcomings lend evidence to a misplaced emphasis on adolescent decision making autonomy in life-and-death situations. Chapters 3, 4, and 5 develop the thesis that a finding of adolescent autonomy that appears to satisfy elements of decision making capacity in order to make a life-and-death decision fails to account for the interests and responsibilities of others in proximity to the adolescent. Those others – parents, health care providers, and the state – are obligated to do what is of benefit to the adolescent and to protect her from harm.<sup>4</sup> The bioethical principle of beneficence will be shown to exert greater moral force in deliberating about life-and-death decisions than will respecting the

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<sup>4</sup> Richard Miller (2003) views obligations of parents and health care providers to be specified in two ways: “first, in acts of beneficent treatment toward children and families; and second, in virtues of character that

questionable autonomy of an adolescent. The priority of patient-centered beneficence in adolescent life-and-death decision making is augmented by interweaving Pellegrino and Thomasma's concept of beneficence-in-trust into the deliberative approach.<sup>5</sup>

Beneficence-in-trust is a reminder of the fiduciary relationship between patient and health care provider. The triadic approach developed in this dissertation expands such a relationship to incorporate the parents.

### **Sketching the contours of the problem**

#### *Decisions about cancer treatment research*

Guidelines for decision making by children for enrollment in cancer research and treatment protocols help to illuminate the unsettled contours of a life- and-death decision making scenario involving an adolescent. According to a national commission and several pediatric specialty committees, children 7 years old and older may offer 'assent,' indicating their agreement to research and treatment. By contrast, children 14 years and older may give 'consent,' viewed as an autonomous directive.<sup>6</sup> The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research recommended that children's objection to participation in research, including

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convey trustworthiness and warmth.” Miller's views will be more fully discussed in later sections of this dissertation. *Children, Ethics & Modern Medicine*. Bloomington: Indiana University Press, 35.

<sup>5</sup> Pellegrino, E.D. & Thomasma, D.C. (1988). *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press.

<sup>6</sup> National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977), "Report and Recommendations: Research Involving Children, Vol. 1," Washington, D.C.: U.S. Printing Office,; Group for the Advancement of Psychiatry, Committee on Child Psychiatry (1989), "Consent, assent, and dissent: children in treatment and research." In, *How Old is Old Enough? The Ages of Rights and Responsibilities. Report No. 126*. NY: Brunner & Mazel; Committee on Bioethics, American Academy of Pediatrics (1995). "Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 95(2), 314-7.

cancer treatment protocols, should be binding unless the particular intervention holds out prospects for direct benefit to the child.<sup>7</sup> 'Direct benefit' encompasses intervention that may save the child's life, prolong it, or enhance its quality. However the parameters for determining such a decision, and by whom, are unclear, contributing to ambiguity regarding 'direct benefit' guidance in the clinical setting.

Leikin, an authority in the area of pediatric consent for research, suggests that when minor 12-15 year olds dissent from research participation, they may be oppositional as a function of their developmental stage. He recommends that if the minor demonstrates intelligent understanding of the treatment protocol and continues to dissent, his or her unwillingness to participate in the research should be respected.<sup>8</sup> This view does not, unfortunately, assist the parents or clinicians in determining whether, and under what circumstances, an adolescent's unwillingness or refusal to participate in life-saving treatment may be overruled.

#### *The Piagetian developmental model*

For the purpose of health care decision making, state laws direct health care providers to consider a patient younger than 18 years of age a legal minor. Although statutory exceptions are based in public health policy considerations, clinical exceptions are largely informed by cognitive research influenced by the classic 1920's work of Jean

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<sup>7</sup> Ibid; National Commission, cited in Fletcher, J.C., Dorn, L.D., & Waldron, P. (1997). "Ethical Considerations in Pediatric Oncology". In, P.A. Pizzo & D.G. Poplack (Eds.), Principles and Practice of Pediatric Oncology, 3rd ed., pp. 1283-1300. Philadelphia: Lippincott-Raven.

<sup>8</sup> Leikin, S.L., (1983). "An Ethical Issue in Biomedical Research: The Involvement of Minors in Informed and Third Party Consent," *Clinical Research*, 31(1), 34-40, 39.

Piaget. In the Piagetian approach to children's competence, children develop through cognitive stages and are unable to grasp certain concepts until they reach the correspondingly appropriate stage.<sup>9</sup> Piagetian-based research suggests that children over 7 years have some decision making skills and that adolescents over 14 years of age may have health care decisional skills comparable to those of adults.<sup>10</sup> Other qualitative studies show that very young children have a far better understanding of illness, even of death, than previously thought.<sup>11</sup>

Mainstream pediatric bioethics, largely influenced by the Piagetian school, continues to view the ability of an older child and young adolescent to make decisions as a skill tied to cognitive development. Acknowledgement of cooperation in research or in a medical treatment plan is afforded by the "assent" of the patient together with the parents' permission.<sup>12</sup> Professional organizations recommend that adolescents demonstrating decision making capacity be allowed to participate in the informed consent and refusal process, so that their acceptance or rejection of medical interventions be fully respected.

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<sup>9</sup> Piaget, J. (1958). *The Child's Construction of Reality*. London: Routledge.

<sup>10</sup> Weithorn, L.A. & Campbell, S.B. (1982). "The Competency of Children and Adolescents to Make Informed Treatment Decisions," *Child Development*, 53, 1589-98; Brock, D.W. (1989). "Children's Competence for Health Care Decisionmaking." In, L.M. Kopelman & J.C. Moskop (Eds.) *Children and Health Care: Moral and Social Issues*, pp.181-212. Boston: Kluwer Academic Pub.; Committee on Bioethics, American Academy of Pediatrics, (1995); Fletcher, J.C., Dorn, L.D., & Waldron, P. (1997).

<sup>11</sup> Donaldson, M. (1978) *Children's Minds*. Glasgow: Fontana; Dunn, J. & Kendrick, C. (1982) *Siblings: love, envy and understanding*. Cambridge, MA: Harvard University Press, cited in Alderson, P. (1992). "In the Genes or in the Stars? Children's Competence to Consent," *Journal of Medical Ethics*, 18(3), 119-124; Bluebond-Langner, M. (1978). *The Private Lives of Dying Children*. Princeton: Princeton University Press.

<sup>12</sup> Leikin, S. (1989). "A Proposal Concerning Decisions to Forgo Life-Sustaining Treatment for Young People," *Journal of Pediatrics*, 115(1), 17-22.

Parental involvement is, nonetheless, still encouraged in these cases.<sup>13</sup> Such guidance is geared toward adolescents who, as a group, are considered to have full decision making capacity.

Alderson notes that Piaget's influence continues to dominate bioethical thought about children's capabilities even though his work is criticized as "unduly abstract, concerned only with intellectual development and not with the child's emotions or relationships, or practical, social and imaginative talents".<sup>14</sup> In accordance with Alderson's observations, I will show that the determination of adolescent decision making capacity remains largely unsettled, despite mainstream adoption of Piaget's model.

#### *Minor treatment statutes*

Even as health care professionals recognize the role of parental involvement in the older child's medical decisions, public consensus and statutory law ensure that a minor's access to certain kinds of treatment outweigh a parent's interest in supervising the adolescent's health care. Every state has a statute allowing the unemancipated mature minor, ranging in age from fourteen to seventeen years, to consent to treatment for sexually transmitted diseases.<sup>15</sup> Many states also permit minors to consent to alcohol- and substance-abuse treatment and mental health care. These minor treatment statutes, justified by the common law mature minor doctrine, are based on the premise that the medical care sought by the minor is relatively low risk and is for the minor's "own good."

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<sup>13</sup> Committee on Bioethics, (1995), 317.

<sup>14</sup> Alderson, P. (1992).

<sup>15</sup> Holder, A.R. (1989). "Children and Adolescents: Their Right to Decide about their own Health Care". In L.M. Kopelman & J.C. Moskop (Eds.), *Children and Healthcare: Moral and*

Oberman is critical of the poorly defined term ‘maturity’ in minor treatment statutes.<sup>16</sup>

In her view, minors have been extended the ostensible "right" to access specific medical treatment for the utilitarian goals of protecting society and promoting minors' best interests. When no public consensus exists on whether permitting access to a given treatment furthers either of these two goals, minors will be denied access.

Practically, the mature minor's consent is not applicable in ambulatory care settings because parents can usually not be held financially responsible for non-emergency hospital care for which they have not given permission. Thus, in what Beauchamp and Childress describe as the first sense of informed consent, a mature minor may autonomously authorize an intervention in a non-ambulatory setting, but may not,, in the second sense of informed consent, effectively authorize it.<sup>17</sup> Buchanan and Brock establish a similar distinction between decisional competence and decisional authority.<sup>18</sup> They note that the presence of parental and legitimate third party interests in making decisions for a child interfere with the child's right to decide. Buchanan and Brock further indicate that such decision making interests are “an important and inadequately appreciated difference in the function or role of the competence determination in children and adults.”<sup>19</sup>

### *Best interests*

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*Social Issues*, 161-72. Boston: Kluwer Academic Pub.; Oberman, M. (1996). “Minor Rights and Wrongs.” *Journal of Law, Medicine & Ethics*, 24, 130.

<sup>16</sup> Oberman, M. (1996), 131.

<sup>17</sup> Beauchamp, T.L. & Childress, J.F. (2001), 78.

<sup>18</sup> Buchanan, A.E. & Brock, D.W. (1989). *Deciding for Others: The Ethics of Surrogate Decision Making*. NY: Cambridge University Press, 234-5.

The decision making standard customarily invoked for use with the young pediatric patient is that of "best interests." Those advocating for children's rights claim that the best interest standard is inappropriate, because no one, not even the parents, can truly know the interests of the child.<sup>20</sup> Purdy and others reject this claim on the grounds that adults, by virtue of their greater experience, and especially parents, because of the intimate bond they have with their child, can certainly know and anticipate their child's "best interests."<sup>21</sup> Professional organizations recognize that application of the best interest standard, which may encompass many social, cultural, and religious perspectives, must be monitored to prevent parental neglect or abuse.<sup>22</sup> Determining the 'best interests' may be a point of contention between parents and care givers, especially when the adolescent appears to be developmentally equipped to offer either assent or dissent, consent or refusal.

The best interest standard is further refined in this dissertation by appealing to Pellegrino and Thomasma's concept of 'beneficence in trust' as an underpinning of the triadic approach for adolescent life-and-death decision making. As conceived by Pellegrino and Thomasma, 'beneficence in trust' is intended to preserve, or hold in trust, the goal of acting in the best interests of one another in a doctor-patient relationship. Developed in response to their view of the irreconcilability of the principle of autonomy with the principle of beneficence, but not specifically directed to the pediatric setting,

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<sup>19</sup> Ibid., 235.

<sup>20</sup> Cohen, H. (1980). *Equal Rights for Children*. Totowa, NJ: Littlefield, Adams.

<sup>21</sup> Purdy, L.M. (1992). *In Their Best Interest? The Case Against Equal Rights for Children*. Ithaca, NY: Cornell Univ. Press.

Pellegrino and Thomasma describe two sets of stakeholders – the patient and physician – who act in relation to carry out the best interests of the patient.<sup>23</sup> Where the patient is an adolescent, and for the purpose of constructing an approach to guide decision making, the parents are necessary components to form a triadic relationship with the teen patient and health care providers. The triadic approach describes such a relationship as a ‘therapeutic alliance,’ based in part on work by Richard Miller, to be further expanded in Chapter 2.<sup>24</sup> ‘Beneficence in trust’ acknowledges the voice of the patient, as well as the fiduciary role of clinicians. The approach developed herein expands ‘beneficence-in-trust’ to also incorporate the obligations of parents in health care decision making.

### *Exemplar cases*

Two quite different case scenarios illustrate the complexities of adolescent life-and-death decision making among two fifteen year old boys, AJ and BJ, who are faced with the prospect of life-and-death medical interventions. These cases, described briefly at this time, will be referenced, and augmented, throughout this dissertation.

AJ has dealt with the symptoms of cystic fibrosis for as long as he can remember. He has had countless hospitalizations, but has been able to keep up with his school work. His entire family knows how to perform the respiratory treatments he has had to endure for years. AJ’s prognosis is quite poor. Although he has been on a respirator before, he understands that the next time he is hospitalized with a pulmonary infection, he may again need to be intubated and ventilated in order to supplement his failing respiratory system. The next intubation might be the one from which he will never recover and will need to remain on the respirator until he dies. AJ does not want to be intubated and ventilated when that time comes. He would rather die.<sup>25</sup>

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<sup>22</sup> Committee on Bioethics (1995), 315.

<sup>23</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 54-5.

<sup>24</sup> Miller, R. (2003).

<sup>25</sup> Case in this early presentation is loosely adapted from Alderson, P. (1993). *Children’s Consent to Surgery*. Philadelphia: Open University Press, 159-63.



BJ is an all-around sports nut. He had a painful swollen area at his left knee for a month before it was definitively diagnosed as synovial sarcoma, a deadly soft tissue cancer. In the conference with the physicians, above the knee amputation was given as the only reasonable chance of cure. BJ and his parents were told that the cancer, which responds poorly to chemotherapy and/or radiation therapy alone, has only a less than 10% recurrence rate with amputation. Surgery is scheduled for the following week. The night before, BJ is resolute in his unwillingness to have the surgery. He would rather die than have the amputation.<sup>26</sup>

These case scenarios introduce several considerations that complicate an analysis of adolescent life-and-death decision making. Considerations regarding the adolescent include duration and severity of illness, burdens of treatment relative to expected benefits, cognitive maturity, experience with decision making, and experience with life-threatening events or death. Considerations also involve the ethical integrity of those who are immediately proximate to, and those more remote from, the adolescent: the parents or guardians, siblings, extended family and friends, health care professionals, and the state, as an entity interested in protecting the well-being of minors.

Strict adherence to a legal bright line of majority in determining whether or not adolescents should make any medical decisions about themselves is not necessarily appropriate given the variability of maturity among adolescents.<sup>27</sup> However, the conclusion that seemingly capable adolescents should be permitted to make their own decisions about their life-or-death is also not appropriate, considering the variable maturity but also the relevant duties and interests of others in making decisions for

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<sup>26</sup>Adapted from a teaching case. "Medical Ethics for Medical Students", Medical College of Virginia School of Medicine, Richmond, Virginia. Spring 1997. L. Lyckholm, M.D., case author. Used with permission.

<sup>27</sup> Oberman, M. (1996), 131.

adolescents. This dissertation will argue in support of the claim that adolescents, those who are legal minors, should not be permitted to make their own life-and-death decisions in cases where medical treatment is deemed to be beneficial, primarily where possible benefit is expected to outweigh the burden of treatment. Prior experience of the adolescent with serious illness – her own or that of a family member or friend - may play a role in consideration of an adolescent's refusal of life-and-death treatment. However, unless the illness experience was quite serious, it is unlikely that an adolescent (indeed anyone) can reasonably relate it to their own life-and-death scenario which will be unique in presentation, prognosis, and urgency.

My analysis will be limited to a contemporaneous context, that is, where the life-or-death decision is made concurrently with the adolescent's on-going physical decline, rather than at some future time. An emphasis on contemporaneous decision making is chosen for several reasons. First, the considerations involved in whether an adolescent can, and has the right to, make such decisions for him- or herself are exceedingly complex without speculating about the stability of decisions to be acted on prospectively. Second, even though advance directives, as decision making vehicles for adults rendered incapacitated, receive much coverage in the literature and in clinical practice, studies indicate that they are often disregarded.<sup>28</sup> A third reason for attending to

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<sup>28</sup> The SUPPORT Principal Investigators (1995). "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," *Journal of the American Medical Association*, 274, 1591-98; Hoffman, D.E., Zimmerman, S.I., & Tompkins, C.J. (1996). "The Dangers of Directives or the False Security of Forms," *Journal of Law, Medicine & Ethics* 24, 5-17.

contemporaneous, rather than advance, decision making is because adolescents, as minors under the law, are precluded from issuing formal advance directives.<sup>29</sup>

In the health care of children and adolescents, parents or guardians are, for the most part, viewed to be in the best position to make decisions on behalf of their children. As those decisions are made in the context of life-and-death scenarios, they are to reflect the best medical interest of the minor in consultation with health care providers. The situation is not dissimilar from that of relatives acting as surrogate decision makers in the best medical interests of their adult loved one. The complexity of the concept of best interests and the principle of beneficence is discussed in the next section.

### **Best Interests and the Principle of Beneficence**

In the case of questionably competent adults, next-of-kin, other legal guardians, or health care providers may attempt to assert their authority in the event the adult patient refuses the suggested intervention plan that is viewed to be of great medical benefit to the patient. Surrogate decision makers are charged to represent either the best interests of the never-competent patient or the substituted judgment of a formerly competent adult who has communicated her treatment wishes.<sup>30</sup>

The surrogate decision maker is recognized as the person named as proxy in an advance directive or durable power of attorney for health care document. In the absence of such documents, most states prioritize the legally recognized surrogate decision maker as being first the spouse, followed by those having the closest biological relation to the

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<sup>29</sup> McCabe, M.A., Rushton, C.H., Glover, J., Murray, M.G., & Leikin, S. (1996). "Implications of the Patient Self-Determination Act: Guidelines for Involving Adolescents in Medical Decision Making," *Journal of Adolescent Health* 19, 319-24.

patient.<sup>31</sup> The surrogate or proxy must determine, within a background of the patient's own preferences and the guidance of the health care team, the intervention of highest probable net benefit among all available treatment options. Such a decision made by surrogates is generally respected when it concurs with the recommendation of the health care team. Because the surrogates must evaluate qualitative factors such as pain and functional ability, the best interests standard is undeniably a quality-of-life criterion. It is one thing to determine one's own best interests as a capable, autonomous decision maker. It is quite different to undertake the weighing of risks and benefits for another based on the often controversial criteria of what is "best."<sup>32</sup>

Nonetheless, doing what is best for the patient is the physician's historical Hippocratic imperative.<sup>33</sup> Beneficence means to act to benefit, or do good for, the patient. The overly beneficent, or paternalistic, physician feels he or she knows, certainly better than the patient herself, what the best possible medical intervention would be for a particular problem and proceed to do just that, without respect for the patient's own wishes.

Paternalism refers to the intentional overriding of one person's known preferences by

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<sup>30</sup> Buchanan and Brock, (1989), 135.

<sup>31</sup> As Buchanan and Brock point out, the fundamental notion here is much broader. The family is whomever the patient is most closely associated with. Chapters 4 and 5 provide an expansive discussion of family rights and responsibilities.

<sup>32</sup> Chapter 3 will expand on the interests and 'goods' of the adolescent patient. The question of whether basic goods lend themselves to 'weighing' is hotly debated among consequentialists and natural law scholars. One of the most notable dialogues took place between the Catholic moral theologian Richard McCormick and the Catholic philosopher Germain Grisez. Resources to this debate include: McCormick, R.A. "Ambiguity in Moral Choice," in R.A. McCormick & P. Ramsey (Eds.), *Doing Evil to Achieve Good: Moral Choice in Conflict Situations*, pp. 7-53. Chicago: Loyola Univ. Press; Grisez, G. & Shaw, R. (1974). *Beyond the New Morality: The Responsibilities of Freedom*. Notre Dame: Univ. of Notre Dame Press.

<sup>33</sup> Drane, J. (1994). *Clinical Bioethics: Theory and Practice in Medical-Ethical Decision Making*. Kansas City, Mo.: Sheed & Ward, 41.

another, who justifies his or her action with the goal of benefiting or avoiding harm.<sup>34</sup>

This interpretation of paternalism reflects the lovingly protective approach a father might exhibit toward a young child.<sup>35</sup> In medical contexts, the term has acquired a negative connotation and paternalism may promote an adversarial relationship between the patient, family, and health care provider.

Feinberg distinguishes between weak and strong paternalism to illuminate types of paternalistic intervention.<sup>36</sup> In weak paternalism, the agent intervenes in order to protect persons from substantially nonvoluntary actions that may derive from inadequate information or mental impairment causing irrational thought. In strong paternalism, the agent seeks to benefit another person by overriding his risky, albeit voluntary, informed, and autonomous choice.

The bioethics movement emerged, in part, as a reaction to overly paternalistic health care by patient's rights groups who believed that patients ought to be able to determine for themselves whether to submit to the physician's plan of treatment. Contemporary bioethical thought views the capable adult patient as an individual with a right to self-determination, a view with philosophical roots in the writings of Immanuel Kant and John Stuart Mill.<sup>37</sup>

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<sup>34</sup> Beauchamp, T. & Childress, J.F. (2001), 178.

<sup>35</sup> Mahowald (1993) uses a 'parentalist' model to describe an egalitarian family relationship, which nevertheless acknowledges a difference between parents and children. She views the term as straddling the overprotective influence of 'paternalism' and the nurturing freedom of 'maternalism'. *Women and Children in Health Care: An Unequal Majority*. NY: Oxford Univ. Press, 33.

<sup>36</sup> Feinberg, J. (1971). "Legal paternalism," *Canadian Journal of Philosophy* 1, 105-24; Beauchamp & Childress (2001), 181. Feinberg later termed these concepts soft and hard paternalism, respectively.

<sup>37</sup> See especially: Kant, I. *Groundwork of the Metaphysic of Morals*, H.J. Paton (trans.). NY: Harper & Row, 1956; Mill, J.S. "On Liberty," in *Utilitarianism; On Liberty; Essay on Bentham*. M. Warnock (Ed.), NY: Meridian, 1962.

## **Participation in Decision Making – Respect for Developing Autonomy**

Respect for persons and their autonomy persists as a dominant ethical principle in patient care although it exists in constant tension with the principle of beneficence. Patients who are clearly competent, who consent to, or refuse, recommended treatment, and who are legally empowered to speak for themselves are in the best strategic position to have their autonomy respected. Adolescent patients, as a group, and adult patients exhibiting questionable capacity challenge the extent to which choices can, and ought to, be respected. Surrogates and providers may feel compelled to intervene if the questionably capable patient appears to be making decisions that threaten her well-being.

In many medical settings, an adolescent with a chronic terminal illness or a teen newly diagnosed with a potentially fatal disease participates with his or her parents and the health care providers in decisions related to medical treatment and end-of-life care. In this dissertation ‘participation’ in decision making means that the adolescent’s views are listened to and carefully considered, but do not trump the beneficent actions of providers and parents, especially in life-or-death circumstances. Fostering such participation, in the form of discussion that encourages sharing of the adolescent’s perspective, reflects profound respect for the adolescent’s budding autonomy and the strength of a mutual parent-child relationship.<sup>38</sup> However, in other similar scenarios, willing and seemingly capable adolescents may arbitrarily be permitted less participation in decision making.

### *Limiting participation in decision making – the category standard*

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<sup>38</sup> Thomas H. Murray (1996). *The Worth of a Child*. Berkeley: Univ. of California Press, 61-2. Adolescent autonomy and parent-child mutualism will be fleshed out in greater detail in subsequent chapters.

One factor limiting participation and authority in decision making may be a strict legal interpretation of the adolescent's standing under the law by parents or guardians, health care providers, and the state. In all states, legal majority is attained at age 18.<sup>39</sup> Those parents and health care providers upholding the view that adult maturity and responsibility begin at one's eighteenth birthday maintain that adolescents should have little or no formal decision making role in serious matters, even if those matters concern them directly. Acting on the position that older children are not legally permitted to make such decisions, even if they display an acute understanding of their situation, may help adults achieve a measure of control over their child's tragic situation. This position utilizes a category standard for exclusion, similar to what is used for some questionably capable adults.<sup>40</sup> However, the indisputable nature of this category standard draws a 'bright line' at the age of 18 in order to limit adolescent life-and-death decision making opportunities.

A case which illustrates the exclusionary category standard applied to adolescent life-and-death decision making is *In the Matter of Long Island Jewish Medical Center*.<sup>41</sup> In 1990, Philip Malcolm, a cancer patient just seven weeks shy of his eighteenth birthday, had refused to consent to the recommended course of treatment on religious grounds. His

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<sup>39</sup> However, states also have exceptions to the age of majority. Some require the age of 21 to purchase alcohol, or as young as 13 to be charged as an adult in criminal proceedings. See, Morrissey, J.M., Hofman, A.D., & Thorpe, J.C. (1986). *Consent and confidentiality in the health care of children and adolescents: A legal guide*. NY: Free Press.

<sup>40</sup> Categories used to exclude decision making by some groups of adults include: mental illness, critical illness, cognitive impairments, or advanced age. See Boyle, R.J. (1997) "Determining Patient's Capacity to Share in Decision Making." In, J.C. Fletcher, P.A. Lombardo, M.F. Marshall, & F.G. Miller (Eds.), *Introduction to Clinical Ethics*, 2<sup>nd</sup> ed., pp. 71-88. Frederick, MD: University Publishing Group, 74. See also the same chapter title and author in *Fletcher's Introduction to Clinical Ethics* (2005), 3<sup>rd</sup> ed., J.C. Fletcher, E.M. Spencer, & P.A. Lombardo (Eds.), pp. 117 – 138, see p.120.

severe anemia, resulting from disseminated malignant disease required immediate stabilization prior to chemotherapy. Treatment gave him a 75% chance of remission for several months to years and a cure rate was 25-30%. Without treatment, Philip would die in a short time. Philip's parents supported his decision prompting the hospital to petition the court for an order to authorize necessary medical intervention. The judge noted that although Philip had an understanding of the basic tenet of the Jehovah's Witness prohibition regarding blood transfusions, Philip was not sufficiently mature to make the decision on his own. In rejecting Philip's request, the judge noted that Philip had never been away from home and had never been on a date.<sup>42</sup>

The category standard for disallowing adolescents from making their own health care decisions is, in the case of Philip, invoked by the health care providers and, ultimately, the state as a practical device for not permitting the adolescent to make the life-and-death decision about himself. Within barely a squeak of age eighteen, legal minority is used as a trump to override Philip's decision, and insulate the state from contributing to his premature death. I submit that the 'bright line' standard in adolescent life-and-death decision making should be viewed as less a restriction on Philip's ostensible autonomy – refusing on the basis of religious reasons - and more as a beneficent approach to preventing the premature death of an adolescent boy.

*Limiting participation in decision making – the outcome standard*

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<sup>41</sup>*In the matter of Long Island Jewish Medical Center*, 557 N.Y.S.2d 239 (1990)

<sup>42</sup>Oberman, M. (1996), at 128-9; See also, Lonowski, S. (1995-96). "Recognizing the Right of Terminally-Ill Mature Minors to Refuse Life-Sustaining Medical Treatment: The Need for Legislative Guidelines to Give Full Effect to Minors' Expanded Rights." *Journal of Family Law*, 34, 421-445.



A second standard that may limit the decision making participation and authority of those with questionable decision making capacity is the outcome standard. The fear of outcome in paternalistic denials of adolescent life and death decision making typically is joined with claims that the teen is unable, by virtue of his age, lack of experience, or other criteria, to make a decision with irreversible consequences. There is a fear on the part of adults, both parents and health care providers, that the young person may make the ‘wrong’ decision. A wrong decision could well involve refusal of a life-saving medical intervention, which, if the refusal is honored, could result in the otherwise postponable or avoidable death of the young person. The adolescent may even be considered a capable decision maker for most scenarios but, in the case of choosing a life-saving intervention, cannot be trusted to make the decision that caring adults know is in his or her ‘best interests.’

Clinicians and parents do claim to know what is in their young person’s ‘best interest.’ Whether “best interests” is an appropriate standard for parental decision making about their children and whether parents are especially privileged in knowing their child’s ‘best interest’ is addressed in Chapter 4. The ‘best interests’ concern becomes the handle that parents and clinicians can grasp to affirm their authority over the young person. This desire to maintain expert authority over the teen is a second feature within the outcome standard to exclude adolescent life-and-death decision making participation and authority.

Parental interests and authority, as well as, the adolescent’s dependence on adults, are presumed in the law. This presumption was affirmed, in the context of commitment of

children to mental hospitals, in the Supreme Court's 1989 finding in *Parham v. J.R.* In his majority opinion, Chief Justice Burger writes:

The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions...Most children even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment.<sup>43</sup>

Parental interests in maintaining decision making authority have some practical justification. Buchanan and Brock describe four persuasive strains of reasoning. First, parents are most likely to have their child's welfare at heart. Second, parents will share in bearing the consequences, especially financial ones, of treatment choices for their child. Third, parents are presumed to convey standards and values to their children. And finally, the family, as a haven of love and intimacy, must be significantly free from oversight and control.<sup>44</sup> These identified parental interests lie in crucial tension with advocates' appeals to allow adolescents their own decision making privileges.<sup>45</sup> Chapter 4 will discuss these and other parental and guardian interests more fully.

Illustrating the complexity of the outcome standard for not permitting adolescent decision making authority is the well-publicized case of Billy Best. In 1994, sixteen year-old Billy Best ran away to Texas from his home in Massachusetts to avoid continuing chemotherapy for Hodgkin's lymphoma. His parents had consented to the

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<sup>43</sup> *Parham v. J.R.*, 422 U.S. 584 (1979); See also, Scott, E.S., Reppucci, N.D., & Woolard, J.L. (1995). "Evaluating Adolescent Decision-Making in Legal Context". *Law and Human Behavior*, 19, 221-244; Weithorn & Campbell (1982), 1589.

<sup>44</sup> Buchanan, A.E. & Brock, D.W. (1989), 232-4.

<sup>45</sup> See especially, Levetown, M (1996). "Ethical Aspects of Pediatric Palliative Care." *Journal of Palliative Care*, 12(3), 35-9.

treatment even though Billy claimed it was killing him rather than curing him. Billy and his parents were told that he had an 80-90% chance of cure with treatment. On his own, he had researched alternative treatments, informing his parents and providers that he wished to forego conventional therapy. When they refused to honor his wish, he ran away threatening to stay away from home until his wishes were honored. After Billy's parents and providers acquiesced, he returned home.<sup>46</sup>

The case of Billy Best is frequently used to support the claim that minors should have the right to make decisions regarding their own life-sustaining treatment.<sup>47</sup> For those wishing to extend decision making rights to mature minors, the publicity and implications of such a case are troubling. Although the concession on the part of Billy's family and physicians is understandable, it is, notes Oberman, "a bizarre standard that allocates adult rights to adolescents whose demand for autonomy takes the form of a grandiose temper-tantrum, as opposed to a reasoned demand for control."<sup>48</sup>

At stake is the very unsettled notion of the role of the child, of the parents and family, and of the state in securing life-saving medical intervention for minors. The roles are unsettled, in part, due to the burgeoning bioethical emphasis on patient autonomy in health care. The principle of 'respect for persons and their autonomy,'<sup>49</sup> recognized as a

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<sup>46</sup> Hawkins, S. (1996). "Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes." *64 Fordham Law Review* 2075, March; Levetown (1996), 37; Rosato, J (1996). "The Ultimate Test of Autonomy: Should Minors Have a Right to Make Decisions Regarding Life-Sustaining Treatments?" *Rutgers Law Review*, 49(1), 1-104, see p. 6-7; Fletcher, J.C., Dorn, L.D. & Waldron, P. (1997).

<sup>47</sup> Ibid.; Rosato, J. (1996), 8.

<sup>48</sup> Oberman, M. (1996), 129.

<sup>49</sup> Current understanding of this principle in bioethics is influenced by the work of Tom Beauchamp and James Childress, who see the principle as *prima facie* binding within a framework of 4 non-hierarchical principles. Beauchamp & Childress, (2001).

driving force in bioethics, is foundational to the notion of self-determination, ‘patient rights’, and informed consent. The challenge of this dissertation is to show that respect for autonomy in the case of adolescent life-and-death decision making is misplaced as primary guidance for clinical practice. The principle of beneficence, particularly as fostered within relationships of trust, is preferable as a guiding principle in the deliberative approach developed herein. In addition, parents, health care providers, and the state ought to view the legal barrier of minority as an advantageous tool to beneficently protect the well-being of an underage, inexperienced young person in life-and-death decision making.

The family can be seriously impacted when adolescents and parents disagree on the type and degree of medical care to be given. Adolescent refusal of life-or-death treatment, if acted on, can mean an earlier death than if the treatment were to be administered. In the adult, refusal of life-saving treatment is an expression of autonomy and is the respected right of a fully capable patient. But children are not adults, at least not legally (with some exceptions), and are dependent on their parents for most kinds of support. Thus, although adolescents ought to be able to participate in life-and-death decisions being made about them, clinicians, parents, and adolescents themselves should not expect that adolescents have a ‘right’ to have a refusal of beneficial treatment respected.

## **Conclusion**

Parents are joined by health care providers and the state in trying to protect the best interests of the adolescent. Beneath what can seem like smothering protectiveness, the

dissenting voice of the adolescent patient may have few advocates. Many claim that the adolescent's voice ought to be heard and taken very seriously. They hold that adolescents should not be excluded from the legal rights and protections of the informed consent doctrine. If, they say, adolescents can demonstrate decision making capacity about options that affect their lives, they ought to not only participate in the decision, but ultimately have the authority to make it. While this claim may justify a re-evaluation of an age limit for legal consent, it is also subject to further reflection. Life-and-death decision making does not take place in a vacuum containing only the adolescent patient. An individualistic model of decision making--one that appeals to rights and minimizes responsibilities--is pervasive in our society and may be detrimental to the family's role in safeguarding its own.

We lack a societal framework for deciding whether and how adolescents should be given an authoritative role in life-and-death decision making. We also lack an ethic of the family that is defensible in the face of contemporary claims of children's rights, traditional claims of parental rights and family autonomy, and state claims for the well-being of its citizens. The aim of this project is to develop a deliberative triadic approach to clarify roles and responsibilities of those involved in life-and-death decision making about adolescents in the clinical setting. This approach is one in which 'beneficence' claims on behalf of the adolescent have greater moral force than 'respect for *developing* autonomy.' Establishing the ethical soundness of beneficent clinical practice in adolescent life-and-death treatment is a first step toward recognizing our present inappropriate focus on respect for the adolescent's autonomy in such a setting. An

alternative perspective on decision making by, and for, minors, one that is not rights oriented, is long overdue in pediatric and adolescent health care.

## CHAPTER 2

### The ‘Capacity Problem’ in Adolescent Life-and-Death Decision Making

Two young teenage boys, each 15 years old, are facing the prospect of medical treatment with life-or-death repercussions.<sup>1</sup> The first boy, AJ, has cystic fibrosis, an inherited pulmonary and digestive disorder that he and his family have dealt with all of his life.<sup>2</sup> His case situation is noted to have worsened since its presentation in Chapter 1. AJ was admitted to the hospital because of a severe cold. His condition deteriorated at an alarming rate and he was placed on a ventilator to provide temporary breathing support. Several attempts to wean him from the respirator have failed. Because his lungs are so ravaged by his condition, successful weaning is unlikely. If weaning proves unsuccessful, AJ would require a tracheotomy for long-term pulmonary management. AJ has been told about his situation by the health care providers. He refuses to go through any more weaning attempts or to have a tracheotomy done. He wants the ventilator disconnected. His parents and providers are stunned. AJ says he has suffered enough; he wants to ‘let nature take its course’.<sup>3</sup> Should AJ’s refusal of life-sustaining

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<sup>1</sup> These 2 cases are slight variations from those that appear in Chapter 1. They will be developed as exemplars throughout the dissertation. As a convenience to the reader, all references cited in each previous chapter will be fully cited on their first appearance in each subsequent chapter.

<sup>2</sup> This version of the case is adapted from “John’s Story,” a video recording developed and narratively dramatized by William Bartholome, M.D. (Bioethics Development Group, Midwest Bioethics, 1995). The case has been re-visited and re-worked in various print settings by Dr. Bartholome for specific educational purposes. Depending on the audience and purposes, Dr. Bartholome has set John’s age anywhere between 12 and 18 years. (Personal communication, electronic mail, William Bartholome, M.D., April 24, 1998). On the videotape, which Dr. Bartholome narrates, John is 14, here he is 15. For my purposes, the case represents a narrative exemplar of an adolescent with a chronic-inevitably-fatal disease.

<sup>3</sup> This phrase, usually attributed to older individuals near the end of their lives, indicates acceptance of the inevitability of death; it is shocking when uttered by an older child. The phrase appeared prominently in an article about a 16 year old girl with chronic kidney disease, glomerulonephritis, who refused further

treatment be permitted?

The second teenager is BJ.<sup>4</sup> BJ is a superlative athlete. He excels in all sports, currently as quarterback on his high school football team. A painfully swollen and reddened area on his left knee has been diagnosed as synovial sarcoma, a metastatic soft tissue cancer. The tumor is, as yet, isolated within the knee area. In other similar neoplasms, chemotherapy and radiation have not shown to diminish spread of the tumor. An above-the-knee amputation is deemed to have a high cure rate (90%) for BJ's type of cancer. BJ says he will not allow an amputation of his leg. He claims that sports are his life and he will not and cannot live without his leg. Parents and providers are shocked at his refusal. Should BJ be permitted to refuse life-saving treatment?

Were these two boys eighteen years old or older, respecting their refusal of life-saving medical intervention, however difficult, is based on the legal presumption that an adult is an autonomous moral agent with the capacity to act on his or her own conception of personal well-being.<sup>5</sup> In the case of minors,<sup>6</sup> however, there is no corresponding legal

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treatment including renal dialysis after her first kidney transplant failed. The parents concurred with their daughter's wish. The hospital staff was stunned that the girl was permitted to refuse a treatment that could prolong her life. Schowalter, J.E, Ferholt, J.B., & Mann, N.M. (1973). "The Adolescent Patient's Decision to Die." *Pediatrics*, 51, 97-103.

<sup>4</sup> This case appears in a slightly different form in Chapter 1 where boy 'B' is named Chris. Adapted from a teaching case. Spring 1997. "Medical Ethics for Medical Students", Medical College of Virginia School of Medicine. Laurie Lyckholm, M.D. case author. Used with permission.

<sup>5</sup> Buchanan, A.E. & Brock, D.W. (1989). *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge Univ. Press, 90.

<sup>6</sup> All 50 states legally acknowledge age 18 as the age of majority, however many states enforce statutory restrictions beyond age 18 on specified activities such as alcohol purchase and consumption.



presumption of their autonomy.<sup>7</sup> Ethically, they ought to be able to ‘participate’ or be ‘involved’ in decisions,<sup>8</sup> if they choose to do so, but any choice of theirs that is in opposition to parental wishes or provider recommendations is legally subject to being overruled. Because of their ages, these boys might be considered incapable of important decision making.<sup>9</sup> An incapacity to make medical decisions about oneself is incompatible with the prized qualities of autonomy and self-determination. By contrast, an autonomous, self-determined adult patient is in the ethical and legal position to give informed consent or refusal for medical intervention by virtue of being deemed a capable decision maker.

This chapter will begin to consider whether autonomy, in the context of life-and-death decision making, can, and ought to be, attributed to adolescents. I will contend that adolescents’ capacity is often overestimated in life-and-death decisions about themselves. This contention faces at least two challenges. First, an influential position in the bioethics

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<sup>7</sup> Interestingly, Canadian law allows for a presumption of the ability to give consent. The law states “each individual is legally and mentally capable of giving consent in the absence of proof to the contrary. Whether a child can consent or not depends on the child in question, his or her mental ability and the treatment or procedure which the child is asked to understand.” See Rozovsky, L.E. (1997). “Children, Adolescents, and Consent.” In, *The Canadian Law of Consent to Treatment*, 2<sup>nd</sup> ed. Toronto: Butterworth’s, 61-75. Cited in: Doig, C. & Burgess, E. (2000). “Withholding Life-Sustaining Treatment: Are Adolescents Competent to Make these Decisions?” *Canadian Medical Association Journal*, 1585-8, p. 1586.

<sup>8</sup> The pediatric ethics and legal literature, together with professional guidelines, often stress ‘participation’ and ‘involvement’ by the young adolescent in medical treatment decisions. However, the extent of ‘participation’ or ‘involvement’ is rarely defined and parents are usually in a position to trump their child’s decision. See, for example, Hawkins, S. D. (1996). “Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes.” *64 Fordham Law Review* 2075, see p. 2076; McCabe, M.A. (1996). “Involving Children and Adolescents in Medical Decision Making: Developmental and Clinical Considerations.” *Journal of Pediatric Psychology*, 21(4), 505-16.

<sup>9</sup> A category standard of capacity. See Boyle, R. J. (1997). “Determining Patients’ Capacity to Share in Decision Making.” In, Fletcher, J.C., Lombardo, P.A., Marshall, M.F., & Miller, F.G. (Eds.), *Introduction to Clinical Ethics*, 2nd ed., 71-88. Frederick, MD: Univ. Pub. Group. See p. 74.

and law review literature holds that adolescents are as competent as adults in health care decision making.<sup>10</sup>

The second challenge stems from the fact that some kinds of medical decision making, such as obtaining substance abuse treatment, reproductive health care, even abortions in some states, are already legally available to adolescents without their parents' involvement.<sup>11</sup> The availability of such treatments does not, however, diminish the significance of my argument for two reasons. First, medical treatment decisions currently available to adolescents by statute do not necessarily validate adolescents' competency. Instead of emphasizing the adolescent's autonomy to make decisions, the intent of such statutory provisions is quite paternalistic and utilitarian by striving to

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<sup>10</sup> This position is supported by only a handful of frequently cited studies that appear to validate the adolescents' equal ability to make health care decisions about themselves. See, Weithorn, L.A. & Campbell, S.B. (1982). "The Competency of Children and Adolescents to Make Informed Treatment Decisions." *Child Development* 53, 1589-98; Scherer, D.G. & Reppucci, N.D. (1988). "Adolescents' Capacities to Provide Voluntary Informed Consent." *Law and Human Behavior* 12, 123-141; Lewis, C.C. (1981). "How Adolescents Approach Decisions: Changes Over Grades Seven to Twelve and Policy Implications." *Child Development*, 52, 538-44; Ambuel, B. & Rappaport, J. (1992). "Developmental Trends in Adolescents' Psychological and Legal Competence to Consent to Abortion." *Law and Human Behavior*, 16, 129-54. A sampling of non-research articles also conclude that adolescents can, and should, make health care decisions about themselves. See, for example: Levetown, M.(1996). "Ethical Aspects of Pediatric Palliative Care." *Journal of Palliative Care*, 12(3), 35-9; Weir, R.F. & Peters, C. (1997). "Affirming the Decisions Adolescents Make about Life-And-Death." *Hastings Center Report*, 27(6), 29-40; an entire issue of the Midwest Bioethics Center *Bioethics Forum*, 11(4), 1995 dedicated to "Minors' rights in health care decision making"; Hanisco, C. (2000) "Acknowledging the Hypocrisy: Granting Minors the Right to Choose their Medical Treatment." *16 New York Law School Journal of Human Rights* 899; Rosato, J. (2002) "The end of adolescence: Let's Get Real: Quilting a Principled Approach to Adolescent Empowerment in Health Care Decision-Making." *51 DePaul Law Review* 769. The claim that adolescents should make such decisions for themselves is, upon further reading, primarily in reference to decisions about life-sustaining treatment where the adolescent has been suffering from illness for a prolonged period of time. See also, Doig, C. & Burgess, E. (2000).

<sup>11</sup> See Virginia Code 54.1-2969 Authority to consent to surgical and medical treatment of certain minors. Section E: "A minor shall be deemed an adult for the purpose of consenting to:" 1) Medical or health services needed to determine the presence of or to treat venereal disease or other reportable contagious disease, 2) services related to birth control, pregnancy or family planning, except for the purposes of sexual sterilization, 3) services related to treatment or rehabilitation for substance abuse, and 4) services needed for treatment or rehabilitation for mental illness or emotional disturbance. Virginia Code 16.1-241 V

protect teens and society from greater harms that would accrue without medical intervention.<sup>12</sup> Second, the stakes in adolescent life-and-death decision making are arguably much higher than for other kinds of treatment. These high stakes call for a closer examination of capacity in teens and older children.

### **Exceptions to the Minor's Inability to Consent to or Refuse Treatment**

Despite the formal legal restriction on minors' consenting to medical treatment, there are exceptions. The first traditional exception pertains to emancipated minors. This status, varying from state to state, generally applies to minors not living at home, who manage their own finances, and whose parents have surrendered parental duties. In some states it also applies to minors who are parents, are married, or are in military service.<sup>13</sup>

The second exception to the restriction on minors' consent to medical treatment consists of statutory provisions. Such provisions allow the minor with a specific condition or disease to seek treatment without parental consent. These conditions or diseases, which vary among states, include: abortion, pregnancy, contraception, venereal

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regarding minors receiving abortion without parental or guardian consent if minor is sufficiently mature and informed and without notification if deemed by judge to be in adolescent's best interest.

<sup>12</sup> Oberman, M.(1996). "Minor Rights and Wrongs." *Journal of Law, Medicine & Ethics*, 24, 127-38, see p. 131.

<sup>13</sup> Ibid.,130; Angela Holder writes that Anglo-American courts have recognized the emancipated minor for over 200 years. In addition to those categories listed in the text, such adolescents include: college students, runaways, and pregnant minors. Holder, A.R. (1989). "Children and Adolescents: Their Right to Decide about their Own Health Care." In, L.M. Kopelman & J.C. Moskop (Eds.), *Children and health care: Moral and social issues*, 161-172. Boston: Kluwer Academic Pub., 162; see Virginia Code 16.1-333. Findings necessary to order that minor is emancipated. Only 3 conditions apply in Virginia: 1) a valid marriage, 2) active duty in United States military service, and 3) living separate and apart from parents or guardian and fully self-supporting.

disease, alcoholism, drug abuse, psychiatric or mental health care, sexual assault or abuse, and blood donation.<sup>14</sup>

A third exception, the mature minor doctrine, grew out of a series of United States Supreme Court cases in which minors were ruled to be sufficiently mature to consent to their own contraceptive and reproductive health care, and later, abortion services.<sup>15</sup> The comprehensiveness and applicability of the mature minor doctrine is subject to on-going debate. For example, Jennifer Rosato holds that all exceptions to minors' inability to consent to medical treatment, including the mature minor rule, are not broad enough to protect a minor's right to refuse life-sustaining treatment.<sup>16</sup> In contrast, Michelle Oberman argues that the mature minor rule is overly broad because it rests on factors that have little to do with maturity, but more to do with politics.<sup>17</sup> Furthermore, as Richard Redding points out, the Supreme Court has not articulated any standards for determining whether a minor is mature.<sup>18</sup> Similarly, the case law of state and federal courts provides no clear guidance on the matter of mature minors. Rather, the judge's decision making is

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<sup>14</sup> Rosato, J.L. (1996). "The Ultimate Test Of Autonomy: Should Minors have a Right to Make Decisions Regarding Life-Sustaining Treatment?" 49 *Rutgers Law Review* 1, pp. 29-30. In her footnote 113, Rosato provides statutory citations for states allowing 17 year olds to consent to blood donation. These include California, Florida, Louisiana, Pennsylvania, and Tennessee. In Virginia a minor of 17 years may only consent to blood donation if a parent or guardian also consents, see Virginia Code 54.1-2969.

<sup>15</sup> Oberman, M. (1996), 131. See also *Carey v. Population Services, International*, 431 U.S. 678(1977); *Ohio v. Akron Center for Reproductive Health, Inc.*, 497 U.S. 502(1990); and, *Planned Parenthood of S.E. Pennsylvania v. Casey*, 505 U.S. 833(1992).

<sup>16</sup> Rosato, J. (1996), 33.

<sup>17</sup> Oberman, M. (1996), 131.

<sup>18</sup> Redding, R.E. (1993). "Children's Competence to Provide Informed Consent for Mental Health Treatment." 50 *Washington & Lee Law Review*, 695, see p. 715, note 129.

to reflect “personal and societal values and mores.”<sup>19</sup> Legal definitions of maturity thus appear to be elusive and open to the subjective interpretations of the judge.<sup>20</sup>

### **Informed Consent or Refusal of Medical Treatment**

Ethically and legally, the informed consent doctrine promotes the dual values of well-being and self-determination,<sup>21</sup> values that reflect the ongoing tension between the beneficence and autonomy principles in bioethical theory.<sup>22</sup> Many, however, believe that respect for self-determination or autonomy, although conceptualized as one of four *prima facie* binding principles,<sup>23</sup> receives greater emphasis in the clinical setting than the other principles. Some voice concern that the autonomy model permits patients to think about themselves and act upon their own desires without adequate regard for others, such as family, with whom the patient is intimately involved.<sup>24</sup> Others believe that the beneficent

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<sup>19</sup>In the concurring opinion of Justice Stevens in *Belotti v. Baird*, 443 U.S. 622, 655-6 (1979).

<sup>20</sup> Another “exception” is made for emergencies, in which event any minor of any age can be treated without consent. This exception is premised in the guardian’s implied consent to treatment, not on the minor’s ability to comprehend and consent to care. Adults are also subject to undergoing treatment for medical emergencies without first giving consent. Boyle, R.J. (2005). “The Process of Informed Consent.” In, J.C. Fletcher, E.M. Spencer, & P.A. Lombardo (Eds.), *Fletcher’s Introduction to Clinical Ethics*, 3rd ed., 139-158. Hagerstown, MD: University Publishing Group, 146.

<sup>21</sup> Brock, D.W. (1993). *Life and Death: Philosophical Essays in Biomedical Ethics*. NY: Cambridge Univ. Press, 24-28.

<sup>22</sup> Faden, R.R. & Beauchamp, T.L. (1986). *A History and Theory of Informed Consent*. NY: Oxford Univ. Press, 97.

<sup>23</sup> Beauchamp, T.L. & Childress, J.F. (2001). *Principles of Biomedical Ethics*, 5th ed. NY: Oxford Univ. Press, 12-4.

<sup>24</sup> Hardwig, J. (1990). “What about the Family?” *Hastings Center Report*, March-April, 5-10.

concerns of clinicians and family members take a back seat when a competent adult expresses her sense of well-being in an autonomous decision either favoring or refusing life-saving medical intervention.<sup>25</sup>

Some advocate a similar approach to respect for autonomy for adolescents and older children in life-and-death medical situations.<sup>26</sup> With roots in the child rights movement, advocates of adolescent life-and-death decision making argue that older children should have the right to make such decisions about themselves by themselves. If the adolescent meets the requirements of the informed consent/refusal doctrine, advocates argue, he or she ought to be permitted to express and authorize her autonomous decision.

Informed consent and refusal, as recognized in legal and medical practice, presuppose cognitive qualities and processes. An adult individual is considered an autonomous decision maker if he or she is cognitively able to meet the elements of valid informed consent or refusal.<sup>27</sup> At a minimum, and depending on the perspective taken, these elements include: 1) competence 2) voluntariness, 3) disclosure, and 4) understanding. Some authorities list fewer elements conceiving each of the above as more

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<sup>25</sup> Brock (1993) reminds us that the moral doctrine of informed consent entitles but doesn't require active decision making by patients, 33.

<sup>26</sup> See note 10.

<sup>27</sup> The terms 'autonomy' and 'self determination' are frequently used interchangeably. Herein I distinguish, as do others, between the 'autonomous person' as described by Beauchamp & Childress (1994), 121, which include capacities of self-governance, and 'autonomous choice' which is actual governance. Jay Katz, using different terminology in a similar way, distinguishes a 'psychological autonomy' to denote the capacities of persons to exercise the right to self-determination, whereas self-determination refers to the rights of individuals to make decisions without interference by others. Katz, J. (1984). *The Silent World of Doctor and Patient*. NY: Free Press, 105-110. See further discussion of autonomy in subsequent text.

comprehensive.<sup>28</sup> Other theorists list additional elements that focus on the agents' autonomous action in the informed consent process. These include: 1) understanding the providers' recommendation of a plan, 2) the consent or refusal decision and, 3) authorization of the decision.<sup>29</sup> A combined listing of these seven elements indicates that the informed consent doctrine embraces not only the psychologically autonomous person who possesses decision making attributes, but also the self-determined person who acts on the basis of those attributes. One sense of informed consent or refusal is of an autonomous authorization by an individual deemed to have decisional capacity. A second sense of informed consent refers to effective authorization according to institutional rules.<sup>30</sup> Buchanan and Brock use different language to similarly distinguish two levels of informed consent: decisional competence and decisional authority.<sup>31</sup>

*A paternalistic approach toward minors*

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<sup>28</sup> Brock, D. (1993), 25-48. Brock lists the elements of competence, voluntariness, and understanding. Beauchamp & Faden (1986), 275, submit that the following elements reflect requirements enforced in institutional or regulatory settings: disclosure; comprehension, voluntariness, competence, and consent. Note that since these authors utilize the term 'competence', it is so listed in the text. However, strictly speaking, 'decision making capacity' describes an ethical determination, whereas 'competence' is determined by a judge.

<sup>29</sup> Beauchamp, T.L. & Childress, J. C. (2001), 80.

<sup>30</sup> Ibid.

<sup>31</sup> Buchanan, A. & Brock, D. (1989), 226.

The legal basis of the informed consent doctrine<sup>32</sup> has profound significance in the narratives of AJ and BJ, both of whom are refusing life-saving treatment. In the law, both boys are below the age of majority and hence are not presumed either to have the right of self-determination or to possess autonomy. One question is whether their refusal of treatment could be legally overridden in light of their youth. If, in the law, overriding their refusal is a legitimate maneuver, doing so may well place little emphasis on considerations of their autonomy but focus primarily on protecting them from harm.<sup>33</sup> The law's seemingly bright line demarcation of majority, with some exceptions, is undoubtedly a paternalistic approach to the treatment of minors. Elizabeth Scott notes that "at the heart of this paternalism is a commonly shared intuition that minors have poorer judgment than adults and that they are more likely than adults to make choices that are threatening to their health and well-being."<sup>34</sup> Advocates of children's rights,

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<sup>32</sup> According to Faden & Beauchamp (1986), 28-30, the conceptual framework of informed consent has its roots in the legal system's battery theory of liability. The case of *Schoendorff v. Society of New York Hospitals*, 211 N.Y. 125, 126, 105 N.E. 92, 93 (1914), became an impetus for developing sound informed consent procedures in medical practice. Based in the law's general right of self-determination, the battery theory protects the right to choose whether to permit others to invade one's physical integrity. Its premise has as its moral equivalent the principle of respect for autonomy. A battery cause of action requires that the physician engaged the patient in an ineffective or invalid consent procedure or where the patient had no or minimal understanding of the physician's intended intervention. In the law, the current trend is to base informed consent violation in a negligence action, which is a failure to provide due care. There are five required elements to find negligence: 1) the physician has a duty to disclose information to the patient, 2) the physician breaches the duty, 3) there is a resultant injury which makes the patient worse off; 4) the injury presents as the undisclosed actual or possible outcome; 5) had the patient, here plaintiff, been informed of the outcome she would not have consented. Negligence in the law is based in the duty to exercise reasonable care when interacting with others. It uses the standard of the hypothetical reasonable person as delineating a minimal threshold under which care is insufficient. As such, the legal basis for a negligence action correlates with a general moral principle of respect for persons, and arguably the principle of non-maleficence, doing no harm. Because battery is based in the principles of self-determination and autonomy, which account for the dignity of personal choice, some commentators prefer the battery cause of action as being more consistent with the spirit of the informed consent doctrine.

<sup>33</sup> See previous notes 11, 16, and 17, and corresponding text.

<sup>34</sup> Scott, E. (1992). "Judgment and Reasoning in Adolescent Decision Making." 37 *Villanova Law Review*, 1607, p.1612.



though, claim some success in a handful of judicial opinions that extol children's dignity as persons and more specifically the prevalence of minor treatment statutes that allow teens to seek and consent to medical treatment without parental knowledge or permission.<sup>35</sup> Scott, unconvinced, goes on to argue that gradual shifts in policy toward acknowledging the autonomy of adolescents, while giving the illusion of being less paternalistic do fit snugly within the protectionist stance toward children.<sup>36</sup>

Michelle Oberman forges an argument similar to Scott in terms of the expansion of the mature minor doctrine, especially as it affects medical treatment decisions.<sup>37</sup> Oberman notes that state statutes that permit adolescents to consent to care for sexually transmitted diseases, alcohol- and substance-abuse treatment, and psychiatric care appear to suggest that the legal system is taking steps to acknowledge adolescents as competent decision makers. In reality, these statutes actually empower adolescents as a way to protect society and promote minors' best interests. Oberman points out that decisions issued in those few court cases involving adolescent's refusal of life-saving treatment turned on ambiguous and subjective interpretations of maturity.<sup>38</sup>

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<sup>35</sup> Advocates for children's rights, as well as those for abortion rights, have been dealt setbacks as several states begin to require parent notification of, or permission for, abortion procedures.

<sup>36</sup> See previous note 34. Two landmark Supreme Court decisions that espoused children's rights, *Tinker v. Des Moines School District* 393 S.S. 503 (1969) and *In re Gault* 387 U.S. 1 (1967), were heralded by child right's advocates as highly progressive. On closer examination, however, the rulings tend to reflect traditional societal responses to children's welfare. The *Tinker* ruling appears to affirm the rights of parents to disseminate their political views to their children. The finding in *In re Gault* was meant to offer child criminal offenders better protection if charged as adults than if maintained in the juvenile justice system.

<sup>37</sup> Oberman, M. (1996), 127-38.

<sup>38</sup> Oberman cites *In re E.G.*, 549 N.E. 2d 322 (1989), wherein the court deemed that the mature minor doctrine afforded 17 1/2 year old E.G. the right to refuse life-saving blood transfusions to treat her leukemia; *In the Matter of Long Island Jewish Medical Center*, 557 N.Y.S.2d 239 (1990), wherein the court ruled that 17 1/2 year old Phillip was not sufficiently mature to refuse blood transfusions to treat his cancer; and media reports of 15 year old Benny Agrelo, who, in 1993, ran away from home to avoid taking

*Application of the informed consent doctrine to minors*

Applying the informed consent doctrine to adolescents becomes problematic in two ways. First, the informed consent doctrine, adopted by both medicine and the law for use with adults, presumes autonomy. Applying the doctrine to adults who possess the presumed qualifying attribute is a valid endorsement of its intent. But the doctrine cannot be presumed to apply broadly to adolescents since many more will not possess the qualifying attribute of autonomy. Second, in requiring adolescents to meet the requirements of the informed consent doctrine adolescents must demonstrate adult cognitive behaviors. However, we may not adequately protect adolescents if we ensure that they meet adult-focused elements of informed consent, but overlook other aspects that betray their inexperience and naiveté.

A difficulty in defining decision making capacity lies in the virtually interchangeable usage of the terms ‘capacity’ and ‘competence.’ In Buchanan and Brock’s view, competence is presumed in the adult and is understood as decision making capacity, in which sense competence and capacity are decision relative.<sup>39</sup> However, Buchanan and Brock confuse the terms by referring to adult ‘competence’ as having a general or global status in the legal context.<sup>40</sup> Clinical ethics seeks to more clearly differentiate the terms by assigning decision making capacity to describe functional criteria for performing

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rejection drugs after his liver transplant. In terms of the latter, the court records are sealed, but Oberman makes the assumption that the judge used a formulation of the mature minor doctrine to rule that the state could not force the boy to take his medication. Oberman, M. (1996), 129.

<sup>39</sup> Buchanan, A. & Brock, D. (1989), 18.

<sup>40</sup> Buchanan, A. & Brock, D. (1989), 21.

specific tasks.<sup>41</sup> Since the focus here is on decision making, we can, as do most commentators, distinguish between the two in the clinical setting. Absence of decision making capacity is assessed by health care professionals and absence of competence is a legal judgment made by the courts.<sup>42</sup> Although this distinction is technically correct, it tends to break down in practice. According to Grisso and Appelbaum, when providers determine that a patient lacks decision-making capacity, “the practical consequences may be the same as those attending a legal determination of incompetence.”<sup>43</sup> Nonetheless, for purposes herein, ‘incompetence’ is treated as a global quality reflecting an all-or-none inability to make any health care decisions. ‘Incapacity’ is treated as a decision relative determination for which an individual may be able to make a particular decision at a particular time or place but not under other conditions.

Decision making capacity serves as an entry point to the ethical and legal doctrine of informed consent: if capacity is not present, there is little point in deliberating about other elements, such as understanding or voluntariness. Age parameters present an obstacle for engaging the informed consent process. In the case of older children and adolescents, who may appear to demonstrate decisional capacity according to established criteria, but lack decisional authority because of their age, informed consent or refusal become incoherent.<sup>44</sup>

### **The ‘Capacity Problem’- Generally**

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<sup>41</sup> Boyle (2005), 118-9.

<sup>42</sup> Kopelman, L.M. (1990). “On the Evaluative Nature of Competency and Capacity Judgments.” *International Journal of Law and Psychiatry*, 13, 309-29, p.310.

<sup>43</sup> Grisso, T. & Appelbaum, P.S. (1998). *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. NY: Oxford Univ. Press, 11.

One of the tasks of this chapter is to analyze the validity of the claim made by some advocates that adolescents have the capacity to make life-and-death decisions about themselves. As an introduction to this task, it would be helpful to gain an understanding of the difficulty involved in assessing capacity among adults generally since this is the group whose autonomy is generally presumed.<sup>45</sup> The difficulty in assessing decision making capacity comes in part from the difficulty in defining it. Culver and Gert identified the core meaning of competence as the ability to do a certain task well enough for a certain purpose.<sup>46</sup> Others require a definition of competence to include the capacities, or abilities that comprise competence. Becky Cox White suggests that the list of capacities comprises the eight 'R's': capacities to receive, recognize, and remember relevant information; to relate to oneself, reason about, and rank alternatives; to resolve situations; and to resign oneself to those resolutions.<sup>47</sup>

Three dichotomous conceptualizations of competence add to the confusion over its definition.<sup>48</sup> First, is competence general or specific? Buchanan and Brock, as well as most other theorists, call for competence as being decision-relative, not global.<sup>49</sup> They argue that the requisite capacities should vary with the context. Unfortunately, the almost interchangeable usage of the terms 'competence' and 'capacity' adds to the difficulty of

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<sup>44</sup> Buchanan, A. & Brock, D. (1989), 226.

<sup>45</sup> An additional complication in this section is the seeming interchangeability of the words 'capacity' and 'competence.' Because the cited authors frequently refer to the word 'competence,' it is used, in deference, in the text. However, the ethical connotation of decision making 'capacity' as described above remains operational.

<sup>46</sup> Culver, C.M. & Gert, B. (1982). *Philosophy in Medicine*. NY: Oxford Univ. Press; Kopelman, L.M. (1990), 312.

<sup>47</sup> White, B.C. (1994). *Competence to Consent*. Washington, D.C.: Georgetown Univ. Press, 53.

<sup>48</sup> *Ibid.*, 59-75.

<sup>49</sup> Buchanan, A. & Brock, D. (1989), 18.

assigning relative or global attributes. Second, is competence a threshold or degree concept? Faden and Beauchamp argue that since determining competence must be a gate keeping function - to not allow incompetent persons to give informed consent - it must also be understood as a threshold concept.<sup>50</sup> Buchanan and Brock agree that competence is a threshold concept. The import of the distinction is only whether decisional authority is in the end left with the patient or transferred to a surrogate.<sup>51</sup> Grisso and Vierling, who also view competence as a threshold concept, suggest that the threshold be raised or lowered depending on how much is demanded of the patient in the situation at hand.<sup>52</sup> In the degree conception of competency, the extent to which persons possess particular capacities is emphasized. Persons may be more or less in possession of these capacities, and thus more or less competent. A problem with the degree concept is that there is less precision in the determination of capacity, and greater room for the participation, or intrusion, of others. Another conceptual difficulty with the degree formulation of capacity is that if a person clears the threshold demarcation, the adult's decision should be accepted as the final word. By utilizing a degree distinction, decisional authority may be questioned more readily.<sup>53</sup> In practice, however, the difference between degree and threshold conceptualizations of capacity become blurred. Since there are no objectively established thresholds for every clinical decision, clinicians rely on subjectively determined assessments of decision making capacity.

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<sup>50</sup> Faden, R. & Beauchamp, T. (1986), 288-290.

<sup>51</sup> Buchanan, A. & Brock, D. (1989), 26-29.

<sup>52</sup> Grisso, T. & Appelbaum, P.S. (1998), 23-6.

<sup>53</sup> White, B.C. (1994) makes these points on pp.62-6.

The third dichotomy in the definition of competence refers to whether competence is consequence-dependent or consequence-independent. The situational quality of capacity assessment is particularly troublesome to clinicians who must determine whether the patient before them can make a decision that may have a profound impact on their life.

James Drane and others suggest a sliding scale approach to capacity determinations.<sup>54</sup> In the sliding scale approach, the required evidence of capacity becomes higher as the magnitude and risk involved in a particular decision increases. This approach confuses whether the patient must demonstrate a higher level of capacity or if the providers evaluate capacity with greater rigor when a patient consents to a procedure entailing high risk with little benefit or conversely refuses an intervention entailing little risk but great benefit.<sup>55</sup> Beauchamp and Childress address this confusion by recommending that only the required standards of evidence for determining decision making competence be placed on a sliding scale and not the level of competence.<sup>56</sup>

Conceptualizations of decision making capacity unavoidably reflect a subjective balancing between two often competing goals: to enhance a patient's well-being and to respect the person as a self-determining individual. Even though the adult patient is generally presumed to be a capable decision maker, apparently irrational consents to, or refusals of, medical treatment alert providers to possible inadequacies in decisional capacity. The legal and ethical doctrine of informed consent seeks to balance the good

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<sup>54</sup> Drane, J. F. (1985). "The Many Faces of Competency." *Hastings Center Reports*, April, 17-21; Buchanan & Brock (1989), 51-7.

<sup>55</sup> Buchanan & Brock (1989), 52-5.

<sup>56</sup> Beauchamp & Childress (2001), 76.

of ‘self-determination’ with the good of ‘well-being.’ Seeking the patient’s well-being embraces a paternalistic protection from poor choices. Pursuing respect for the patient’s autonomy embraces societal pressures of upholding liberty and autonomy.

### *Features of decision making capacity*

Grisso and Appelbaum recommend four functional abilities as the focus of capacity assessments by clinicians: 1) the ability to *express a choice*, 2) the ability to *understand* information relevant to treatment decision making, 3) the ability to *appreciate* the significance of that information for one’s own situation, and 4) the ability to *reason* with relevant information.<sup>57</sup> As straightforward as these abilities might appear, their evaluation is unavoidably accompanied by the subjective beneficence-autonomy tension inherent in the informed consent process. Kopelman stresses that assessing decision making capacity is a value-laden enterprise.<sup>58</sup> Immersed within capacity assessments are internal values and external values. Internal values emerge in the problem of what capacity means for a particular decision, as well as in describing the norms people must successfully meet to be deemed competent. External values are introduced by those authorized to make competency assessments. For example, clinicians particularly biased toward preserving patient autonomy may favor a ‘looser’ demonstration of capacity skills than clinicians more biased toward a beneficent, or even paternalistic, perspective.

Determining decisional capacity or competence in order that patients may consent to or refuse medical interventions is a daily activity in the clinical setting. Decisions to be

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<sup>57</sup> Grisso & Appelbaum (1998), 31, italics theirs.

<sup>58</sup> Kopelman, L. (1990), 309.

made by patients range from the mundane (such as choosing the sequencing of nursing care) through unpleasant diagnostic tests to risky surgical or medical interventions. Generally, the patient agrees with the provider and consents to treatments that are deemed to be in her ‘best interests.’<sup>59</sup>

If the patient is clearly an incapable decision maker, perhaps an infant or a demented elderly person, a surrogate decision maker is designated to make a decision on the patient’s behalf. For the infant a surrogate would generally be a parent, and for the elderly patient a spouse or close family member. In addition to incapacity that is certainly associated with infancy and senility, many kinds of short-term or long-standing mental and cognitive impairments<sup>60</sup> can result in profound inability to represent oneself as either for or against the suggested medical intervention.

The presence of an undisputed surrogate does not necessarily expedite the decision making; rather it may prolong the process and encourage further questions about the patient’s best interests or issues of substituted judgment. At such times, safeguards to protect the ‘rights’, dignity, and interests of the patient are usually deployed. Safeguards may include ethics consultation and/or legal intervention.<sup>61</sup> As a last resort in disputes

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<sup>59</sup> ‘Best interests’ is a concept layered with meanings. In the health care context, the term is used in reference to paternalistic medical practice, the patient deciding what is best for him or herself, and the surrogate decision maker deciding what is ‘best’ for a patient who has never demonstrated decision making capacity. For extensive discussions of these concepts in pediatrics see: Goldstein, J., Solnit, A.J., Goldstein, S., & Freud, A. (1996). *The Best Interests of the Child: The Least Detrimental Alternative*. NY: Free Press; Purdy, L.(1992). *In Their Best Interests? The Case Against Equal Rights for Children*. Ithaca, NY: Cornell Univ. Press.

<sup>60</sup> Examples here include head trauma, stroke, mental retardation, schizophrenia, etc.

<sup>61</sup> Legislative action in response to particular cases is intended to protect future patients in similar circumstances. For example, in an effort to protect impaired/disabled infants from being denied medical intervention by their parents or providers, the federal government introduced “Baby Doe” rules. See Robertson, J.A (1986). “Legal Aspects of Withholding Treatment from Handicapped Newborns: Substantive Issues.” *Journal of Health Politics, Policy and Law*, 11(2), 215-230. This legislation, although



between providers and family members, the legal system also functions as a safeguard against *poor* decisions made about never- or no-longer-competent individuals.

Even with available safeguards, medical decision making on behalf of an incapable patient is not, and should not be, routine or straightforward. Every situation's unique circumstances ought to be diligently considered. In 'borderline' cases of capacity the question of who makes the decision becomes much more pressing. Borderline cases may feature mentally ill persons who have vividly lucid periods alternating with unclear thinking. Or, as is the focus here, the 'borderline' case might involve an older child who appears to meet expectations for decision making capacity. Problematically, though, the adolescent is not legally sanctioned to represent himself, and additionally, his stated 'best interests' may not correlate with the judgment of hospital staff or family.

### **The 'Capacity Problem' - Specifically**

This section will discuss the problem of capacity as it impacts adolescent life-and-death decision making relative to four points of consideration. The first point addresses the ambiguity in reliably determining capacity in adults, much less children and teenagers. The evaluative nature of capacity judgments and the clinical lack of anything like a 'capacimeter' make capacity determinations open to wide interpretations by clinicians.

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still in place, has become less rigorously enforced than at its inception. To allow formerly competent adults to exercise their wishes when no longer competent, mechanisms such as Living Wills, advance directives, and durable power of attorney are available. See also, King, N. M.P. (1996). *Making Sense of Advance Directives*, rev. ed. Washington, D.C.: Georgetown Univ. Press. Many states have also enacted 'natural death' legislation that directly address the use of these advance directive mechanisms. See Virginia Health Care Decisions Act, 1992, rev. 1997 enacted in statute at 54.1-2981. Procedure for making an advance directive at 54.1-2983.

The second point is that capacity determinations capture cognitive or intellectual qualities, with a view toward ensuring that adolescents and adults cross the capacity threshold without accounting for possible differences. For example, the qualities of maturity, life experience, or judgment may be very differently demonstrated in adults and adolescents, yet those differences are generally not taken into account in capacity determinations.

The third point questions whether adolescent capacity determinations, as the hallmark criteria for autonomous informed consent and refusal in adults, serve to undermine the bonds of mutuality between the ill adolescent and family. Thomas Murray views mutuality as a model of the parent-child relationship that acknowledges the immense stake parents and children have in each other's flourishing.<sup>62</sup>

Mutuality is based on nurturance and loyalty, reflecting the interactive roles and responsibilities in family life. Overemphasizing adolescent autonomy in life-and-death decision making artificially distorts the child's authority within a family. In trying to ensure the adolescent's autonomy, providers and the state become intruders in what ought to be an intimate parent-child decision.

The fourth and final point enhances the model of mutuality by proposing consideration of a "therapeutic alliance" between providers, parents, and the adolescent. Richard Miller proposes that the aim of pediatric care is for health care providers to forge a "therapeutic alliance" with children and their primary caretakers. Within the alliance, providers "are summoned first to discharge their responsibilities in concert with those of

the family.”<sup>63</sup> The formation of a therapeutic alliance among the stakeholders in an adolescent life-and-death treatment scenario complements Pellegrino and Thomasma’s notion of beneficence-in-trust<sup>64</sup> which relies on acting in relationship in order to act in the best interests of the patient.

Mutuality, therapeutic alliance, and beneficence-in-trust, as concepts that emphasize the central importance of parent-child relationship without losing sight of the individuality of involved parties,<sup>65</sup> will be further elaborated in subsequent chapters. I introduce them here to illustrate their tension with conceptions of the adolescent patient as an autonomous individual and, hence, the most important moral agent in life-and-death decision making.

*Point One: The Ambiguity of Determining Capacity*

Decision making capacity in the health care setting received significantly less attention prior to the stirrings of the biomedical ethics movement four decades ago.<sup>66</sup> Formerly, patients and their families were accustomed to submitting themselves to the medical treatment that their physician deemed to be in their best interest. The shift away from paternalistic medical care toward an understanding of shared decision making

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<sup>62</sup> Murray, T.H. (1996). *The Worth of a Child*. Berkley: University of California Press, 61.

<sup>63</sup> Miller, R.B. (2003). *Children, Ethics, and Modern Medicine*. Bloomington: Indiana University Press, 36.

<sup>64</sup> Pellegrino, E.D. & Thomasma, D.C. (1988). *For the Patient’s Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press.

<sup>65</sup> Ibid.

<sup>66</sup> See Jonsen, A.R. (1998). *The Birth of Bioethics*. NY: Oxford University Press for an extensive historical review of the bioethics movement.

between patients and their physicians<sup>67</sup> led to an emphasis on respecting patient autonomy. The contemporary notion of patient autonomy has little affinity with the Kantian formulation of the terms '*auto*' and '*nomos*', meaning 'self-rule'. In Kant's view 'self-rule' meant to be free from outside and inner forces thereby allowing the person to pursue an action that was the product of a rational will.<sup>68</sup> In the contemporary understanding of 'autonomy,' decision making capacity is a necessary attribute of the self-determining adult who can validly consent to or refuse a proposed medical intervention.

#### Elements of capacity

Decision making capacity comprises several elements. For the purposes of this chapter, the elements named in two well-known sources are combined to produce a more comprehensive perspective. Combining the proposal by the President's Commission for the Study of Ethical Problems in Medicine with empirically validated concepts from the work of Grisso and Appelbaum yields the following elements of decision making capacity: 1) possession of a set of values and goals; 2) understanding the information being presented; 3) appreciation of the information for one's own circumstances, 4) reasoning with the information, and 5) expressing a choice.<sup>69</sup> To say that someone is capable or competent to make decisions about themselves depends on how capacity is

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<sup>67</sup> See President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, (1982). *Making Health Care Decisions, Vol. 1*. Washington, D.C.: U.S. Government Printing Office. Discussion on shared decision making.

<sup>68</sup> Kant, I. (1959). *Foundations of the Metaphysics of Morals*, trans. Lewis White Beck. Indianapolis: Bobbs-Merrill Co.

<sup>69</sup> Grisso, T. & Appelbaum, P.S. (1998), 20. The first 3 elements derive from the President's Commission (1982) report. These overlap with, and are included in, the elements developed by Grisso and Appelbaum.

conceived by the evaluators. If, as Brock points out, competency (or capacity) is a threshold concept that is task specific,<sup>70</sup> then simply evidencing these elements is adequate. If, however, the patient must demonstrate the presence of these elements to a greater or lesser degree depending on the decision to be made, health providers have to evaluate whether a patient demonstrates these qualities well enough. Depending on the situation and circumstances, the patient who demonstrates sufficient cognitive dexterity in the above elements is determined to be a capable decision maker.

For the adolescent, the common law perspective views children as requiring protection, hence their designation as minors. On the other hand, there is on-going pressure in medical, legal, and ethical circles to respect adolescents as persons with developing autonomy who should be able to participate in medical decision making about themselves. Some commentators and professional practice organizations stress the child's ability to participate in decision making, further noting that such participation ought to increase as the child grows older.

Unfortunately, what is meant by child or adolescent 'participation' is often unclear. In some cases, participation appears to fit the model of 'shared decision making,' in which the patient becomes an active participant with the providers and parents in determining a plan of care.<sup>71</sup> In other cases, 'participation' appears to describe a decisional trump over

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<sup>70</sup> Brock, D.W. (1989). "Children's Competence for Health Care Decision Making. In, Kopelman, L.M. & Moskop, J.C. (Eds.), *Children and Health Care: Moral and Social Issues*, 181-212. Kluwer Academic Pub.; Kopelman (1990), 312.

<sup>71</sup> See for example: Erlen, J.A. (1987). "The Child's Choice: An Essential Component in Treatment Decisions." *Children's Health Care*, 15 (2), 156-160.

the recommendations and wishes of providers and parents.<sup>72</sup> In still other sources, ‘participation’ seems to imply that the child be involved in all decision making to the best of his ability, that his views be listened to and considered, but that parents, or state, reserve the final decision on life-saving intervention.<sup>73</sup> In this dissertation the notion of ‘participation’ by adolescents comprises the third option above: the adolescent’s views are considered, but do not trump the beneficent actions of providers and parents, especially in life-or-death circumstances.

### “Capacimeters”

Many attempts have been made to develop a ‘capacimeter,’ an objective test by which decisional capacity can be determined with reliability.<sup>74</sup> Thomas Grisso and Paul Applebaum recently developed an instrument called the MacArthur Competence Assessment Tool - Treatment (MacCAT-T).<sup>75</sup> The result of extensive research and revision,<sup>76</sup> the MacCat-T assesses and rates patients’ abilities within four standards for competence to consent to treatment: 1) understanding of treatment-related information; 2) appreciation of the significance of the information, 3) reasoning in the process of

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<sup>72</sup> See for example: Levetown, M. (1996).

<sup>73</sup> See for example: Gaylin, W. (1982). “Competence: No Longer All or None.” In, W. Gaylin & R. Macklin (Eds.) *Who Speaks for the Child: The Problems of Proxy Consent.*, 27-56. NY: Plenum Press.

<sup>74</sup> Roth, L.H., Meisel, A, & Lidz, C.W. (1977). “Tests of Competency to Consent to Treatment.” *American Journal of Psychiatry* 134, 279-84. Neurological testing, especially the Mini Mental Status Exam, is also used for competency testing, accompanied by the usual incongruity between defining capacity and testing for it.

<sup>75</sup> Grisso, T. & Appelbaum, P.S. (1998).

<sup>76</sup> See for example: Appelbaum, P.S. & Grisso, T. (1995). “The MacArthur Treatment Competence Study, I: Mental Illness and Competence to Consent to Treatment.” *Law and Human Behavior* 19, 105-26; Grisso, T., Appelbaum, P.S., Mulvey, E.P., Fletcher, K. (1995). “The MacArthur Treatment Competence Study, II: Measures of Abilities Related to Competence to Consent to Treatment.” *Law and Human Behavior* 19, 126-48; Grisso, T, Appelbaum, P.S. (1995). “The MacArthur Treatment Competence Study, III: Abilities of Patients to Consent to Psychiatric and Medical Treatments.” *Law and Human Behavior* 19, 149-74.

deciding on treatment, and 4) expressing a choice about treatment. Grisso and Appelbaum emphasize that ‘understanding’ and ‘appreciation’ are related conceptually but are discrete enough as to merit separate classification. The meaning they assign ‘appreciation’ is similar to that of the President’s Commission, which used the term in reference to people who, because of their cognitive deficits or emotional states, fail to accept the relevance of their disorders or potential treatment consequences for their own circumstances.<sup>77</sup> Appreciation also appears to include a set of values and goals as identified by the President’s Commission.<sup>78</sup> Under ‘reasoning’, Grisso and Appelbaum strive to test for cognitive deficits or mental illness that would severely limit rational thinking. They insist that the tool is not intended to penalize people whose reasoning styles do not fit a preconceived notion of ‘normal;’ rather it is to discover individuals who are substantially impaired. Expressing a choice is, for Grisso and Appelbaum, a threshold element. If a patient cannot express a choice, either verbally or nonverbally, after efforts to enhance communication such as the use of translators, there is usually no need to consider their status regarding other abilities.<sup>79</sup>

‘Capacimeters’ are to be utilized with caution and discretion. Grisso and Appelbaum warn against interpreting the experimental measures of decisional capacity elicited by their MacCAT-T test as determinations of legal incompetence to consent to treatment.<sup>80</sup>

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<sup>77</sup> Grisso, T. & Appelbaum, P.S. (1998), 43.

<sup>78</sup> See Grisso and Appelbaum’s (1998) discussion of a man who refused cancer treatment so that his grandchildren would remember him for fishing with them, instead of being ill from the chemotherapy, or the woman who refused treatment for metastasized breast cancer because her religion was based in recovery due to prayer, pp. 46-8.

<sup>79</sup> Grisso, T. & Appelbaum, P.S. (1998), 35.

<sup>80</sup> Ibid., 75. Grisso, T. & Appelbaum, P. (1995), 170.

Kapp and Mossman, however, contend that this warning is not strong enough.<sup>81</sup> After all, they point out, the purpose of developing such tools is to get a more reliable grasp of a patient's capacity to make medical decisions. Clinicians are apt to embrace a test that seems easy to administer and offers the 'security' of reliability.

Current evaluations of patient's capacity, even when performed by mental health professionals, are inevitably mired in the subjectivity of external values. Individuals subjected to capacity assessments are usually the ones who do not meet the clinicians' and family's conception of cooperativeness. They are often the patients who refuse treatment deemed to be in their best interests. As Kapp and Mossman point out, "even if a single assessment instrument were to gain universal acceptance, expert clinical judgment exercised by individual professionals would control the selection of patients who undergo formal assessment."<sup>82</sup> Since a formal capacimetric exam for every required informed consent or refusal would not be practical or desirable, clinicians' targeting of prospective candidates for formal assessment would be an even more important first step in capacity assessments.<sup>83</sup>

Other problems also call for caution on the use of 'capacimeters'. Most of these problems result from the very nature of capacity itself. For example, Kapp and Mossman note that a measurement tool produces results only as accurate and reliable as the

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<sup>81</sup> Kapp, M.B. & Mossman, D. (1996). "Measuring Decisional Capacity: Cautions on the Construction of a 'Capacimeter.'" *Psychology, Public Policy, and Law*, 2(1), 73-95. Although their critique is particularly targeted to the MacArthur group's instrument, many of their identified problem areas can be generalized to any kind of 'capacimeter' and also current clinical assessment for capacity.

<sup>82</sup> Kapp, M.B. & Mossman, D. (1996), 82.

<sup>83</sup> Ibid.



phenomenon it is designed to measure.<sup>84</sup> In other words, capacity, as a concept, is variably subject to state statutory definition and common law interpretation. Perhaps efforts to develop objective capacity measuring instruments are premature in light of limited consensus about what capacity is.<sup>85</sup>

A second problem is whether capacity is ‘all or none.’<sup>86</sup> Conceiving capacity as a fixed concept that is either present or not may contribute to its over- and underestimation. Overestimation of capacity may result from our autonomy-focused desire to give patients the benefit of the doubt. But favoring patients’ autonomy by overestimating their capacity may not protect them from making ill-considered decisions about themselves.<sup>87</sup> Underestimation of capacity may occur with patients who fall into certain categories typically targeted as incompetent. These might include the elderly, the mentally ill, the mentally retarded, and minors. Underestimation of capacity may also result from a patient’s responses.<sup>88</sup> It is not impossible to imagine that a seemingly objective capacity test administered by a paternalistic clinician could find a patient to be an incapable decision maker if the patient’s decision threatened their best medical interest, as conceived by the clinician.

A third problem with the use of ‘capacimeters’ concerns the constancy or stability of capacity over time. Many patients, especially the elderly, may exhibit capacity that

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<sup>84</sup> Ibid., 82.

<sup>85</sup> White, B.C. (1994), 186.

<sup>86</sup> Kapp, M.B. & Mossman, D. (1996).

<sup>87</sup> The tension, of course, lies at the very heart of the informed consent doctrine: balancing self-determination and well-being.

<sup>88</sup> This problem arises from the still unsettled dichotomy between capacity determination as a consequence dependent decision or as a consequence independent decision. See *supra* notes 49-50 and accompanying text.

fluctuates dynamically. The static determination of capacity via an instrument would not adequately capture changes exhibited by many people. Questions about re-administration of a capacity test and under what circumstances are not readily resolved. For example, it is possible that our societal emphasis on autonomy would tempt us to continue testing until we obtained a ‘passing’ capacity score, even though the patient’s abilities wax and wane.

The eagerness to pin down numbers on an easy-to-administer, seemingly objective instrument suggests a fourth problem with capacity measurement. The widespread use of assessment tools could contribute to the bad practice of treating informed consent as an ‘event’ rather than a process.<sup>89</sup> Affixing ‘passing’ or ‘failing’ scores to a test, like finally getting the patient’s signature on a consent form, may, for some clinicians, discourage an active process of discussion with the patient and family.

Consideration of the four problems highlighted here points to the difficulties of assessing capacity in adult patients with or without standardized instruments. The MacCAT-T was developed for, and with, adult patients. At this time, no instrument has been specifically designed for use with older children and adolescents. Developing such an assessment tool for adolescents should be discouraged. Attempting to use the MacCAT-T or another instrument for assessing capacity in adolescents has great risk for failing to capture important features involved in adolescent decision making.

*Point Two: Adolescents’ Capacity Skills: Are They Based Only in Cognition?*

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<sup>89</sup> Kapp & Mossman (1996), 85.

As the previous section illustrated, decision making capacity is riddled with ambiguity. Moreover, the ethical nature of decision making capacity becomes clear in the subjectivity inherent in questions such as: who is capable, and how is that capacity determined? The purpose of such questions, is, of course, to establish whether a patient is able to autonomously provide a legally recognized informed consent or refusal. As has been previously mentioned, the legal and ethical doctrine of informed consent requires that a patient be a capable decision maker, that she has been adequately informed about the treatment and alternatives, that she understands the recommended plan and alternatives, that she express a choice, and that she do so in a voluntary manner. Establishing that a patient is a capable decision maker is, then, the first hurdle to be crossed in the informed consent/refusal process.

Under American law, adults are presumed competent, minors are not. There are, nonetheless, advocates for adolescent life-and-death decision making who appeal to psychological research that appears to indicate an adult-equivalent level of understanding and reasoning in persons age fifteen. Following is a brief summary of the developmental data that are relevant to a general assessment of the decision making capacities of older children and adolescents. This summary highlights the ethical questions inherent in adolescent capacity and its determination.

An ethical analysis of competency studies cannot do justice to the nuances of psychological research best understood by those immersed in the field. At most, this section hopes to uncover some of the current controversies and their effect on the

judgment about the ethical status of the adolescent's decision making capacity. A review of this psychological research will attempt to show that contrary to the assumptions some make about adolescent decision making capacity, the applicable evidence that teens are developmentally equipped to make life-and-death decisions about themselves remains unsettled and inconclusive. Indeed, such assumptions about adolescent capacity, embraced by many in the bioethics community, are based on cognitive models that fail to stand up to conceptual scrutiny.

### Describing adolescence

The claim that adolescents have decisional capacity comparable to adults - and therefore ought to have comparable decisional authority - begs the question of what differences exist between adults and adolescents. Certainly, the age range of 'adulthood' comprises the greater portion of most people's lives, whereas the range of adolescence comprises a much shorter span. Since a general comparison between the decisional capacity of a 35 year old and a 15 year old is pointless, the modified question becomes: what are the differences between the legally recognized age of adulthood and of adolescents only several years younger? A response is complicated by different definitions of the adolescent time frame. The defining ages of adolescence vary even among developmental and behavioral researchers. Some designate adolescence as beginning by age 11 and ending by age 21. Others argue that cognitive and physical development in the child may signal the beginning of adolescence at age 9 and ending by age 17, 18, or 19. There may be few obvious physical or cognitive differences between an eighteen year old and a fifteen year old. Age eighteen only begins the legal

designation of adulthood and is, in fact, considered late adolescence in many child development sources.<sup>90</sup>

Physical and cognitive development does not tell the entire story of adolescent maturation. After all, as Willard Gaylin points out, “we all know when an individual is eighteen; we do not know when an individual is mature.”<sup>91</sup> Empirically, judgment, together with maturity, appears to play a role in ‘growing up’. Scott suggests that there is an intuitive understanding that children are unable to make many decisions because they have poor judgment.<sup>92</sup> Is the source of that intuition lodged in societal understandings of maturity? If maturity is a function of judgment, few older children and adolescents have the cumulative life experiences of adults.

Depending on how the variables of judgment, maturity, and life experience are evaluated young persons may exhibit adequate decision making capacity, according to health care providers, but still have limited authority to follow through on their wishes. In the case of AJ, who has a life-long history of chronic respiratory problems, his capacity to make decisions about himself may be highly influenced by the experiences he has had of personal illness, of frequent hospitalizations, of dying friends. His level of

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<sup>90</sup> Gemelli splits adolescence into two periods: early adolescence (from puberty [about age 12] to age 15 yrs) and late adolescence (from age 16 years to age 19 years). Gemelli, R. (1996). *Normal Child and Adolescent Development*. Washington, D.C.: American Psychiatric Press. The concluding report of the Carnegie Council on Adolescent Development (1995), titled *Great Transitions: Preparing Adolescents for a New Century* identifies three phases of adolescence. Early adolescence falls from 10 to 14. Middle adolescence covers ages 15 to 17. Late adolescence can stretch from age eighteen into the twenties. This last phase occurs for those who delay entry into adult roles because of educational or social factors. Washington, D.C.: U.S. Dept. of Education, Office of Educational Research and Improvement, p. 20.

<sup>91</sup> Gaylin, W.(1982), 28.

<sup>92</sup> Scott, E. (1992).

maturity, which include institutional savviness and many interactions with health providers, may be far more advanced than that of other boys his age.<sup>93</sup>

BJ has no experience with illness. He himself is a picture of athletic strength and accomplishment. His level of maturity is defined by his developmental age and his experiences of an average fifteen year old boy, which experiences do not include frequent hospitalizations, premature death of friends, and many interactions with unknown adults. BJ may have had the advantage of honing his decision making skills in a family context that encouraged his input. AJ, on the other hand, may have been shielded from any decision making in the family. Perhaps because of his fragile health or his own family's dynamics, AJ may not have been afforded opportunities to practice making decisions that affect him. Without considering other personal characteristics of these two boys, it is already abundantly clear that, from an ethical standpoint, their breadth of experience, judgment, and maturity are potentially variable enough to challenge any capacity assessment based solely on cognition.

#### Piaget and stage theories of development

Advocacy for adolescents to make independent medical treatment decisions is based in the assumption that they are capable of meeting the minimal legal cognitive requirement of competence. It is not surprising therefore, writes Elizabeth Scott, that much of the research on minor's medical decision making is structured to evaluate

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<sup>93</sup> It is important to note though that the alleged maturity demonstrated by chronically ill children may be a maturity specific to understanding, even manipulating, their disease. This specific maturity does not guarantee a general maturity. This point was made by Robert Orr, MD at the Nov. 1998 American Society for Bioethics and Humanities conference in Houston, Texas.

competence under informed consent tests.<sup>94</sup> The primary conceptual basis for this research is situated in the work of Swiss psychologist, Jean Piaget, who, working primarily in the 1920's and 1930's, continues to be recognized as having developed the most widely applied and influential model of the child's cognitive development. Piaget, who also influenced Lawrence Kohlberg's work on moral development in children, was a stage theorist.

Piaget posited an elaborate progression of stages where, beginning in infancy, each succeeding level of cognitive development reflects a particular way of intellectually assimilating new information. Piaget believed in the predictable cognitive unfolding of children, similar to the physical stages of development which are scarcely affected by external forces. He thought that children in the concrete operations stage, between ages 7 and 11 years, were rarely able to grasp certain abstract concepts.<sup>95</sup> Beginning in early adolescence, roughly 11-15 years of age, a major and final shift in intellectual organization takes place. This shift into the formal operations stage is achieved to some degree by late adolescence in all normal individuals.<sup>96</sup> The achievements of this stage are marked by a newly developed ability to manipulate abstract information, to reflect on one's own thoughts, and to apply logic to problems.<sup>97</sup> Piaget arrived at these conclusions

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<sup>94</sup> Scott, E. (1992), 1623.

<sup>95</sup> Alderson, P. (1993). *Children's Consent to Surgery*. Philadelphia: Open Univ. Press, 62.

<sup>96</sup> One of the best primary sources for Piaget's developmental theory is: Inhelder, B. & Piaget, J. (1958). *The Growth of Logical Thinking from Childhood to Adolescence*. For a comprehensive secondary source see Worrell, J. & Danner, F. (Eds.)(1989). *The Adolescent as Decision Maker: Applications to Development and Education*. San Diego: Academic Press.

<sup>97</sup> Danner, F. (1989). "Cognitive Development in Adolescence." In, J. Worrell & F. Danner (Eds.), *The Adolescent as Decision Maker: Applications to Development and Education*, 53-83. San Diego: Academic Press, 56.

by way of an observational methodology that emphasized scientific and epistemological thinking in problem solving.

Unfortunately, Piaget's very emphasis on rigid, formulaic thinking is a major reason for opposition to his work. Replication of experiments designed by Piaget and colleagues failed to verify the findings that older adolescents and even adults perform well on formal tasks.<sup>98</sup> In a concession to his critics, Piaget acknowledged that formal abilities might not develop as early as he had reported and that abilities, although still universally achieved, might have their expression limited by familiarity with particular content.<sup>99</sup> This acknowledgement appears to recognize that formal operational thought may be affected by life experiences to which one had been exposed, although Piaget only addressed the kind of physical knowledge that would be directly learned from experience with the environment.<sup>100</sup>

Another reason for Piaget's disfavor among developmentalists is that researchers primarily interested in the affective and interpersonal domains of cognitive development have little affinity with Piaget's logical approach to problem solving in adolescence. Critics of Piaget's stage theory object to the contrived experimental method and the denial of competing or complementary forces in cognitive development, such as the child's relationships, emotions, or social and imaginative talents.<sup>101</sup>

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<sup>98</sup> Ibid., 58.

<sup>99</sup> Ibid.; Piaget, J. (1972). "Intellectual Evolution from Adolescence to Adulthood." *Human Development*, 15, 1-12.

<sup>100</sup> Danner, F. (1989), 60.

<sup>101</sup> Alderson, P. (1992). "In the Genes or in the Stars? Children's Competence to Consent." *Journal of Medical Ethics*, 18, 119-124, p.120.



Stage theories generally are under fire from research showing that cognitive development is more continuous, gradual, and variable than stage theory suggests.<sup>102</sup> Additionally, research pointing to the overlapping and recurrence of ‘stages’ conflicts with an insistence that the stages are discrete. Empirical studies deny the strict ‘staircase’ progression of child development that many see as Piaget’s legacy, although Piaget himself repudiated the stringent interpretation of his theory. In a critique of Piaget, Shayer writes, “Among the children of 12 can be found every Piagetian level of behavior ranging from that of the average 6/7-year-old to that of the top 10 percent of 16-year-olds.”<sup>103</sup>

Despite criticisms about the modern relevance of Piaget’s stage theory, commentators on bioethical issues in pediatrics often continue to defer to Piaget’s stage-based cognitive development theory as the authoritative interpretation of childhood decisional capacity.<sup>104</sup> Perhaps one reason for this bioethical deference is the compatibility of basic themes. Piaget tended to see the child as isolated, autonomously working out individual conclusions, unaffected by race, class, poverty, illness, or disability. Alderson suggests that “such abstraction characterizes mainstream bioethics, which perhaps accounts for Piaget’s lasting influence.”<sup>105</sup> The staircase metaphor suits an elegant research design

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<sup>102</sup> Scott, E. (1992), 1632.

<sup>103</sup> Shayer, M. (1980). “Piaget and Science Education.” In S. Modgil & C. Modgil (Eds.). *Towards a Theory of Psychological Development*, pp. 699-731. Windsor, Berks: NER Publishing, 705. David F. Bjorklund offers an apologetic for Piaget’s roundly denounced theory by suggesting that his biologically-based ideas can serve as underpinnings for development of an evolutionary theory of child development. See, “In search of metatheory for cognitive development (or, Piaget is dead and I don’t feel so good myself).” *Child Development*, 68(1), (1997), 144-8, p. 147.

<sup>104</sup> See for example, Moreno, Jonathan D. (1989). “Treating the Adolescent Patient: An Ethical Analysis.” *Journal of Adolescent Health Care*, 10, 454-9, p. 455; Buchanan & Brock (1989).

<sup>105</sup> Alderson, P. (1992), 120-1.

and simplifies the complexities of child development. But critics argue that, empirically, it is overly optimistic and fails to capture the full story of child development.<sup>106</sup>

What might that full story, the ethical narrative, of the child's decision making capacity be? The aim here is to show that decision making capacity does not rely solely on the increasingly sophisticated cognitive functions of the child's and adolescent's brain. There are other factors to consider such as the child's formative environment, the child's life experiences, particularly with illness and death, and psychological concepts such as judgment or maturity. Most of us would undoubtedly agree that decision making has much to do with how 'smart' we are, but disagree about how much those other ingredients contribute to the decisions that we make. The silence of research about these questions and issues is deafening; however the few studies that have employed either a non-Piagetian framework or have been largely qualitative indicate that other factors do have some kind of role in both adult and adolescent decision making, especially in life-threatening scenarios.

#### The Weithorn-Campbell study

Despite the concerns over the shortcomings of the Piagetian, or stage, framework, the bioethics and law literature continues mention of one well-known 1982 study as a major empirical source on decision making capacity in adolescents. Lois Weithorn and Susan

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<sup>106</sup> Gardner and colleagues questioned the level of 'scientific authority' demonstrated by the American Psychological Associations' filing of amicus briefs in 1985 and 1987, which argued to sustain lower court rulings against parental consent for abortion. Gardner, et al. were critical of the briefs' inclusion of Piaget's stage theory of cognitive development. Additionally, they objected to the few studies (only two, at their writing: Lewis' study and the Weithorn and Campbell study) that actually compared adolescent and adult decision making. Gardner, et al. concluded that too few studies, as well as an impaired developmental framework, were used to overstate what is known about adolescents' decision making skills. Gardner, W.,

Campbell sought to align their study with legal standards of competency which, although minimally elucidated in the law, serve nonetheless as criteria for determining competency.<sup>107</sup> The legal standards they included are: a) evidence of choice (the simple expression of a preference relative to the treatment alternatives); b) 'reasonable' outcome of choice (the option selected corresponds to the choice a hypothetical reasonable person might make); c) 'rational' reasons (the treatment preference was derived from rational or logical reasoning), and d) understanding (comprehension of the risks, benefits, and alternatives to treatment).<sup>108</sup> In their research design, four groups of young people, ages 9, 14, 18, and 21 years of age, were asked to respond to hypothetical medical dilemmas involving treatment decisions for diabetes, epilepsy, depression, and enuresis.

According to Weithorn and Campbell, minors aged 14 and above were found to demonstrate a level of competency equivalent to that of adults.<sup>109</sup> While nine year olds demonstrated similar decision outcomes as the other groups, they experienced difficulty in understanding and reasoning about the information given.

The finding that adolescents of 14 years of age, perhaps even younger, demonstrate adult decision making ability is substantiated in a small number of other empirical studies.<sup>110</sup> One of the more recent studies that also compared responses over a range of ages, 13-21, looked at the decision making capacity of young women facing the real life

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Scherer, D. & Tester, M. (1989). "Asserting Scientific Authority: Cognitive Development and Adolescent Legal Rights." *American Psychologist*, 44(6), 895-902, pp. 895-8.

<sup>107</sup> Weithorn, L.A. & Campbell, S.B. (1982).

<sup>108</sup> Weithorn, L. (1982) "Developmental Factors and Competence to Make Informed Treatment Decisions." *Child & Youth Services*, 85-100; Weithorn & Campbell (1982), 1590.

<sup>109</sup> Weithorn, L.A. & Campbell, S.B. (1982).

<sup>110</sup> See for example, Scherer, D.G. & Reppucci, N.D. (1988); Lewis, C.C. (1981); Ambuel, B. & Rappaport, J. (1992).

predicament of unintended pregnancy. Ambuel and Rappaport found that among study participants considering abortion, those aged 14 through 21 years showed no statistical difference in competence. Among those participants not considering abortion, adolescents aged 15 and younger were “clearly less competent than the adult criterion group in both volition, the degree to which a participant’s decision appears to be voluntary and independent, and cognitive competence.”<sup>111</sup> The importance of Ambuel and Rappaport’s study in the face of on-going societal disquiet concerning the appropriate roles of young, pregnant girls and their parents in the abortion decision is significant, but regrettably it is not helpful in advancing empirical information about adolescent capacity in decision making.<sup>112</sup> Even though it is one of only a few studies to compare adolescent and adult performance under real-life conditions,<sup>113</sup> its results do not readily inform questions about the competency of adolescents in life-and-death decision making. In dealing specifically with the problem of adolescent medical decision making, the Weithorn and Campbell study continues, for many writing in bioethics and pediatrics and for the law, as the consummate validation of adolescents’ capabilities in non-abortion related medical treatment decisions.<sup>114</sup>

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<sup>111</sup> Ambuel, B. & Rappaport, J. (1992), 145.

<sup>112</sup> I agree here with Elizabeth Scott’s views that tying adolescent decision making competence to abortion decisions is a misguided project because of the polarization of views on abortion and its unavoidable political ramifications. Additionally, Scott sees that such psychological research places too much emphasis on the legitimacy of the informed consent doctrine and begins with the assumption that adolescents and adults are not significantly different in how they comply with the doctrine’s standards. Scott (1992), 1630-1, footnote 94.

<sup>113</sup> Scott, E.S., Reppucci, N.D., & Woolard, J.L. (1995). “Evaluating Adolescent Decision Making in Legal Contexts.” *Law and Human Behavior*, 19, 221-244, at 226.

<sup>114</sup> For example, see references to the Weithorn & Campbell article in the following articles affirming the adolescent’s ability to make such decisions: Committee on Bioethics, American Academy of Pediatrics, (1995). “Informed Consent, Parental Permission, and Assent in Pediatric Practice.” *Pediatrics*, 95(2), 314-7; Weir, R. F. & Peters, C. (1997); Leikin, S. (1993). “The Role of Adolescents in Decisions

Concerns about the Weithorn and Campbell study are less often voiced than are its positive attributes. The authors acknowledge that their sample included “‘normal,’ white, healthy, individuals of high intelligence and middle-class background.”<sup>115</sup> The term ‘normal’ is of course open to wide interpretation. The sample’s good health makes it particularly difficult to generalize to the discussion about adolescent life-and-death decision making. Adolescents who would be subject to such decision making are far from healthy. They may have been very recently diagnosed with a potentially fatal disease that needs immediate intervention. They may have been chronically ill, more or less severely, all or much of their lives and are now facing the inevitability of their disease course, or even a new and different life-threatening disease. Given the restrictions on the sample, the results cannot reliably be generalized to acutely or chronically ill adolescents.

Additionally, individual and ecological variations,<sup>116</sup> not accounted for by the framework of Piaget’s predictable age-stage development model, receive minimal attention. For example, Weithorn and Campbell mention that within their 14 year old group, a small, but statistically significant number of teens made their treatment decisions for epilepsy based on their perception that a reasonable outcome of treatment would not include medications that might have an effect on their physical attractiveness.<sup>117</sup>

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Concerning their Cancer Therapy.” *Cancer, Supplement*, 71(10), 3342-6; Grisso, T. & Appelbaum, P. S. (1998), 76; Buchanan & Brock (1989), 215-260.

<sup>115</sup> Weithorn & Campbell (1982), 1596.

<sup>116</sup> Terminology used by Ambuel & Rappaport (1992), 133, to distinguish the framework of predictable cognitive and social development from a framework of development dependent on individual and ecological, or environmental, factors.

<sup>117</sup> Weithorn and Campbell (1982), 1596. A typical medication used for epilepsy is Dilantin (phenytoin). Possible adverse reactions that effect bodily appearance include: nystagmus, slurred speech, skin rashes,

Supporting a finding about teens' fear of physical change, a study of renal transplant patients found that several teenage girls voiced an objection to immunosuppressive drug regimen even though the new graft risked a life-threatening rejection. These girls stated that the drugs caused their appearance to be particularly repugnant to them, creating such problems in their social relationships that taking the drugs "was not worth it."<sup>118</sup> Many factors that may affect decision making especially among young persons, such as considerations of body image, self-esteem, peer and family acceptance, general affect, and judgment, are noticeably absent from a Piagetian framework that is largely cognitively focused.

#### Non-Piagetian research and 'maturity'

A handful of qualitative studies, widely distant from a Piagetian framework, have tried to establish the competence and wisdom of children who find themselves faced with premature death from cancer or with intrusive medical treatments or procedures for chronic conditions. Myra Bluebond-Langner, in her anthropologic study of children suffering from cancer, found that children as young as five years had a very vivid understanding of their illness, their options, and their likely death at an early age.<sup>119</sup> Sadly, these children often lived their remaining days in an unspoken collusion with parents who refused to accept that their children knew they were hopelessly ill.

Bluebond-Langner's work is especially important in demonstrating that even young

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coarsening of facial features, and gum hypertrophy. *Physicians' Desk Reference*, 57, 2003, Montvale, NJ: Thompson PDR, 2531-51969-70.

<sup>118</sup> Korsch, B.M., Fine, RN, & Negrete, VF (1978). "Noncompliance in Children with Renal Transplants." *Pediatrics*, 61, 872-76, especially pp. 872 and 874.

children have a rudimentary ability to understand their predicament and ought to be informed about it.

Priscilla Alderson goes further in trying to show that children not only ought to be kept apprised of their conditions but should have a hand in deciding what will be done to them. Her sociological study of 120 young patients, their parents, and 70 health professionals suggests that capacity develops, or is at least demonstrated, in response to experience and high expectations of the child's participation.<sup>120</sup> Alderson, who vigorously opposes the Piagetian framework,<sup>121</sup> concludes that competence, which she broadly defines as being informed and wise, does not develop gradually and predictably over time by ages or stages.

Few children in Alderson's orthopedic study were facing life-or-death interventions.<sup>122</sup> Of those facing life-extending surgery, all of the children said they would agree to it. However, Alderson's interview with a nurse on the heart-lung transplant unit provided anecdotal evidence of children as young as seven being able to authoritatively refuse transplant surgery. Upon being asked about the understanding of these children, the nurse responded: "They are the most sure, mature children. They're physically immature, but their understanding of life-and-death knocks spots off us. I

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<sup>119</sup> Bluebond-Langner, M. (1978). *The Private Worlds of Dying Children*. Princeton: Princeton Univ. Press.

<sup>120</sup> Alderson, P. (1993).

<sup>121</sup> Alderson, P. (1992), 120-1.

<sup>122</sup> Some types of proposed life-extending interventions include a lung transplant for cystic fibrosis or a heart transplant for severe heart disease. Alderson, P. (1983), 159-63.

think they're immature in some of their attitudes, but their understanding of their own well-being and what life is all about is mature.”<sup>123</sup>

The qualitative, phenomenological research by Bluebond-Langner and Alderson was conducted with chronically ill children. In Bluebond-Langner's work with oncology patients, the children had been undergoing treatment for some time, treatment that often has horrific side effects. Alderson's work primarily with orthopedic patients looked at children who had sustained frequent orthopedic surgeries primarily for congenital disorders. A relevant question is whether experience with disease and its treatment privileges chronically ill children to a competency status where they would be better qualified to decide on life-saving treatment than would non-experienced teens.

The well-known aphorism that is bandied about pediatric cancer wards - “maturity comes in a bottle” (of chemotherapeutic infusion) - seems to have some common-sensical basis in reality. But we can also intuit that these young people, although mature in talking about their disease, may lag behind in other areas. For example, children who must not risk infection or injury may not be able to participate in activities that afford opportunities to develop social maturity. However, since capacity in the informed consent model primarily looks at attributes of understanding and reasoning, their cognitive ability to incorporate necessary information about their disease process may enable them to appear as competent decision makers who satisfy the elements of informed consent. Because the informed consent framework features a cognitively-based decision making capacity, it is conceptually unable to alert providers to other areas of

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<sup>123</sup> Alderson, P. (1983), 162.



immaturity. Intellectual dexterity may, in part, inflate these children's appearance of competency. Similarly, previously healthy adolescents who are acutely diagnosed with a potentially fatal disease may have 'different' kinds of maturity which could compensate for their lack of disease savviness and still result in the appearance of a capable decision maker.

Maturity is clearly a relative concept, influenced by many factors, including the circumstances that have led the adolescent to articulate a treatment preference.<sup>124</sup> It has no established role in determining capacity or in the informed consent framework. Child rights advocates argue that by dwelling on a demonstration of maturity in adolescents, we hold them to a higher standard than we do adults, some of whom are very 'immature' but are nevertheless able to give informed consent or refusal if they are deemed to meet the criteria. Statutory provisions and judicial reference to the 'mature minor' do not establish that maturity is a quantifiable or readily distinguishable characteristic. Indeed the 'mature minor' category may reflect political agendas and social utility. The concept of maturity alone is not sufficient to determine adolescent decision making capacity separately from cognition. Consideration of maturity is augmented by several interdependent concepts that contribute to a comprehensive understanding of adolescent decision making capacity. The next section examines the concept of judgment.

#### Adolescents' judgment in decision making

The discomfort we have in allowing teenagers to refuse treatment with life-or-death implications may be a reflection of a societal intuition that adolescents make poorer

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<sup>124</sup> Oberman, M. (1996), 129.

choices than adults.<sup>125</sup> Cognitively-focused research, however well-designed, fails to account for the psychosocial aspects of differences between adults and adolescents. As an example, recall that in Weithorn and Campbell's study, adolescents as young as 14 years old displayed decision making skills similar to those of adults, especially in the areas of reasoning and understanding.<sup>126</sup> However, in the area termed "'reasonable' outcome of choice", the same group showed statistically significant differences in how their responses correlated with the responses a hypothetical 'reasonable' person might give.<sup>127</sup> The differences were surmised to be due to worries about resultant physical appearance if a certain recommended treatment were undertaken.<sup>128</sup> So, although the reasoning process of these adolescents was similar to that of adults, concerns about body image were different. This unsurprising finding tends to be minimized by those eager to uphold the similarities between adolescent and adult decision making. In response to worries that the informed consent model fails to adequately account for differences between the two, Elizabeth Scott offers the concept of 'judgment' as a non-cognitive distinguishing factor between adolescent and adult decision making.<sup>129</sup>

At first glance 'judgment' appears to exude an ambiguity similar to the slippery concept of maturity. Scott and colleagues submit that a judgment framework, including not only understanding and reasoning ability, but also other subjective factors that drive

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<sup>125</sup> Scott, E. (1992), 1636.

<sup>126</sup> Weithorn, L. & Campbell, S. (1982).

<sup>127</sup> Weithorn, L. (1982), 90

<sup>128</sup> Alderson, P. (1983), 162.

<sup>129</sup> Ibid; Scott, E.S., Reppucci, N.D., & Woolard, J.L. (1995). "Evaluating Adolescent Decision-Making in Legal Context." *Law and Human Behavior*, 19, 221-244. This latter article elaborates many ideas first presented in Scott (1992).

the choices of adolescents and adults, eludes any kind of competency testing in the informed consent model.<sup>130</sup> One might ask if focusing on adolescent judgment is justified when the legal capacity of adults is not evaluated this way. Recall that child rights advocates ask a similar question about ‘maturity’.

Scott and colleagues present two arguments to justify an emphasis on adolescent judgment.<sup>131</sup> First, the informed consent framework presupposes that most adults will use good judgment in making their health care decisions. Hence, the social benefit of respecting the autonomy of adult decision makers overrides the social burden of those few ‘outliers’ who choose poorly. But if adolescents, as a group, choose poorly, there is substantial social cost. A second argument reflects the assumption that adults make their decisions, however ‘good’ or ‘bad,’ based on individual values and preferences. In the case of adolescents, their values and preferences are presumed to be based on age-related developmental characteristics that will change with maturity. There is thus a good reason to protect their prospects as adults from immature and youthful judgment.<sup>132</sup>

Another argument for rejecting a purely cognitive-based approach to informed consent and refusal for adolescent life-and-death decision making might even take us beyond a ‘judgment’ metaphor. ‘Judgment’ gives an impression of evaluating the self-determining status of adolescents. Laurence Steinberg and Elizabeth Cauffman, like Scott, argue that disparities in judgment between adolescents and adults are due to a variety of cognitive

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<sup>130</sup> Scott, E.S., Reppucci, N.D. & Woolard, J.L. (1995), 237.

<sup>131</sup> Ibid.

<sup>132</sup> Laura Purdy (1992) makes a similar argument in *In Their Best Interest? The Case Against Equal Rights for Children*.

and psychosocial influences that are developmental in nature.<sup>133</sup> Because Steinberg and Cauffman expand on Scott's judgment framework, their general model of 'maturity of judgment' will be described here.

Multiple factors related to 'maturity of judgment' likely influence decision making. Steinberg and Cauffman, both ecologically-oriented, developmental psychologists,<sup>134</sup> posit that these factors fall into one of three categories of over-arching dispositions: 1) responsibility, entailing autonomy and independence, self-reliance, and clarity of identity; 2) temperance, incorporating the abilities to curtail impulsivity and seek advice; and, 3) perspective, including the ability to acknowledge the complexity of a situation, as well as, being able to envision a larger context.<sup>135</sup> They offer a thorough literature review of research relevant to each of the three dispositions.

For the first disposition, responsibility, the authors conclude that developmental research is insufficient across adolescence and young adulthood to warrant conclusions about specific ages to pinpoint shifts in responsibility.<sup>136</sup> On the disposition of temperance, Steinberg and Cauffman note that although research is scant, there is an indication that adolescents have greater difficulty controlling their impulses than do

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<sup>133</sup> Steinberg, L. & Cauffman, E. (1996). "Maturity of judgment in adolescence: Psychosocial factors in adolescent decision making." *Law and Human Behavior*, 20, 249-272. See also Cauffman, E. & Steinberg, L. (1995). "The Cognitive and Affective Influences on Adolescent Decision-Making." *Temple Law Review*, 68, p. 1763.

<sup>134</sup> For Steinberg and Cauffman, an ecological orientation influences their work by noting that an "individual's maturity of judgment must be evaluated in light of a particular decision and a specific situation." As developmental psychologists, they consider whether developmental trends in maturity "may inform discussions of adolescent decision making across a variety of legal contexts." See Steinberg & Cauffman (1996), 252.

<sup>135</sup> Steinberg, L. & Cauffman, E. (1996), 252.

<sup>136</sup> Ibid, 258.

adults. One reason for this appears to be greater mood volatility. But, once again, a paucity of studies spanning mid- to late-adolescence provides little insight into when the adolescent may have her moods and impulses under better control.<sup>137</sup>

The final disposition, perspective, reveals a greater concentration of research on a wider age span. Evidence appears to indicate that during adolescence, children become less egocentric. A cluster of studies demonstrates that, by mid-adolescence, some domains of the perspective disposition, such as formal reasoning and moral reasoning, appear already fixed. In terms of the domain of future time perspective, research appears to indicate continued development beyond mid-adolescence through the last year of college. Steinberg and Cauffman caution however that since none of this research was linked to the judgment concept, it is difficult to infer how perspective might relate to the decision-making abilities of adolescents and adults.<sup>138</sup>

Developmental research reviews, such as those by Steinberg and Cauffman and Mann, Harmoni, and Power,<sup>139</sup> lament the paucity of research on psychosocial factors in adolescent decision making. The authors are particularly troubled by research methodologies that focus on a discrete age range within adolescence, as opposed to a comparative methodology that spans adolescence and early adulthood.<sup>140</sup> Such studies

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<sup>137</sup> Ibid 262.

<sup>138</sup> Ibid, 267.

<sup>139</sup> Ibid; Mann, L., Harmoni, R., & Power, C. (1989). "Adolescent Decision-Making: The Development of Competence." *Journal of Adolescence*, 12, 265-278.

<sup>140</sup> The span of age covered by Weithorn & Campbell is, of course, one of the highly favored qualities of their study. They demonstrated that cognitively, competency of 14 year old is similar to that of 18 and 21 year olds.

would be extremely useful in evaluating similarities and differences in decision making as adolescents move into adulthood.

The idea that proof of greater decision making dexterity is demanded from children and adolescents than from adults merits serious attention. Competent adults are legally at liberty to make poor decisions. It is the task here to examine whether adolescents ought to have similar liberty. Another limitation of these studies is that they look at healthy adolescents outside of a health care context. A more complete picture of adolescents' maturity of judgment needs to examine domains within a health care context among children who are chronically or acutely ill.

Aside from a small number of qualitative studies focusing on the ill child's understanding of her disease, few studies look at elements of the informed consent process among ill children. Of note is a study reported by Dorn, Susman, and Fletcher<sup>141</sup> on 44 boys and girls ages 7 to 20 years. Twenty of the children were admitted to an inpatient pediatric unit for experimental treatment of cancer. The remaining children were admitted for an intensive experimental treatment of extreme obesity. The participants and their parents received verbal and written explanation of the experimental studies for which they were admitted. The researchers returned days later to test the children on knowledge of research participation, their perceived control of the situation, their state of anxiety, and their stage of cognitive development according to a Piagetian measure. Surprisingly, age and cognitive development did not significantly affect the

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<sup>141</sup> Dorn, L.D. Susman, E. J. & Fletcher, J.C. (1995). "Informed Consent in Children and Adolescents: Age, Maturation and Psychological State." *Journal of Adolescent Health*, 16, 185-90.

children's knowledge about research participation. Rather, those children who scored a higher perception of control had a correspondingly higher knowledge of research participation.

In an earlier publication, Susman, Dorn, and Fletcher<sup>142</sup> specifically looked at reasoning about illness among the same sample, as well as a comparison group of healthy children and adolescents. Consistent with a stage approach to development, they found that the stage of cognitive development accounted for more variation in reasoning about illness, generally, than any other measure. Their sole emotional factor of anxiety had no effect on reasoning. Patients' perception of locus of control accounted for significant variation in the stage of reasoning about their own illness. In this study, it appears that cognitive testing is consistent with the Piagetian developmental framework. However, factors such as perception of control introduce variables not readily accounted for in a cognitively-focused model.

A qualitative study by Janet Deatrck examined how adolescents who were asked to participate in orthopedic surgery decisions felt about being involved in the decision.<sup>143</sup> Semi-structured interviews were performed with twenty-four boys and girls, together with their parents. The adolescents had a mean age of 14 years and an average of 3 previous hospitalizations and surgeries each. For the most part, the adolescents found it to be positive that their parents and health care givers wanted to involve them so much in

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<sup>142</sup> Susman, E.J., Dorn, L.D., & Fletcher, J.C. (1992). "Participation in Biomedical Research: The Consent Process as Viewed by Children, Adolescents, Young Adults, and Physicians." *Journal of Pediatrics*, 121, 547-52.

<sup>143</sup> Deatrck, J.A. (1984). "It's Their Decision Now: Perspectives of Chronically Disabled Adolescents Concerning Surgery." *Issues in Comprehensive Pediatric Nursing*, 7, 17-31.

deciding whether and when to have surgery. However, Deatruck points out that the adolescents were troubled that parents and staff did not acknowledge the difficulties they had in deciding. "In particular, adolescents described difficulties interpreting the varying opinions of physicians and handling their parents' spoken or unspoken desires...while the adolescent's involvement helped parents to feel better about the decision, it made the adolescents feel worse in some respects."<sup>144</sup>

A probe into the adolescent's ability to make life-and-death decisions must also consider the teen's understanding of the concept of death. In reviewing more than 50 studies that have examined children's understanding of death, Speece and Brent conclude that by age 10 most children have a mature, cognitive understanding of death based on a set of relatively distinct components. Three of the most widely studied components are: 1) universality (an understanding that all living things die); 2) irreversibility (the physical body of a living thing that has died cannot be made alive again); and, 3) nonfunctionality (understanding that all life-defining functions cease at death).<sup>145</sup>

Myra Bluebond-Langner's interviews with fatally-ill children revealed that these children's acquisition of a mature understanding of death depended on a number of factors, including the child's experience with illness, temporal concerns, life circumstances, and self-concept.<sup>146</sup> Susan Jay and colleagues and John Spinetta have reviewed studies of children with life-threatening illness concluding, respectively, that such children have an advanced understanding of the concept of death and that fatally-ill

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<sup>144</sup> Ibid, 26.

<sup>145</sup> Speece, M. W. & Brent, S. B. (1992). "The Acquisition of a Mature Understanding of Three Components of the Concept of Death." *Death Studies*, 16, 211-229, p. 211.



children were more aware of death than chronically ill children.<sup>147</sup> Elizabeth Kubler-Ross' work with dying children indicates that the poems and drawings of terminally ill children show an acute awareness of their imminent death.<sup>148</sup> She notes that "all children know (not consciously, but intuitively) about the outcome of their illness."<sup>149</sup> Interviews with dying children often illustrate how much children know in spite of how little we tell them.<sup>150</sup> Experience with death is discussed here as a separate consideration in evaluating adolescents' ability to make life-or-death treatment decisions. I submit, however, that experience with the dying of others who had the same disease can be folded into the earlier life experience and maturity discussion. Such knowledge and understanding of death can expand the adolescent's frame of reference about the consequences of her refusal of medical intervention. Adolescents newly diagnosed with a potentially fatal illness will not have a compatible personal context to explore their understanding of what the disease entails, although they may have more or less acquaintance with the dying and death of friends or family members.

Giving children and adolescents information so that they may make an informed decision is another necessary element of the informed consent process. Providing information about specific proposed treatments by health care professionals and parents, together with the adolescent's understanding of such information, are distinct elements of the informed consent process but are also inextricably woven into the cognitive features

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<sup>146</sup> Bluebond-Langner, M. (1978), 52-3.

<sup>147</sup> Jay, S. M., *et al.*, (1987). "Differences in Death Concepts between Children with Cancer and Physically Healthy Children." *Journal of Clinical Child Psychology*, 16, 301, pp.301-2; Spinnetta, J. J. (1989). "The Dying Child's Awareness of Death: A Review." *Psychological Bulletin*, 81, 256.

<sup>148</sup> Kubler-Ross, E. (1983). *On Children and Death*. NY: Macmillan.

of decision making capacity. The information must be available or dispensed before it can be understood by a cognitively capable decision maker. The 1995 position statement by the American Academy of Pediatrics' Committee on Bioethics maintains that even though the informed consent doctrine has only limited direct application in pediatrics, providing information to the child or adolescent and parents is mandatory.<sup>151</sup> The Committee argues that although older children and adolescents are not in a legal position to give informed consent or refusal because of their minority, their assent should be sought for any and all treatments. Strategies for gaining such assent include: 1) helping the child patient gain a developmentally appropriate awareness of her condition; 2) telling the patient what he or she can expect with treatments; and, 3) assessing the patient's understanding of the information and what factors might be influencing her responses. The Committee notes that there are clinical situations where the youngster's persistent refusal to assent, or dissent, ought to be ethically binding. The parents' role in this assent process is one of permission.<sup>152</sup> The Committee supports the suggestion of the limited empirical data that adolescents age 14 and older may have as well developed decisional skills as adults for making informed health care decisions. Teens of this age may indeed engage in informed consent, where no parental permission requirement

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<sup>149</sup> Ibid, 1.

<sup>150</sup> See also Bluebond-Langner, M. (1978).

<sup>151</sup> Committee on Bioethics, American Academy of Pediatrics (1995).

<sup>152</sup> The American Academy of Pediatrics' Committee on Bioethics (1995) sees that parental permission articulates what most would agree represents the 'best interests of the child,' p. 315. The concept of 'best interests' will be examined in the next chapter.

obtains. However, the Academy continues to suggest parental involvement as appropriate.<sup>153</sup>

### Reflections on Points One and Two

This broad review of adolescent developmental data leaves us in the uncomfortable, untidy position of acknowledging that, criticisms aside, Piaget's theories of children's cognitive development appear to provide an empirical framework for research that supports thinking about most adolescents as attaining decision making capacity at about age 14 or 15. In fact, some research, especially about the understanding of death concepts, appears to point to even younger minors being able to make personal decisions. However, the claim that adolescent decision making competence involves more than cognitive capacity is also valid. Unfortunately, research in this area is limited by an inadequate understanding of the psychosocial factors involved, and how they might best be studied. Hence, there is insufficient evidence to reject the findings of cognitive studies. Nonetheless, this research does supplement the debate on competency by recognizing environmental and psychosocial influences that affect children as they pass through adolescence.<sup>154</sup> Wallace Mlyniec fuels the debate when he quips that "Piaget's cool calculating fifteen-year-old appears to be subject to some very hot influences during adolescence."<sup>155</sup>

One reason why we are entangled in this web of understanding adolescent capacity stems from the desire to adapt the informed consent doctrine to individuals who are only

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<sup>153</sup> Ibid, 317.

<sup>154</sup> Mlyniec, W. J. (1996). "A Judge's Ethical Dilemma: Assessing a Child's Capacity to Choose." *Fordham Law Review*, 64, 1873-1915, p.1884.

beginning to develop into young adults. Informed consent, which finds its moral foundation in the principle of respect for autonomy, is an ambiguous concept, designed to protect the liberties of patients from overzealous paternalistic physicians. To the extent that older children and adolescents are in a moral position to receive and understand information about their condition, the informed consent element that requires health care professionals to provide such information is highly applicable. But whether the adolescent should be considered a capable and autonomous decision maker about treatments with life-and-death consequences remains unsettled.

So far, I have proposed two points of consideration about the question of adolescent decision making capacity. The first point of consideration addressed the ambiguity of the capacity concept as applied to adults, whose capacity is presumed. Efforts at developing ‘capacimeters’ are plagued by a competition between relevant internal and external values - of what capacity means in a particular case and what it means to others. Attempts to apply imperfect rating instruments to adults with questionable capacity raise the concern that such instruments may also be applied to adolescents as a group.

The second point addressed in this chapter examined the validity of founding the adolescent’s claim to decision making capacity in the construct of cognitive functioning. Advocates appeal to the cognitive similarity of adolescent decision making with that of adults in maintaining that adolescents ought to pass that ‘ultimate test of autonomy’ by having a right to make decisions concerning life-sustaining treatments about

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<sup>155</sup> Ibid.

themselves.<sup>156</sup> Most empirical research has been guided by a Piagetian developmental model which lends itself to conformity with the features of a capable decision maker: ability to express a choice, understanding, and reasoning ability. However, there are other psychosocial features, many of which distinguish the *Sturm and Drang* of adolescence from adulthood, that are not acknowledged in such research.

The task of illustrating the misguided emphasis on adolescent decision making capacity has not captured the roles of others who are involved in the decision making about the adolescent. In pediatrics, the parents and family and the clinicians, representing the state, form the other sides of a triadic guidance approach targeting interests and responsibilities. I offer two additional points of consideration in the problem of adolescent life-and-death decision making capacity that address the role of the family and health care providers.

*Point Three: What Does Adolescent Decision Making Capacity Say about Autonomy and the Role of the Family?*

The third consideration relates to adolescent capacity, insofar as what assessing such capacity in the context of the informed consent doctrine says about the possible autonomy of the teenager and his or her role in the family. Whether or not an adolescent is deemed to have capacity and autonomy does not tell the whole story of how the life-and-death decision is made. In the case of adults, satisfying the element of capacity within the informed consent model presumes that the patient is an autonomous, self-determined decision maker with a stable sense of self, established values, and mature

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<sup>156</sup> Reference to Jennifer L. Rosato's (1996) title, "The ultimate test of autonomy: Should minors have a

cognitive skills.<sup>157</sup> For adolescents, the element of decision making capacity is not clearly satisfied, nor is the autonomy of an adolescent a presumed expectation of cognitive dexterity.

Providing a context for establishing a sense of self and a values system is a primary role of the adolescent's family. A parent-child mutuality that is rooted in nurturance and loyalty reflects the interactive roles and responsibilities in family life.<sup>158</sup> Children and adolescents have the benefit of living within the context of a family, wherein parents, siblings, and other relatives pay an extraordinary amount of attention to their welfare. Admittedly, this ideal scenario does not exist for all young people, but for purposes of this project I will assume that it exists for most.<sup>159</sup> Perhaps, then, it is not too much of a stretch to suggest that adolescent life-and-death decision making ought to be centered in the context in which the adolescent lives - the family - rather than centered in the person of the adolescent, who is only just developing a sense of autonomous personhood.

*Point Four: The relationship between health care providers, family, and the adolescent facing life and death*

The fourth and final consideration of capacity as it impacts adolescent life-and-death decision making involves the role and relationship of health care providers vis-à-vis the adolescent and family. I have argued that the unsettled status of adolescent decision making capacity should discourage an emphasis on adolescent autonomy. For this

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right to make decisions regarding life-sustaining treatment?" See note 14.

<sup>157</sup> Harrison, C., Kenny, N.P., Sidarous, M., & Rowell, M. (1997). "Bioethics for Clinicians: 9. Involving Children in Medical Decisions." *Canadian Medical Association Journal*, 156, 825-8, p. 825.

<sup>158</sup> Murray, T. (1996). See note 62 and accompanying text.

reason, a proper context for such decision making lies within the family relationship. In addition, Point Four notes that expanding the relationship to include health care providers facilitates the forming of a therapeutic alliance.<sup>160</sup>

As was briefly discussed in an earlier section and will be more fully expanded in Chapter Five, a therapeutic alliance ought to be initiated by the health care providers. Providers, in recognizing their own obligation of beneficent practice, foster the family's duty to protect the adolescent's present and future interests in the face of life-and-death decision making. The principle of beneficence-in-trust, the foundation of the triadic approach to be developed herein, points to a recognition of the fiduciary obligation of providers to act in the best interests of the patient, and thereby the family.<sup>161</sup>

We have not – and can not - then, completely dismiss the problem of adolescent decision making capacity as we close this chapter. Advocates for respecting adolescent decision making capacity and authority - regardless of the decision to be made - will continue to appeal to the bioethical principle of respect for autonomy based on cognitive criteria of capacity. Points Three and Four in this chapter – the role of the family and the fiduciary relationship with providers – will be developed as two integral elements of a triadic approach to adolescent life-and-death decision making. The adolescent facing life-and-death – her interests, roles, and responsibilities – comprises the third element of the triadic approach and is the subject for the next chapter. By conceptualizing the

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<sup>159</sup> In the law, the authority of parents as protectors and those who know the child's 'best interests' is presumed. For a discussion on the trials of adolescents without parents or guardians, see *The Adolescent Alone: Decision Making in Health Care In The United States* (1999). NY: Cambridge University Press.

<sup>160</sup> See Miller, R.B. (2003).

<sup>161</sup> Pellegrino, E. D. & Thomasma, D.C. (1988).

adolescent facing life-and-death as residing on one side of a triangle, the emphasis on her decision making capacity and autonomy diminishes. It also reinforces the responsibilities of the parents and health care providers, as representatives of the state, in ensuring that appropriate considerations are applied in decision making about an adolescent's life-and-death situation.



## CHAPTER 3

### **Adolescents' Interests, Rights, and Responsibilities in Making Life-and-Death Decisions about their Medical Treatment**

This chapter begins an exploration of each component of the triadic approach for adolescent life-and-death decision making. An examination of interests, rights, and responsibilities of ill adolescents refusing to undergo life-saving medical treatments will serve as a starting point for examining these concepts and their interface within the other components in the triadic approach. In the previous chapter, our current understanding of adequate decision making capacity to consent to, or refuse, treatment, was shown to have a misplaced emphasis on an adolescent's cognitive appreciation of the particular situation and decision being faced.

Although some, or even many, adolescents meet the generally understood legal elements of decision making capacity, it is not clear those elements are ethically sufficient. The capacity elements have widespread use in health care and the law. These elements broadly include: 1) the ability to express a choice; 2) the ability to understand information relevant to treatment decision making; 3) the ability to appreciate the significance of that information; and 4) the ability to reason with relevant information.<sup>1</sup> Explicitly missing from these cognitively-based capacity elements are considerations of "life experience," maturity, and judgment<sup>2</sup> - considerations which have an unknown

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<sup>1</sup> Grisso, T., & Appelbaum, P.S. (1998). *Assessing Competency to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York: Oxford University Press, 23-6.

effect on the adolescent's ability to make a meaningful, future-oriented decision about herself.

Unfortunately, emphasizing the adolescent's limited life experience and untested judgment skills does not necessarily illuminate the adolescent capacity problem. Rather, such an emphasis may serve to marginalize children and adolescents from decision making about their medical care, since their temporal life experience, relative to that of adults, is limited. We are left, then, in what appears to be an irreconcilable position.

If we were to agree that life experience should be a necessary element in decision making capacity, we may be requiring more of seriously ill adolescents than we might of seriously ill adults faced with similar types of decisions. Health care and the law have generally dealt with the problem of adolescent decision making by appealing to adolescents' rights and autonomy. The phrase, 'mature minor,' invokes the possibility of respecting an adolescent's refusal of life-saving treatment in the same way as we would an adult's refusal, even though qualities like judgment and experience are overlooked and the courts have avoided even defining 'maturity'.<sup>3</sup> The difficulty of attributing these characteristics to adolescents offers further reason for not allowing them decision making authority for life-and-death medical interventions. I argue that handing adolescents life-and-death decision making rights, which are deemed to be an adult prerogative, is a disservice for which their youth leaves them unprepared and vulnerable.

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<sup>2</sup> Elizabeth Scott advances the concept of judgment as a criterion for decision making capacity. Scott, E. (1992) "Judgment and Reasoning in Adolescent Decision Making." 37 *Villanova Law Review* 1607.

<sup>3</sup> Redding, R.E. (1993). "Children's Competence to Provide Informed Consent for Mental Health Treatment." 50 *Washington & Lee Law Review* 695, p. 715, note 129.

Let us revisit the scenarios of two boys presented in the last two chapters. AJ finds himself in an acute exacerbation of a life-long inevitably fatal disease. The other boy, BJ, finds himself newly diagnosed with a catastrophic life-threatening disease. Both boys refuse medical treatment that could save their lives. It is arguable that the basis of AJ's refusal is his feeling that he "can not tolerate another day of illness and/or treatment."<sup>4</sup> It might also be arguable that BJ's refusal, because he is new to life-altering illness, is based on fear and refusal to contemplate continued life without an intact body. Perhaps we may surmise that at least one of their common interests in the setting of each scenario is to not be inflicted with painful treatments and procedures even if they were to be life-saving or -prolonging. One question asks if such an interest points to a right for their life-or-death treatment refusals to be respected by their families and by their health providers. A follow-up question asks whether, if there were such a right, both boys would have it to the same degree.

Intuitively, the differences between AJ and BJ making decisions about life-or-death treatment seem to come down to their experience. However, it is unclear what type of 'experience' is meant. AJ has gained his experience by virtue of the unfortunate illness he was born with. Perhaps nonrebuttable decision making authority ought to be viewed as his consolation, maybe even his right, for having tolerated years of medical intervention. If so, perhaps the contrary ought to be considered for BJ who is very 'new' to serious illness and has not had life-long medical intervention. It is not evident from the case whether BJ may have vicarious 'experience' with illness or hospitalization by

way of a close relative or friend. Such second hand experience can profoundly shape BJ's thinking about his own proposed treatment and ought not be dismissed as inconsequential.

We have already considered the possibility that chronically ill teens, subjected some, most, or all of their lives to countless treatments and procedures, are 'forced' to mature at a rate far faster than their well peers.<sup>5</sup> The adolescent acutely diagnosed with life-threatening disease would not have the same hospital savviness, based on personal experience, as would a chronically ill child. We wonder if the chronically ill adolescent 'deserves' more respect for autonomy in making his or her own decisions about life-saving treatment and if the acutely ill adolescent 'deserves' less respect for autonomy in making similar decisions. Worthy of consideration, however, is whether the experience with illness and death must be a personal one. Although BJ may not have had personal experience with illness, pain and suffering, he may have witnessed the hospitalization and medical care of a close family member or friend. By discounting the amount of 'respect for autonomy' he deserves because of his inexperience with personal illness, we fail to acknowledge how he may have internalized his exposure to others' protracted illness, death and dying. I argue that autonomy is a straw man in this scenario, complicating the discussion by virtue of its ambiguity in the adolescent setting.

### **Interests of Adolescents with Serious Illness**

To speak of adolescents' interests in accepting or refusing life-or-death treatment is

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<sup>4</sup> Phrase borrowed from Penkower, J. (1996). "Comment: The Potential Right of Chronically Ill Adolescents to Refuse Life-Saving Medical Treatment – Fatal Misuse of the Mature Minor Doctrine." 45 *DePaul Law Review* 1165, p. 1165.

<sup>5</sup> See discussion in Chapter 2, especially text corresponding to footnotes 122-7.

to speak of what matters to them in the scenario at hand. A practical problem faced by parents, health care providers, and the adolescents themselves when they refuse life-saving treatment is that the adolescents are teen-agers first and patients second.<sup>6</sup> As teenagers, adolescent patients must deal with the usual emotional upheavals surrounding appearance, peer group, and relationships with family that are complicated enough when the teen is physically healthy. Working through issues of dependence on parents, while at the same time striving for independence and a search for personal identity, proves a challenge to almost every young person. The tense dynamic is further complicated by the problem of a life-threatening chronic or acute illness that compounds the adolescent's already high-strung emotional state.

How might the interests of a 'healthy' adolescent compare with those of an adolescent suddenly or chronically confronted with a life-threatening disease? Interests shared between the two include the importance of peer groups and a sense of belonging. The sense of belonging is typified by an intense desire to fit in with friends. This desire relates to a conscious fussing over appearance and arguing with parents who seek to rein in their adolescent. The teen wants to be in charge of her life, a desire in contradiction with the reality that she still needs and wants her parents.

When the 'healthy' adolescent is involved in medical treatment, she is as interested in being included in decision making about her health care as she is in making decisions in the home situation. Chronically ill adolescents have the same developmental needs as

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<sup>6</sup> Slap, G. B. & Jablow, M. M. (1994). "Debating rights of young patients." *New York Times*, November 10, late edition final, Section C, Page 1, Column 1. Highlighting the cases of Billy Best and Benny Agrelo in 1994 in asking whether adolescents have the right to refuse medical treatment. Of course, a sick adult is

other adolescents. Unfortunately, meeting those needs is limited by at least three areas not encountered by the well teen: the relentlessness of chronic disease (being sick); the demands of treatment; and the likelihood of early death.<sup>7</sup> Within these limitations, the chronically ill adolescent continues to struggle with the pursuit of ‘normalcy.’<sup>8</sup> Being able to grasp a sense of what is normal must be difficult when the adolescent’s perception of herself and her place in the world is skewed by an indefinite sick role. In contrast, the acutely diagnosed adolescent is suddenly confronted with a realization that ‘normalcy’ no longer exists in the way she knew it. The former ‘normal’ world is abruptly threatened with pain, permanent bodily impairments, and death. In light of these ‘distractions,’ claiming that adolescents have a right to, and should, make the ultimate decision about life-saving medical treatment suggests a moral insensitivity to their needs for support and protection.

#### *Dynamics of chronic illness in adolescence*

Psychosocial research on adolescents with chronic illness reflects a shift toward recognizing that chronically ill adolescents encounter similar challenges regardless of the particular characteristics of their condition.<sup>9</sup> Much recent research also compares healthy teens with cohorts of chronically ill teens diagnosed with diverse diseases. The literature tends to distinguish chronic-inevitably-fatal diseases, such as cystic fibrosis and cancer, from other menacing, largely disabling, but non-fatal conditions, such as diabetes

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also a person first and patient second. However, the presumed innocence of adolescents, by virtue of their age, and society’s protective sensibilities towards them, makes their situation arguably more compelling.

<sup>7</sup> Penkower, J. (1996), especially pp.1211-15.

<sup>8</sup> Ibid.

<sup>9</sup> Wolman, C., Resnick, M. D., Harris, L. J., & Blum, R. W. (1994). “Emotional Well-Being among Adolescents with and without Chronic Conditions.” *Journal of Adolescent Health* 15, 199-204, p.199.

mellitus. One of the largest recent studies compared almost 1,700 chronically ill adolescents with 1,650 'well' adolescents with a mean age of fifteen years. Wolman and colleagues found that adolescents with chronic conditions did less well than their peers without chronic conditions on a number of psychological outcomes: emotional well-being, worries and concerns, and body image.<sup>10</sup> For chronically ill adolescents, a healthy body image rated slightly higher than family connectedness as a source for emotional well-being. For adolescents without chronic conditions, family connectedness rated higher than body image. The authors suggest these findings show that regardless of disability or chronicity, strong emotional development is associated with a strong sense of self and strong family cohesion and support.

Another study looked at whether adolescents in matched groups, by gender and age, manifested comparable psychosocial difficulties of teens with cystic fibrosis, diabetes, and well controls.<sup>11</sup> The mean age was slightly over 14 years. Using standardized instruments and semi-structured interviews, the findings reveal that adolescents with cystic fibrosis and diabetes perceive that they have adequate social support, are socially competent, feel in control of their lives, and use similar coping mechanisms as healthy control adolescents. The interview process revealed that adolescents with serious chronic disease, regardless of disease type, consider the illness to have a detrimental impact on certain aspects of their daily life. The chronically ill adolescents, particularly those with cystic fibrosis, expressed concern about their future health. They especially had fears about dying. In addition, these adolescents were worried about the impact of

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<sup>10</sup> Ibid.

their health status on their parents, siblings, and relatives. A study of adolescents with insulin dependent diabetes mellitus showed quite different results in measures of life impact.<sup>12</sup> An equal number of boys and girls with a mean age of 16 felt that diabetes was having a moderate impact on their lives, and they had few worries about the disease. The reported impact of the disease on boys and girls was the same, although girls worried about it more. The teens generally perceived a good quality of life, nevertheless clinical depression was highly correlated with lower measures of quality of life.

A qualitative study of 23 middle adolescents with chronic diseases found that the overall theme in these young peoples' lives was: "it's hard".<sup>13</sup> The 23 subjects, ages 13 to 16 years, had chronic diseases that shared the following attributes: the need for daily treatment regimens, periods of stability mixed with periods of exacerbation, and usually a nonfatal illness trajectory. Additional themes revealed by the interview data include: "it takes extra effort", "it's restraining", "it's painful," and "it's a whole bunch of worries". Asked about their perspectives in dealing with the chronic illness, most of the adolescents felt that talking to someone - family and friends were preferred over health professionals – was helpful. Most helpful was talking one on one with another adolescent also living with the same illness. Some adolescents felt it was important that they recognize that individuals without a chronic illness cannot understand what they are going through. The adolescents used different strategies to try to develop or maintain a positive sense of self.

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<sup>11</sup> Capelli, M., McGrath, P. J., Heick, C. E., Macdonald, N. E., Feldman, W. & Rowe, P. (1989). "Chronic Disease and its Impact: The Adolescent's Perspective." *Journal of Adolescent Healthcare*, 10, 283-288.

<sup>12</sup> Grey, M., Boland, E. A., Chang, Y., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). "Personal and family factors associated with quality of life in adolescents with diabetes." *Diabetes Care*, 21(6), 909-914.

<sup>13</sup> Woodgate, R. L. (1998). "Adolescents' Perspectives of Chronic Illness: 'It's Hard.'" *Journal of Pediatric Nursing*, 13(4), 210-23.



These findings are also borne out in a study of adolescents with cystic fibrosis who needed to discover a new baseline in comparing themselves, not to healthy peers, but to other adolescents with cystic fibrosis.<sup>14</sup>

Important themes of family support and positive self-image appear as concomitant elements to the adolescent's adjustment to chronic illness. Family and adult support is also a theme in pediatric cancer, which is often classified as a chronic illness because of its increasingly non-fatal trajectory. Results of a study of 70 children with cancer matched with 70 control classroom peers showed that children receiving chemotherapy were remarkably similar to case controls on measures of emotional well-being and even better on several dimensions of social functioning.<sup>15</sup> The children with cancer did report a lower athletic self-concept, but the researchers noted that this perception was not pervasive, and could in fact be protective. The researchers speculate that these children's positive social reputation with teachers and peers may be the result of many supportive adults helping the child through repeated stressful experiences during their treatment. The ages ranged from 8 to 15, with a mean age of 11, slightly younger than the reference age for this dissertation. Nevertheless, pre-adolescence and adolescence are marked by development of autonomy and individuation from family. Continuing strong relationships with parents and other adults appear to provide the chronically ill young person with the support needed to cope with the daily vicissitudes of treatment.

### *Dynamics of adolescent life-threatening illness*

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<sup>14</sup> Christian, B., and D'Auria, J. (1997). "The Child's Eye: Memories of Growing Up with Cystic Fibrosis." *Journal of Pediatric Nursing*, 12, 3-12.

The adolescent with life-threatening illness is interested in pursuing independence from parents, but his or her efforts are thwarted by the demands of the disease. Eugenia Waechter describes such adolescents as being bitter, angry, and bewildered.<sup>16</sup> They may be bitter and resentful toward their parents on whom they must now depend even more. Strength, beauty, and body image continue to be ultimate concerns, and as they fail, friends feel too vulnerable and withdraw. The ensuing anger felt by the ill adolescent is perpetuated by a move to set oneself apart to prevent exclusion and pity from friends. Conflicts with parents are intensified with the increased alienation from former friends. According to Waechter's observations, as the seriously ill adolescent becomes more lonely and dependent on parents, she resents her overdependence, and may then reject her parents.<sup>17</sup> Social relations suffer as the teen perceives being viewed differently by peers, finding it difficult to explain more and more school absences, and is mostly unsure if it is worth maintaining close friendships. Conflicts between parents and the ill adolescent become intensified. The adolescent feels her parents are 'babying' her. Out of anger and desperation, she may also begin failing to comply with treatment regimens. An overarching uncertainty about the future contributes to arrested cognitive growth. It is unsurprising that an adolescent faced with such a dismal life picture thinks about death and suicide.<sup>18</sup>

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<sup>15</sup> Noll, R. B., Gartstein, M. A., Vannatta, K., Correll, J., Bukowski, W.M., & Davies, W. H. (1999). "Social, Emotional, and Behavioral Functioning of Children with Cancer." *Pediatrics*, 103(1), 71-8, p. 73, 75, 76.

<sup>16</sup> Waechter, E. H. (1987). "The Adolescent with Life-Threatening Chronic Illness." In, T.Krulik, B.Holaday, I.Martinson (Eds.), *The Child and Family Facing Life-Threatening Illness: A Tribute to Eugenia Waechter*, 190-200. Philadelphia: J.B. Lippincott Co.

<sup>17</sup> Ibid.

<sup>18</sup> See Capelli, M. et al (1989) at note 11.

The psychological dynamics of a seriously ill adolescent have been noted to vary by age. Waechter categorizes her observations for the young and mid-adolescent facing the prospect of death from life-threatening illness.<sup>19</sup> The young adolescent is resentful at the prospect of having a newly opened world closed shut on her. She often does not know where to direct her bitterness and anger and may struggle in isolation. In mid-adolescence, the young person has begun to taste independence and finds the prospect of its being dashed away a cruel reality.<sup>20</sup> Teens in mid-adolescence take great interest in their appearance and are demonstrating high self-esteem as they begin to contemplate their future. A life-threatening illness will, notes Waechter, “strip him of his competency and of his future.”<sup>21</sup> The older adolescent may develop a rage at parents, at health care providers, at the futility of life. Even with open communication, the adolescent patient may direct a sudden rage at family, although the older teen is usually better at controlling these feelings. Waechter points out that the adolescent patient generally explodes when she is the last to find out about a medical treatment to be tried. She is indignant about the lack of communication but often continues to smile at hospital personnel for fear that she will be excluded from decision-making processes in the future.<sup>22</sup>

Clearly, the ordeal of the adolescent with life-threatening illness is agonizingly difficult. Waechter’s observations suggest that very ill adolescents are sensitive to their budding autonomy being pulled out from under them by the prospect of premature death.

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<sup>19</sup> Waechter (1987) does not apply discrete ages to these categories. For some perspective, see Gemelli, R. (1996). *Normal Child and Adolescent Development*. Washington, D.C.: American Psychiatric Press. Early adolescence is from about age 12 to 15 years and late adolescence is from age 16 to 19 years. Also see discussion in Chapter 2.

<sup>20</sup> Waechter, E. (1987), 194.

<sup>21</sup> Ibid.

Their interests in self-determination are couched in the psychological and developmental realities of adolescence. Adolescents, especially those in young and middle adolescence, are developing physically, cognitively, and psychologically. Even though an adolescent may appear to be almost adult and communicate in a ‘grown-up’ manner, he or she lacks, by virtue of youth, experience, judgment, and maturity.<sup>23</sup>

This brief review suggests that the teen with chronic-inevitably-fatal disease may be eager to reduce or eradicate the suffering of the remaining time left. On the other hand, the adolescent acutely diagnosed with a life-threatening illness has little experience of the inevitable pain and discomfort involved in many treatment procedures and is, in all likelihood, very anxious and fearful. The whirl of emotions, fears, and concerns experienced by an acutely diagnosed adolescent cast great doubt on his interest and ability in making a credible life-and-death decision about himself, by himself. Yet, the informed consent elements utilized in medicine and the law rely on cognitive function and can readily be achieved by many, if not most, adolescents. The next section explores the adolescent’s interests relative to illness and decision making.

*Tension between the sick adolescent’s interests and ‘best interests’*

The child-family-state triad is the generally recognized concept affecting minors in health care decision making.<sup>24</sup> An appeal to the child-family-state triad signals the simultaneous consideration of the minor’s best interests, of parental rights and family

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<sup>22</sup> Ibid.

<sup>23</sup> Steinberg, L. & Cauffman, E. (1996). “Maturity of Judgment in Adolescence: Psychosocial Factors in Adolescent Decision Making.” *Law and Human Behavior*, 20(3), 249-272.

<sup>24</sup> Britner, P.A., LaFleur, S.J., & Whitehead, A.J. (1998) “Evaluating Juveniles’ Competence to Make Abortion Decisions: How Social Science can Inform the Law.” *5 Univ. of Chicago Law School Roundtable* 35, p.37.

integrity, and of the state's duties and powers.<sup>25</sup> The triad may incorporate conflicting and possibly extreme perspectives that require delicate balance. Differing perspectives held by parents and health care providers can vary the compositional equality of the child-family-state triad.

As example, three differing perspectives are briefly mentioned. First, a radical, albeit widely accepted, perspective regarding the family is described as 'family libertarianism', which emphasizes parental rights and family privacy. This perspective maintains that parents should have absolute autonomy in raising their children, including making decisions about their medical treatment, since parents have their child's best interests at heart. Second, a common perspective regarding the state is a 'state interventionist' approach to protect the health interests of children who cannot protect themselves. In non-life-threatening cases, the state tends to allow the assertion of parental autonomy.<sup>26</sup> However, in life-threatening situations, the state, drawing on its *parens patriae* power,<sup>27</sup> may occasionally override the parents' refusals of life-saving treatment.<sup>28</sup> Since health care providers are the ones to initiate an action on behalf of the minor when life-saving medical treatment is refused, their interests are seen to merge with those of the state.

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<sup>25</sup> Ibid.

<sup>26</sup> See, for example: *In re: Seiferth*, 127 N.E. 2d 820 (NY 1955) in which the New York Court of Appeals upheld a father's refusal for corrective cleft lip and palate surgery on his 14 year old son. The father professed belief in mental healing forces and the court was reluctant to intervene. See Wadlington, W. (1994). "Medical Decision Making for and by Children: Tensions between Parent, State, and Child." *1994 University of Illinois Law Review* 311, p.318.

<sup>27</sup> Hartman, R.G. (2002) writes that although the history of the *parens patriae* doctrine is rather ambiguous, it has come to mean that the state has an obligation and a right to protect the interests of its legally disabled citizens, those who can't protect themselves, including children. "Coming of Age: Devising Legislation for Adolescent Medical Decision-Making." *28 American Journal of Law & Medicine* 409, p. 905.

<sup>28</sup> Britner, et al. (1998), 38. See *In the Matter of Long Island Jewish Medical Center*, 557 N.Y.S. 2d 239 (1990). Seventeen and one half year old Phillip and his parents refused blood transfusion to treat his cancer. Phillip was deemed immature and his parents' refusal was not upheld.

Finally, a radical perspective regarding the child, the ‘children’s rights’ position, emphasizes the importance of extending to minors some, or all, of the same treatment decision rights enjoyed by adults.<sup>29</sup> This position maintains first, that some minors are competent to make their own decisions and second, that the Supreme Court has rightly extended constitutional protections of privacy to minors over the last three decades. The family and state perspectives are more fully discussed in subsequent chapters. The perspective involving the child is more fully developed here.

Advocates of the ‘child rights’ position in its extreme are termed ‘child liberationists.’ Laura Purdy,<sup>30</sup> in her strong critique of child liberationists who argue for ‘equal rights’ for children, finds that liberationists stress capacities much more than actions. Making future plans involves cognitive capacities, which may, arguably, be present for adolescents. However, acting on such plans involves character traits, or personal qualities that afford the ability to carry out such plans. Purdy terms such character traits as enabling virtues: “they help us get what we want.”<sup>31</sup> These traits include rationality, hard work, and the desire for excellence, all directed toward helping us achieve our goals. This rather Aristotelian conception of the good life is under-girded by the core virtue of self-control, which is the capacity to resist temptations that interfere with a previously set goal. Purdy stresses that it is in children’s interest for limits to be set on their freedom so that they may learn and practice self-control for their future. Self-control is not the only virtue, but it is the one upon which all other enabling virtues are based.

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<sup>29</sup> Ibid., 39.

<sup>30</sup> Purdy, L. (1992). *In Their Best Interest? The Case against Equal Rights for Children*. Ithaca: Cornell Univ. Press.

<sup>31</sup> Ibid., 47.

Purdy submits that children are not necessarily aware of their best interests in either the short or long term. It is therefore the responsibility of the child's guardians or parents, who know most about them and almost always have their best interests at heart, to make such decisions on their behalf. One reason is that the young must be given an opportunity to grow up so that they may eventually avail themselves of their developing autonomy. Allowing them to make life-altering decisions at too young an age, when they do not possess complete or even partial decision making capacity, deprives them of opportunities they may have had. Because children and adolescents cannot make decisions with a view to an as-yet unimaginable future, it is unjust and unethical for us to allow them to do so. Purdy defends a child protectionist stance in most areas in which children are not free to actively participate.<sup>32</sup> I agree with Purdy's view that the language of rights as it involves children and adolescents undermines the parent-child relationship, and diminishes the responsibilities parents have toward their children.

### **Adolescent 'Rights' to Make Serious Health Care Decisions**

One problem with 'rights talk' for adolescents is that it is unevenly actualized in practice. To have a right to do something means at least that no one may intrude on your choice except in very limited circumstances.<sup>33</sup> Such a definition points to a capacity to think rationally, form plans, and make choices. If an individual possesses this capacity or agency he or she is entitled to respect for choices about life to the same degree of respect

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<sup>32</sup> Purdy, L. (1992). Unfortunately, Purdy does not specifically consider the problem of adolescents refusing life-saving treatment. Although, second-guessing is inadvisable, her work is consistent with a view that children and adolescents should not be allowed to make life-altering decisions on their own.

<sup>33</sup> Cohen, H. (1980). *Equal Rights for Children*. Totowa, NJ: Rowman & Littlefield. Cohen, as a child liberationist, defines 'rights' fairly conventionally, but insists on their broad application to children.

accorded to all other rights holders.<sup>34</sup> If a rights holder is entitled to the same respect as all others, then one either has the same rights as others or has none of those rights. This characteristic of equal respect is a primary consideration, according to Teitelbaum, of assessing whether children's or adolescents' so-called rights are essentially meaningful.<sup>35</sup>

There is another problem with how the traditional understanding of rights as a political function disenfranchises the minor. Standard rights theories based on a respect for the choices of others create a "space" around the individual.<sup>36</sup> An adolescent with life-threatening illness, already feeling isolated from friends and family, is hardly in need of more 'space' around her. Yet, the distance and adversarial tone imposed by rights rhetoric<sup>37</sup> aids to alienate the adolescent from his or her parents, family, friends, and health care providers. Transferring the legal and ethical concept of rights normally reserved for adults to seriously ill adolescents without adequate reflection about what it means to give minors rights and what those rights may mean for them is a disservice and misrepresentation of their presumed authority.<sup>38</sup>

### *Historical development of adolescent rights*

Despite the 'rights talk' that infuses contemporary bioethics and health care, our social tendency has been to regard adolescents as non-autonomous, thereby not having full

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<sup>34</sup> Teitelbaum, Lee E. (1999). "Children's Rights and the Problem of Equal Respect." 27 *Hofstra Law Review* 799, p. 802.

<sup>35</sup> Ibid.

<sup>36</sup> Ibid.

<sup>37</sup> Beauchamp, T.L. & Childress, J. F. (2001). *Principles of Biomedical Ethics*, 5th ed. New York: Oxford University Press, 361. "...the language of *claims* and *entitlements* is often unnecessarily adversarial."

<sup>38</sup> Even abortion rights, the paradigm of adolescent rights, for better or worse, are not essentially envisioned as allowing adolescent girls' autonomy. See Oberman, M. (1996). "Minor Rights and Wrongs." *Journal of Law, Medicine & Ethics*, 24, 127-38, p.131. The volatility of abortion rights generally makes this area a political powder keg. The aim of this chapter is not to dwell on abortion rights for minors, but rather to



decision making capacity. The beginnings and endings of adolescence are unclear, even though the law clearly demarcates age 18 as the portal to adulthood. Tracing the philosophical roots of society's regard for the capabilities and status of adolescents leaves us with the unfortunate situation of referring to them as 'children' in a general way without detailing ages to which the label is given.

Child savers of the late 1800's, intent as they were in fostering the child's special needs for protection and development, and not the child's autonomous right to make his or her own choices, implicitly embraced John Stuart Mill's theory of human liberty.<sup>39</sup> For Mill, individual 'liberty'

is meant to apply only to human beings in the maturity of their faculties. We are not speaking of children, or of young persons below the age which the law may fix as that of manhood or womanhood. Those who are still in a state to require being taken care of by others, must be protected against their actions as well as against external injury.<sup>40</sup>

Conceptions of childhood are, of course, dependent on cultural roles that are established for the young. Contemporary society's extension of compulsory education into late childhood is blamed for prolonging childhood and creating an artificial category, termed adolescence.<sup>41</sup> This extension is nonetheless a reality for our youth who are maintained in roles of dependence on their parents until they finish their high school, and possibly college, educations. In his *Groundwork*, Kant noted that autonomy is the end or

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note that judicial decisions in this area have accounted for the basis of some holdings regarding adolescent end-of-life decision making.

<sup>39</sup> Hafen, B.C. & Hafen, J.O. (1996). "Abandoning children to their autonomy: The United Nations Convention on the Rights of the Child." 37 *Harvard International Law Journal* 449, pp. 451-2.

<sup>40</sup> Mill, J. S. (1962). *Utilitarianism, On Liberty, Essay on Bentham*. New York: Penquin/Meridian, 135.

<sup>41</sup> Minow, M. (1986). "Rights for the Next Generation: A Feminist Approach to Children's Rights." 9 *Harvard Women's Law Journal* 1, p. 9.

culmination of education.<sup>42</sup> For that reason education must be compulsory for children. Kant held that children do not possess autonomy, but they have the capacity to develop it. They are certainly persons, even though they are less rational and autonomous. For Kant, children ought to be treated not as autonomous, but rather in a way that respects their right to become so.<sup>43</sup>

The “invention” of adolescence can be traced to protections established by reformers during the Progressive Era at the turn-of-the century. Protective notions such as compulsory schooling, child labor laws, and the juvenile court system furthered children’s dependence on adults and legally removed them from the adult spheres of the marketplace and civic community.<sup>44</sup> Development of the juvenile court system was fueled by notions of the child as a creature different from adults. Ideas about the child ranged from innocence and impressionability to the child’s dangerousness to society. Focusing public attention on the plight of children also aided the efforts of humanitarian reformers.<sup>45</sup>

### *Adolescent rights in the law*

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<sup>42</sup> Kant, I. (1964) *Groundwork of the Metaphysics of Morals*, trans. JH Paton. New York: Harper & Row.

<sup>43</sup> Blustein, J. (1982). *Parents and Children: The Ethics of the Family*. New York: Oxford University Press, pp. 86-7. Compulsory education was also necessary by virtue of parents’ innate preference for their own child. Parents unfortunately tend to focus on their child’s future prosperity, giving attention to the learning of skills as a means, not an end. The inability of parents to teach universalizability to their children inhibits the transformation of the culture into a moral whole. For this rather utilitarian reason, Kant also saw that education must be compulsory.

<sup>44</sup> Minow, M. (1986), 8-9.

<sup>45</sup> *Ibid.*, 9. Minow notes that the work of many women reformers, such as Jane Addams and Lillian Wald, used the banner of the child to push forward humanitarian concerns and paternalistic measures for health, education, labor legislation, and richer city environments.

By the mid-twentieth century, more recent reformers were critical of social policy that excluded young people from the adult world and responsibility.<sup>46</sup> Child liberationists pushed to expand the definition of who is a self-determining person and who can make claims recognized by the law. Notable decisions in the legal landscape appeared to affirm a movement toward increased children's' rights. Some early landmark cases include *Brown v. Board of Education*<sup>47</sup> which accorded equal treatment to children regardless of race and *In re Gault*<sup>48</sup> which required delinquency proceedings to ensure procedural protections similar to adult criminal courts, thereby affirming children be treated as rights-bearing persons and not the subjects of paternalism. Two additional cases *Tinker v. Des Moines Independent Community School District* and *Planned Parenthood of Central Missouri v. Danforth* found, respectively, that children's free speech rights do not disappear at the school house gate, and that a minor has the same right as an adult woman to make an abortion decision without intervention from the state or other persons, such as parents.<sup>49</sup> The Supreme Court has determined through these cases and others that the Constitution protects minors in critical areas of due process, free speech, and privacy. The judicial recognition of a right to privacy, especially, has had a significant impact on an adolescent's perceived right to make health care decisions.

State laws reflect provisions for meeting children's welfare rights and their right to seek mental health, substance abuse, reproductive health care, and some other age-

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<sup>46</sup> Farson, R. (1974). *Birthrights*. New York: Penguin Books. See also Cohen, H. (1980).

<sup>47</sup> 347 U.S. 483 (1954).

<sup>48</sup> 387 U.S. 1 (1967)

<sup>49</sup> Respectively, 393 S.S. 503 (1969) (holding a school rule preventing expression of political views by wearing a black armband as unconstitutional); 428 U.S. 52 (1976) (rejected a statute requiring parental consent to a minor's abortion).

restricted pursuits, commonly referred to as “statutory rights.” Welfare, or positive rights, is most pervasively recognized as pertaining to children. Such rights find expression in the laws of every state and in international declarations of children’s rights.<sup>50</sup> Some of these rights, for example education, are ‘compulsory’ (that is children are required to accept them), but are also free. Such rights are based on ‘needs’ rather than choices. For example, a child may not refuse her ‘right’ to education, nor may a neglected child refuse her ‘right’ to be a foster child because her home is inadequate. Though these are claimed as rights, there is no equal respect for actual choices, as there would be for adults. For example, the right to education may be viewed as an instrument for the child’s own good. But it also has the utilitarian aim of enhancing the greater social good by producing better, productive citizens.<sup>51</sup>

Statutory rights enacted for older minors are not conceived as welfare rights. Such laws permit older children to engage in activities that are generally permitted for adults and generally prohibited for minors.<sup>52</sup> Additionally there is no fixed single age of majority for these particular rights. For example, purchasing tobacco and voting are permitted at age 18, alcohol can be purchased at age 21, many kinds of employment, marriage, and eligibility for the death sentence are permitted at age 16. Permission to drive, and a ‘maturity’ assessment for seeking mental health, substance abuse,

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<sup>50</sup> In 1989, the United Nations General Assembly adopted a new Convention on the Rights of the Child (CRC). The United States is the only one of the major countries not to ratify it, even though American child rights advocates took the lead in developing the CRC. Reasons for not ratifying may include a traditional American reluctance to adopt international human rights treaties, as well as, a profound hesitation to embrace the notion of choice-based autonomy that conceptually dominates the CRC. See Hafen, B.C. & Hafen, J.O. (1996). Of additional interest, especially since child rights advocates advanced the process, the CRC defines every person under 18 as a child, unless national law grants majority at an earlier age.

<sup>51</sup> See previous note 41.

reproductive, and abortion services are awarded at age 16, often lower.<sup>53</sup> Teitelbaum notes that these age limits do not reflect legislative conclusions about the relationship of levels of competence to age. A striking example is of mandated changes in drinking age. Most states lowered the age for alcohol purchase from 21 to 18 years after adoption of the Twenty Sixth Amendment which lowered the voting age to 18.<sup>54</sup> The decrease in the drinking age was based on a conclusion that kids old enough to die in the military should be able to buy their own beer. The later increase back to age 21 was not based solely on empirical evidence that eighteen-year-olds were incompetent to drink responsibly, but rather was tied to a Congressional decision to make state highway funding contingent on an increased drinking age.<sup>55</sup>

It is important to note that these statutory rights, albeit directed at different ages, are not rights in the usual adult sense. For example, parental permission is required for marriage at 16 years, and parental notification or consent before an abortion can be performed is quickly becoming the norm in many states (as is the case in Virginia).<sup>56</sup> Rather than creating spheres of autonomy for minors, Teitelbaum argues, these laws transfer responsibility for decisions about competence with respect to these activities from public to private authority – here, the authority of parents.<sup>57</sup> Minow, writing from a feminist perspective, agrees that the basic legal framework governing children rests on a sharp distinction between public and private responsibilities for children. The framework

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<sup>52</sup> Teitelbaum, L. (1992), 806-7.

<sup>53</sup> Ibid.

<sup>54</sup> The Amendment's passage was also in response to the outcry over the injustice to young people, who were old enough to serve in the military, but were unable to vote for or against those who put them there.

<sup>55</sup> Teitelbaum, L. (1999), 807.

<sup>56</sup> Virginia Code 16.1-241; see also footnote 35 in Chapter 2.

assigns child care responsibility to parents, and thereby avoids public responsibility for children.<sup>58</sup> Although all 15 year olds may be treated equally under the law, all seventeen year olds may not be treated equally in regard to what their parents will allow them to do. There is no consistency as to what parents will permit for their adolescents in this private sphere of authority.<sup>59</sup> If adults' rights are not respected, adults have the option of going to court. Adolescents must first invoke their 'maturity' in a legal setting.<sup>60</sup>

For the most part, adolescents are given 'rights' in our society for our good and convenience. These include the 'right' to seek mental health and substance abuse treatment, and obtain an abortion. Abortion is a vexing area because its mere mention conjures images of political volatility, when in truth the adolescent girl's decision making capacity is hardly what is at issue.<sup>61</sup> But, it would appear that at least in the area of medical treatment, the child liberationists have succeeded in beginning to secure minors

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<sup>57</sup> Teitelbaum, L. (1999), 809.

<sup>58</sup> Minow, M. (1986), 7.

<sup>59</sup> Ibid.

<sup>60</sup> See Zavala, S. (1999). "Defending Parental Involvement and the Presumption of Immaturity in Minors' Decision to Abort." 72 *Southern California Law Review* 1725. Zavala advocates 2 levels of 'maturity' exception hearings for abortion. Since the record shows that the vast majority are approved, she suggests that following a finding of immaturity or maturity, the second step should be a determination of whether or not it is in the best interests of the incompetent minor to involve her parent(s) in the decision to have an abortion. More specific guidelines need to be developed about the 'best interests' concept. The best interests standard, "provides little real guidance to the judge, and his decision must necessarily reflect personal and societal values and mores whose enforcement upon the minor...is fundamentally at odds with the privacy interest underlying the constitutional protection afforded her decision" *Bellotti v. Baird*, 443 U.S. 622, 655-56 (1979)(Stevens, J., concurring)

<sup>61</sup> What is at issue is the energy directed by both the pro-life and pro-choice camps in keeping the issue of abortion in the public consciousness. Pro-life factions see that removing a layer of the girl's autonomy by requiring parental notification chips away at the current legally permissible status of abortion. Pro-choice factions see that parental notification in and of itself delimits the rights of the adolescent to seek and obtain an abortion.

their ‘rights’. Afterall, claim the child liberationists, mature minors have a right to make decisions about themselves, by themselves. To the contrary, Michelle Oberman<sup>62</sup> points out that, far from providing minors with new rights, statutory regulations serve the purpose of social utility by ensuring that adolescents seek the help they need so that they do not endanger themselves or others. What appears to be a victory by child liberationists can, from a different perspective, be seen as another brick in the child protectionist edifice.

This dissertation requires that we remove ourselves from the constraints of the abortion problem and legitimately consider whether the adolescent ought to have the right to make life-or-death decisions about herself. Arguably, the adolescent whose own life may be in irreversible jeopardy as a result of the decisions she makes is more compelling than is a fetus who may be threatened by a teenage girl’s abortion decision. We have handed pregnant adolescents certain adult rights because of political expediency or social utility, but such similar reasons do not exist for handing very ill adolescents adult rights over life-and-death decision making. And there is good reason not to do so.

In the previous chapter I suggested that the analogy of abortion did not readily inform the situation of adolescent refusal of life-sustaining or life-saving treatment. One reason lies in the distinction between requesting and obtaining a medical procedure with its attendant risks,<sup>63</sup> and refusing medical intervention.<sup>64</sup> Jan Costello questions the

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<sup>62</sup> Oberman, M. (1996).

<sup>63</sup> The risks of abortion are for the female patient. Abortion does, of course, cause the demise of the fetus.

<sup>64</sup> This distinction is to be further distinguished from one made by Beauchamp and Childress in reference to the presence of a negative right to abortion as recognized by the Supreme Court. The constitutional right of privacy is construed by the Court as a negative right that limits state interference. The Court further denied

legitimacy of distinguishing the abortion decision from settings where adolescents may be in a position to make other medical decisions about themselves. She notes that the abortion decision has three special characteristics: It (1) has critical implications for the minor's future; (2) is time-sensitive and cannot be postponed until the minor reaches legal adulthood; and (3) is inextricably linked with an individual's personal values.<sup>65</sup> In examining how an adolescent's refusal of psychotropic medications compares to the abortion decision, she notes that both the medication and abortion decision share these same special characteristics, and should therefore not be distinguishable in practice. Indeed on the surface, the characteristics also appear to satisfy conditions surrounding a refusal of life-sustaining treatment scenario. In terms of the first characteristic, the decision to refuse has fatal implications for the minor's future. The refusal is definitely time sensitive since the adolescent's life and death hangs in the balance. The third characteristic, that the decision is inextricably linked with an individual's personal values, is undoubtedly correct.<sup>66</sup> The characteristics of abortion decision making resonate with those inherent in adolescent life-and-death decision making. Unfortunately, the state of the discussion about adolescent decision making capacity is driven more by abortion rights rhetoric than by advances in understanding adolescent decisional capacity. The legal assignment of 'rights' language to the abortion decision quickly distances it

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a positive right to provide aid and assistance for nontherapeutic abortions. Beauchamp, T. & Childress, J.F. (2001), 359.

<sup>65</sup> Costello, J. (1998) "Making Kids take their Medicine: The Privacy and Due Process Rights of De Facto Competent Minors." *31 Loyola of Los Angeles Law Review* 907, p. 914. Criterion 2 stems from the *Belotti II* decision, 443 U.S. 622, 655-56 (1979). The third criterion is based in the *Planned Parenthood of S.E. Pennsylvania v. Casey*, 505 U.S. 833 (1992) finding.

<sup>66</sup> A sampling of personal values related to refusal of treatment include: religious basis for refusal (*In re E.G.*), a desire for no more discomfort (Billy Best), a desire for making one's own decisions (Benny Agrelo). See subsequent text.



from the triadic approach being advanced herein as guidance for adolescent life-and-death decision making.

*Equal rights and child liberationists*

Allowing our children, especially teenagers, to make their own important decisions about themselves is in tension with preventing our children from making ‘bad’ decisions that could cause them irreparable harm. This tension is a dialectic between those who would wield the title ‘child liberationists’ and those more demurely termed ‘child protectionists.’ Child liberationists strive toward the ‘liberation’ of children from oppressive and discriminating social and legal structures.<sup>67</sup> These structures, they claim, fail to acknowledge that children have a stake in all decisions made relative to government, education, and custody issues and should consequently have a decision making role. Child protectionists, on the other hand, argue that although children’s interests are undoubtedly affected by social and legal structures, it is the role of adults to act on behalf of children’s best interests.

Child liberationists claim that one should respect children’s present-day freedom regardless of its long-term impact on their developing personhood. The argument is based in the acknowledgement that adults make good and bad decisions. Respect for autonomy gives the adult authority to consent to or refuse recommended medical treatment. Consent would be meaningless without the accompanying right of refusal.<sup>68</sup>

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<sup>67</sup> Cohen, H.(1980), 17.

<sup>68</sup> “Without its corollary [refusal of treatment], the right to informed consent is meaningless.” Marshall, M.F. (1997) “Treatment Refusals by Patients and Clinicians.” In, J. Fletcher, P.A. Lombardo, M.F. Marshall, & F.G. Miller (Eds.), *Introduction to Clinical Ethics*, 2<sup>nd</sup> ed., 109-26. Frederick, MD: University Publishing Group, 110.

However the inadequacy of some adults' decisionmaking skills is not the standard on which respect for autonomy is based.<sup>69</sup> The claim that some bright adolescents are wiser than some stupid adults is also not a defensible argument for equal rights for children.<sup>70</sup> Purdy and Ross agree that adolescents are different enough from adults that granting them equal decision making rights obfuscates the over-riding importance of helping them develop self-control and other enabling virtues to lead a satisfying life.<sup>71</sup>

Endorsing equal rights for children, in the forms child liberationists advocate, is an untenable proposal with enormous repercussions. It would mean that children could make binding contracts, and would lead to the dissolution of child labor laws, mandatory education, statutory rape laws, and child neglect statutes.<sup>72</sup> It would make children ill-prepared for their future and make them exceedingly vulnerable to predatory adults. But perhaps even more disturbing is Howard Cohen's proposal that children be allowed to change families either because their parents are inadequate or because other adults offer more niceties. Such an endorsement ignores the importance of the intimate parent-child relationship and how most parents strive to advocate for their child's best interests. Accompanying Cohen's idea of voluntary family membership is the notion that children ought to be able to contract with an adult for assistance in negotiating the political and social requirements of daily life.<sup>73</sup>

### **Adolescent Refusal of Life-Or-Death Treatment**

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<sup>69</sup> Ross, L.F. (1995). *Children, Families and Health Care Decision-Making*. NY: Clarendon Press, 25.

<sup>70</sup> Purdy, L. (1992), 78.

<sup>71</sup> Ross, L.F. (1995), 25, 78.

<sup>72</sup> Ross, L.F. (1995), 43-4.

<sup>73</sup> Cohen, H. (1980); see also Ross, L.F. (1995).

Adults' decision making capacity is presumed. Capacity is often questioned when the adult patient refuses recommended medical treatment, especially when treatment is deemed to be beneficial or even life-saving. When an adult refuses under such circumstances, great effort is undertaken – many questions are asked and perhaps consults are obtained - to discern the presence of decision making capacity. If capacity is present, further probing is indicated to discover the root of the refusal. Is it a religiously-based refusal? Is the refusal based on financial reasons? Is the refusal based on the patient's sense that he or she has 'had enough' after a protracted illness course? Or is the patient really not capable to make this decision? Is she depressed, confused, or otherwise mentally impaired? In our autonomy-driven society, the presumption is that capable adults know what is in their best interests. Afterall, no one is more privy to, nor more interested in, their needs, desires, and goals than they are themselves. It is the ethical and legal prerogative of the capable adult to consent to and refuse health care based on their own understanding of their own best interest.

A variation of the well known Dax Cowart case provides an example of the difficult situation confronted by the minors, parents, and health care providers in treatment refusal cases.<sup>74</sup> Imagine a 15 year old Dax as victim of an explosion that caused severe burns to his face and much of his body. We know that despite the adult Dax's on-going and

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<sup>74</sup> Strong, C. (1995). "Respecting the Health Care Decision-Making Capacity of Minors." *Bioethics Forum*, 11(4), 7-12, at 9. Strong proposed this altered Dax scenario as an instance of when an adolescent's refusal of treatment may not be immediately respected. Dax's case first appeared in White, R.B. (1975) "A Demand to Die." *Hastings Center Report*, 5, pp. 9-10. For those unfamiliar with Dax's case, Dax is the former Donald Cowart who underwent extensive long term treatment for critical burn injuries sustained during a propane gas explosion in Texas. He experienced excruciating pain, ultimately losing his vision and fingers. Dax became a successful lawyer, but continues to maintain that doctors violated his right to choose not to be treated.

adamant refusal of life-saving treatment, his mother and providers chose to override his refusal in favor of efforts to save his life and begin rehabilitation. Dax's refusal was attributed to shock from the recent trauma, from pain, from pain medication, and could not be understood as something a capable patient would do. Perhaps a younger Dax, in conversation, would say that he does not want a life where he can no longer play football and have the active lifestyle he once had. Discussions with him show that he has a poor understanding of what his life might be like with rehabilitation and the passage of time, but then we realize again that he is only 15 years old. Additionally, the traumatic injury occurred recently, and Dax may not yet have recovered from the psychological shock.

For these reasons, young Dax may well be assessed to lack decision making capacity to make such irreversible decisions, even though he may exhibit the cognitive elements of decision making capacity. Child rights advocates would push for letting the young Dax make his own decisions if he seems 'mature.' The case has come to be, through the real Dax's own efforts, a paradigm for illustrating that respecting treatment refusal from a competent adult is a moral directive.<sup>75</sup> The principle of respecting persons and their autonomy takes precedence in Dax's case and most other scenarios involving capable adult decision makers.<sup>76</sup>

Conveying a similar respect for refusal of life-saving treatment onto an adolescent with developing autonomy warrants serious consideration. In this hypothetical scenario,

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<sup>75</sup> Dax's case has been the subject of continuous analysis in the bioethics literature. See, for example: Marshall, M.F. (1997) in Fletcher, et al, 109-10; "A dialogue between Dax Cowart and Robert Burt" (1998). *Hastings Center Report*, 28(1), 14-24.

<sup>76</sup> Rare exceptions would include Jehovah's Witness refusal of blood where young dependents were at risk of losing a parent and treatment of a pregnant woman carrying a developed fetus. See for example, the case of Angie Carder, *In re A.C.*, 573 A.2d 1235 (D.C. App. 1990).

the young Dax can be beneficently treated and legally protected from his poor decision because of his minority. The legal bright line for adolescent majority provides leverage for providers and parents to act in order to protect the patient's best interests in the context of the adolescent patient's known wishes and values. The beneficence-based triadic approach is directed more toward the beneficent action of providing life-saving medical intervention and pain alleviation – both of which have significantly improved during the last 30 years - and less toward the idea of overriding young Dax's refusal. Embracing the principle of beneficence-in trust assists in turning the conceptual focus towards an approach that secures the adolescent's developing autonomy in the consideration of best interests.<sup>77</sup>

*Implementation of the triadic approach for adolescent life-and-death decision making*

The triadic guidance approach presented in this dissertation accounts for an integrated therapeutic alliance initiated by the health care providers and forged with the sick adolescent and parents. Within a therapeutic alliance, the three sets of moral stakeholders act to resolve the impasse created by the adolescent refusing recommended life-and-death medical treatment. The triadic approach recognizes that the adolescent may not fully appreciate her best interests, so that her health care providers and parents are obligated to pursue “sliding degrees of paternalism”<sup>78</sup> in order to ensure her protection. Obligations

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<sup>77</sup> Pellegrino, E.D. & Thomasma, D.C. (1988). *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press, p. 51. Note that Pellegrino and Thomasma acknowledge that “age is a relative matter since children mature at different rates, physically, intellectually, and psychologically. Many children under the legal age for independence can make competent decisions, while more than a few over that age cannot do so. This holds true for age in adulthood as well, though the presumption is always in favor of legal competence,” p.154.

<sup>78</sup> Howe, E. (2005). “Treatment Refusals by Patients and Clinicians.” In, J.C. Fletcher, E.M. Spencer, & P.A. Lombardo (Eds.), *Fletcher's Introduction to clinical ethics*, 3rd. ed., 159-174. Hagerstown: University Publishing Group, 162.

of beneficence on the part of parents and health care providers and the state are discussed in the next two chapters.

Pellegrino and Thomasma, in their development of the principle of beneficence-in-trust, present three rules that may justify necessary medical paternalism. Recall that the concept of beneficence-in-trust was primarily developed in the context of adult patients who are in fiduciary, or trusting, relationship with their physician. Accordingly, incorporating these rules into the triadic approach for adolescent life-and-death decision making expands Pellegrino and Thomasma's original conceptualization to include adolescent minors and their parents. The first rule – the weak form – is the least severe in that it attempts to “reverse a potentially reversible condition impeding competence.”<sup>79</sup>

By utilizing the weak rule, providers act in the best interests of the patient by overcoming a temporary impediment. As Pellegrino and Thomasma point out, strictly speaking this rule does not employ paternalism since the goal is to restore competence. As such it is not applicable to the pediatric setting. However its use can be the first step in better educating a refusing adolescent about the illness or intervention she is facing.

The second rule – the intermediate form – comes closer to applicability with adolescents, especially those in circumstances similar to that of AJ. This rule requires providers to “always act to reverse trauma or illness in spite of contrary expressions until the condition is judged irreversible and hopeless.”<sup>80</sup> Using this rule to treat the young Dax would be a justified paternalistic action to protect his best interests.

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<sup>79</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.

<sup>80</sup> Ibid.

The final rule – hard form – is reserved for psychiatry patients, and has relevance in pediatrics. In implementing this rule, providers engage in “necessary medical paternalism” to reverse a “psychiatric disorder which impedes the patient’s capacity to function as a person or social being.”<sup>81</sup> In the adolescent life-and-death scenarios which are the focus here, the third and final rule is construed as the provider acting as necessary in order to save the adolescent’s life, a good that is underappreciated by an immature, inexperienced, frightened, and refusing adolescent. Just as there may be little chance of restoring the competency of a psychiatric patient before intervening, similarly an adolescent will not become a capable decision maker before treatment is necessary. These three rules of escalating paternalism are justified by the larger goal of beneficence in the face of an adolescent’s refusal of life-and death medical intervention. They will be referenced as difficult cases are discussed in this and subsequent chapters.

*Clinical accounts of adolescent treatment refusal*

The pediatric literature offers few accounts of adolescents refusing life-saving medical treatment.<sup>82</sup> An optimistic view is that refusal of life-and-death treatment by adolescents is a relatively uncommon occurrence. However, when such cases do occur they challenge parents or guardians and health care providers to do what is in the adolescent’s best interests in the face of the teen’s emotional claims that her rights are being ignored. In this section I review several clinical cases and provide guidance for resolution based on the triadic approach for adolescent life-and-death decision making.

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<sup>81</sup> Ibid., 158.

<sup>82</sup> Refusal of recommended life-saving medical treatment occurs relatively rarely. However, cases of treatment non-compliance problems are an on-going concern

More than 20 years ago, a journal article revealed refusal of treatment as a “new dilemma” for pediatric oncologists.<sup>83</sup> At the time, the authors speculated that the improved prognosis due to better and more aggressive use of anticancer treatment modalities brought forth problems that were not evident when death was an inevitable and relatively quick outcome of the illness. As the authors admit, although the prognosis has improved, not everyone is willing to accept the rigors of recommended therapy.<sup>84</sup> The authors classified four types of refusals involving 13 patients over five years. Only four concerned refusal by the patient.

Two refusal narratives involved two 18 year olds whose cases were particularly distressing for the authors. The young men were then, as they would be now, too old for judicial referral. Some time before refusal of further treatment, both boys had undergone amputations for osteogenic sarcoma together with 4 – 6 months of follow-up treatment. Each boy had a 55% chance of a 3 year survival, which was deemed a good prognosis at the time of writing. One boy said that continued treatment interfered with his ability to farm and provide for his family. He compared his desired fate to how lame or defective animals are treated on the farm: they are allowed to die. The other boy wanted to stop treatment because he felt it interfered with his dream to be a truck driver. The families were encouraged to talk with their sons. They did so but the young men still refused further treatment.<sup>85</sup>

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<sup>83</sup> Lansky, S. B., Vats, T., Cairns, N.U. (1979) “Refusal of Treatment: A New Dilemma for Oncologists.” *The American Journal of Pediatric Hematology/Oncology*, 1(3), 277-281.

<sup>84</sup> Ibid., 277.

<sup>85</sup> Ibid, 279-80.



Most developmental research places eighteen year olds in the category of older adolescents. That is they are still developing maturity in terms of future goals, temperance, and judgment.<sup>86</sup> By virtue of these boys' legal status of majority, their refusal was honored, as it likely would be today. Granted we know little about the facts of these cases. However, it is certain that in appearing to override the principle of beneficence in order to respect the boys' autonomy, moral traces are left behind.<sup>87</sup> That is, health care providers and other stakeholders involved in these boys' cases may sustain residual regret about their inability to discourage the boys' refusal of further treatment in light of ethical and legal requirements to allow the boys to do so. Nozick's moral traces are also undoubtedly evident in adult refusal cases, wherein the decision of a capable adult is regrettably respected although medical treatment is deemed to be life-saving.

These cases beg the question of the extent to which adults' refusals ought to be honored. Standing by to allow a person with a good chance of living the right to die seems morally inadequate. However, since our society greatly values the right to self-determination, many would say that we then risk the consequences of these relatively few cases of refusal.<sup>88</sup> Limiting the freedom of a capable adult to refuse treatment is ethically and legally unacceptable. But children's freedom should be limited when it seriously

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<sup>86</sup> See Gemelli, R. (1996), footnote 19.

<sup>87</sup> A concept developed by Robert Nozick. Cited in Beauchamp, T. & Childress, J.F. (2001), 406.

"...when a prima facie obligation is outweighed or overridden, it does not simply disappear or evaporate. It leaves moral residues or what Nozick called 'moral traces.' Even when moral agents act correctly in overriding a prima facie obligation, regret is the morally appropriate attitude."

<sup>88</sup> Ruth Macklin uses similar reasoning in her argument against forced cesarean sections. Discussing a case of a pregnant woman's refusal of a cesarean section to remove a fetus with signs of distress, Macklin advises that the best solution is to honor the rare case of a woman's refusal. A possible consequence is that some fetuses who could be saved would die or be born impaired. "This consequence would be tragic, but it is the price that must be paid for protecting the rights of all competent adults..." Macklin, R. (1987). *Mortal Choices: Ethical Dilemmas in Modern Medicine*. Boston: Houghton Mifflin, 179.

interferes with their best interests and prerequisites for their future development.<sup>89</sup> The triadic approach tempers an adolescent's claim to refusal of life-and-death treatment by incorporating the beneficent obligations of parents and health care providers into deliberations about life-and-death interventions

Limiting the freedom of adolescents to refuse life-and-death decisions must necessarily consider the prognosis. Prognostic statistics can not predict the standing of a particular patient. They offer a gamble in addition to supplying objective information about the possibility of recovery and cure based on a certain sample size for which there is data. Although assigning an explicit percentage is cautiously undertaken, an adolescent with brief, but life-altering experience with critical illness (as the young men in the case above), is presumably owed the potential life-saving treatment, despite his refusal, when a good prognosis for cure is less than 30-40%. This is an individual who has some experience with inevitably fatal disease, but stands a chance of seeing a disease-free future. An acutely-diagnosed adolescent deserves significantly lower prognostic percentages in making decisions about medical intervention. In these cases, the beneficent obligations of parents and health care providers to offer all opportunities for advantageous treatment should be to listen carefully and give credible consideration to the adolescent's views, but must supplant the adolescent's refusal at least in the first treatment attempt.

In one of the first psychological studies of treatment refusal among pediatric cancer patients, the researchers described several personality factors which seemed contributory

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<sup>89</sup> Purdy, L. (1992), 222.

to the refusal.<sup>90</sup> The sample of ten adolescents who refused cancer treatments over a 2-year period were carefully matched to a control group of non-refusing patients. The adolescent refusers reported higher levels of trait anxiety, religiosity, and external locus of control than did their compliant counterparts. Refusers tended to believe that their illness was either ‘not changing’ or actually ‘getting better’ during their refusal. This belief was likely due to the absence of chemotherapy side effects. These patients tended to focus on the treatment’s side effects as undesirable.

The refusers also uniformly believed that their chances of cure without further treatment were still ‘good to excellent.’ Stressful situations were regarded as extremely threatening and aversive. Their extreme sense of external control over their illness, i.e. a strong belief that one’s life is controlled by luck, fate, or God, seemed to afford them a protection against experiencing severe anxiety, although as a group they tended to regard stressful situations as extremely threatening and aversive. The refusers tended to think their illness was beyond the realm of anyone’s control, their own or their physician’s. Koocher suggests that patients with this type of personality style who refuse treatment would not likely respond favorably to confrontational or ‘scare tactics’.<sup>91</sup> Such anxiety-inducing interventions would tend to heighten the defensive processes, and rigidify the focus on refusing treatment. Note that Koocher gives no alternative suggestions for how to handle these kinds of adolescent patients other than suggesting general anxiety-reducing approaches to use with all young cancer patients. These approaches include

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<sup>90</sup> Blotcky A.D., Cohen D.G., Conatser C. & Kopovitch, P. (1985). “Psychosocial Characteristics of Adolescents who Refuse Cancer Treatments.” *Journal of Contemporary Clinical Psychology* 53, 729-31.

<sup>91</sup> Koocher, G. P. (1986). “Psychosocial Issues during the Acute Treatment of Pediatric Cancer.” *Cancer*, July 15 Supplement, 468-72, p. 471.

discussions early in the disease process about their fears, concerns over changes in physical appearance, worries about friends' reactions, treatment side effects, and painful medical procedures. Engaging adolescents early into the treatment process gives them, according to Koocher, a heightened sense of control as well as a reduction in anxiety.<sup>92</sup>

What Koocher and other psychologists avoid is a frank discussion of how far to go in respecting adolescent refusal of treatment. The purpose of the triadic approach is to minimize the question of adolescent autonomy in treatment refusal and to emphasize the focus on beneficence-in-trust by parents and clinicians. Although an adolescent may actively participate in discussion about her medical treatment, the triadic approach acknowledges that her decision making capacity is limited by virtue of her developing autonomy. By inviting the adolescent to fully articulate her views and values, parents and clinicians acknowledge her role as the person facing the difficult life-and-death circumstances. Actions taken on the part of parents and clinicians must appeal to the adolescent's best interests – the principle of beneficence – and may or may not be consistent with her desire to refuse treatment. Nevertheless, the adolescent's contributory views, albeit consisting of treatment refusal, may prove valuably influential in determining how or if certain medical life-saving treatments are initiated.

The adolescent's personal or witnessed experience with illness, pain, and death are invited conversations that are not to be overlooked in beneficent deliberation by parents and clinicians. Such experiences, although contributing to the adolescent's narrative, do not determine whether, or if, the adolescent has more or less authority to refuse life-

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<sup>92</sup> Ibid.

saving intervention. The following case illustrates the difficulty of deferring to the ‘experience’ of an adolescent in order to heed his refusal of life-saving treatment.

The case of treatment refusal by a 13 year old boy appeared in a pediatric journal’s “Challenging Case” section.<sup>93</sup> Jorge refused bone marrow transplantation for acute lymphocytic leukemia. He was first diagnosed and treated nine months earlier, experiencing remission in the first month. Six months of intensive consolidation requiring numerous hospitalizations was followed by maintenance chemotherapy. Jorge and the family related well to the treatment team. During his second month of maintenance therapy, Jorge seemed eager to resume his life. On a routine clinic visit, a bone marrow aspiration detected resurgence of his leukemia. Jorge and his family were devastated, especially after hearing that Jorge’s only real chance of survival was bone marrow transplantation. Because there was no living related donor, he would be placed on a waiting list. The prognosis was given at 40% survival and disease-free for 5 years. Jorge and his family agreed to visit the transplantation center. At the center, they were told about the lengthy seclusion, the pain that could be expected, the possible side effects, and the likelihood of success. Jorge asked few questions but, overall, related poorly to the transplant staff. Upon returning home, Jorge announced that he would refuse transplantation and did not want to be placed on the list. A meeting of the treatment team the next day found Jorge very firm in his decision. He had read about other teenagers who had chosen to die rather than accept additional painful treatments. His parents were

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<sup>93</sup> Stein, M.T. (1998). “Decision Making about Medical Care in an Adolescent with Life-Threatening Illness.” *Developmental and Behavioral Pediatrics*, 19(5), 355-8.

firm in insisting that every possible treatment be pursued. They wanted Jorge placed on the waiting list, despite Jorge's adamant objections.

The commentators on this case consider possible reasons for his refusal including dislike of the referral transplant center, anger, and clinical depression. Two commentators note that children and teenagers who are being treated for life-threatening illnesses have high rates of depression that may be amenable to treatment.<sup>94</sup> They suggested some possible avenues for dealing with Jorge's refusal, such as referral to another center, treatment of clinical depression, and allowing an opportunity for Jorge to express his concerns. Providing a forum for the young person to share concerns and the reasons for them can, even more than the other suggestions, lead to a mutually-agreed upon plan for treatment that suits the adolescent's need for some semblance of control over the situation in which he finds himself.<sup>95</sup>

Clearly, the commentators were not willing to respect Jorge's refusal, a decision with which I agree. Were Jorge 15 or 16 my recommendation would be the same. Jorge's illness course has been relatively short, albeit onerous. Jorge's family and health care providers have a duty to try to save his life, over his objections, given a projected 40% survival after bone marrow transplant. Should Jorge's transplant result in adverse effects that are excessive and are not viewed by Jorge as being worth the prospect of benefit, his resultant refusal for continued treatment ought to be a considered option by parents and providers, not in terms of respecting autonomy, but as a beneficent appreciation for burdens outweighing benefits of treatment. This course of action is consistent with

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<sup>94</sup> Ibid., 356. Robert Wells and Steve Stephenson commented on this case.

Pellegrino and Thomasma's second, intermediate rule for intervention on behalf of beneficence-in-trust: act to reverse illness in spite of contrary expressions until the condition is irreversible and hopeless.<sup>96</sup> The triadic approach relies on expressed views of the adolescent, however enacting those views is a function of beneficent regard for the adolescent rather than respect for his autonomy. Jorge's refusal, together with his expression of reasons and values ought to be viewed by parents and providers as a valid statement of his interests.<sup>97</sup> However, in the interests of beneficence-in-trust, they remain interests that can not be acted upon in the life-and-death scenario, but may guide future actions.

Another teen also decided to take matters into his own hands. Billy Best's story received significant media coverage.<sup>98</sup> The 16 year old boy with Hodgkin's lymphoma refused further rounds of chemotherapy. With continued treatment, his chance of full recovery was about 80%. Billy believed the treatments were painful and contrary to his religious faith. His parents wanted the treatment for him. Feeling he would be forced to submit to chemotherapy, Billy ran away from home, coming back only when his parents and doctors agreed that he would not have to undergo further chemotherapy.

Commenting on this case, Michelle Oberman finds troubling implications for extending rights to supposedly mature minors.<sup>99</sup> Promising Billy that he would not be

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<sup>95</sup> Traugott, I. & Alpers, A. (1997) "In their Own Hands: Adolescents' Refusals of Medical Treatment." *Archives of Pediatric & Adolescent Medicine*, 151, 922-7, p. 926.

<sup>96</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.

<sup>97</sup> Traugott, I. & Alpers, A. (1997), 925.

<sup>98</sup> See, for example: Rosen, M.(1994). "ROAD WARRIOR: Billy Best, 16, fled home to escape chemotherapy and found new friends and a fresh perspective in Texas. So what will happen now?" *People Weekly*, Dec. 12, 48; Negri, G.(1994). "Parents beg ill Norwell youth to call home." *Boston Globe*, Nov. 4, 34.

<sup>99</sup> Oberman, M. (1996), 129.

treated in exchange for returning home is, she argues, an understandable concession. However, Oberman suggests that a 'grandiose temper tantrum' is a strange bid for autonomy."<sup>100</sup>

In this case parents and clinicians lost the opportunity to fulfill their obligation of providing life-saving treatment for this boy. Billy was able to hold hostage his parents, providers, and the state in exchange for being permitted to refuse further treatment. Employing the triadic approach for adolescent life-and-death decision making in this case offers guidance in viewing Billy's refusal and his parents' and providers' capitulation as acts of desperation by all three stakeholders. The triadic approach does not acknowledge adolescent autonomous refusal of life-and-death treatment. Rather it notes the adolescent's refusal as a function of his interest in not undergoing further pain and distress. As Oberman suggests, Billy's temper tantrum does not demonstrate decision making capacity or self-determination. To the credit of Billy's parents and the clinicians, conceding to Billy's demands may have been the most beneficent action they could undertake in light of the likelihood of Billy becoming sicker and dying in an unknown location without the support of loved ones. This case does illustrate a missed opportunity in forging a therapeutic alliance<sup>101</sup> between providers, parents, and the boy in facilitating informed discussion about the indicated medical intervention. In Billy's example, only he was opposed to treatment for religious reasons; his parents wanted the treatment to proceed. The case becomes harder when both adolescent and parents refuse life-saving

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<sup>100</sup> Ibid.

<sup>101</sup> Richard B. Miller utilizes this term to describe the cooperative relationship between pediatric patient, parents, and health care providers that facilitates the obligations of parents and clinicians in ensuring



treatment because of religious proscription. At such time, health care providers must take on the responsibility of protecting the adolescent from harm.

A more complex case of treatment refusal case involves 15 year old Lee Lor who was diagnosed with advanced ovarian cancer during an appendectomy procedure. The tumor and an ovary were surgically removed. Lee and her parents were told that without chemotherapy, she would have only a 10% chance of survival. (The chance of survival with chemotherapy is not given, and may have a bearing on the decision made by the family and clinicians). The family consisted of Hmong refugees who disapproved of the surgical excision and decided that without a guarantee of recovery, Lee would not undergo the discomforts and side effects of chemotherapy. The family was deeply concerned that treatment would disqualify Lee's marriage prospects in the Hmong community. Lee's clinicians contacted child protective services who sent 17 officials to the Lor home to drag Lee to the hospital. She was restrained for chemotherapy and parents were given limited, supervised access to their daughter. Upon release after her first round of chemotherapy treatment, Lee ran away from home, only to return when she learned the judge had lifted the court order to force treatment.<sup>102</sup>

The cultural circumstances of Lee's case point to community driven decision making about the provision of life-saving health care. The question of whether Lee, herself, might contribute her perspective to the decision making about her treatment was immaterial in light of the controlling values maintained by the Hmong community.

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beneficent caring of the pediatric patient. *Children, Ethics, and Modern Medicine* (2003). Bloomington: Indiana University Press.

<sup>102</sup> Traugott, I. & Alpers, A. (1997). One of 3 cases discussed, in addition to that of Billy Best and Benny Agrelo, that received widespread publicity in 1994.

Whether Lee may have been able to discuss her own wishes in a setting removed from her family is unknown. It certainly should have been encouraged.

Trautgott and Alpers suggest that “the values of the adolescent, and sometimes those of his or her parents, in rejecting treatment should be balanced against the medical benefit of improved prognosis.”<sup>103</sup> I disagree with such a balancing in the immediate period of diagnosis with a life-threatening disease. On one hand, balancing quality of life values with prognostic benefit can be appropriate in the scenario of an adolescent with a chronic-inevitably-fatal illness. But, on the other hand, such values are largely untested when a newly diagnosed adolescent refuses life-or-death treatment. In the case of Lee, cultural values are transmitted from the parents to the adolescent and can be enormously compelling. A feasible rule of intervention – in its weak form – is articulated by Pellegrino and Thomasma as a way to enact beneficence-in-trust.<sup>104</sup> In adapting the ‘weak form’ to this scenario, providers intervene to reverse potentially reversible conditions impeding competence in understanding. Their approach with Lee and her parents is to undertake efforts for them to understand the Western view of the proposed potential life-saving intervention.

The cultural issues in this case are difficult and we cannot dispute the seriousness of the providers’ attempts in securing Lee’s treatment. However, we are left to second guess their attempts at securing a therapeutic alliance with Lee and her parents. Providers must facilitate open channels of communication with the refusing adolescent

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<sup>103</sup> Ibid., 925.

<sup>104</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.

and her parents, particularly in cross-cultural dilemmas rife with mistrust and misinformation.

The cases of Jorge, Billy, and Lee highlight a pattern of obligation clinicians have toward employing meaningful communication with a refusing adolescent. In addition, better symptom and anxiety relief for adolescents facing life-threatening illness may serve to mitigate the refusal of treatment. Chapter 5 will address clinicians' obligations more fully.

*The complicated legal resolution of adolescent refusal cases*

The definition of 'maturity' in the law is ambiguous, at best. Although the 'mature minor' concept is commonly invoked, its understanding remains subjective. Jessica Penkower offers a laundry list of factors that the courts have considered in assessing the maturity of adolescents refusing life-saving or recommended medical treatment: 1) the minor's age (*Belcher v. Charleston Area Medical Center*)<sup>105</sup>; 2) judgment (*Belcher*); 3) education (*Cardwell v. Bechtol*)<sup>106</sup>; 4) training (*Cardwell; Belcher*); 5) ability (*Cardwell; Belcher*); 6) experience (*Belcher*); 7) the minor's conduct and demeanor at the time of treatment (*Belcher*); 8) whether the minor exhibits the maturity of an eighteen to twenty-one-year old (*Belcher*); 9) whether the minor understands the basic tenets of her religion

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<sup>105</sup> 422 S.EE.2d 827 (W.Va 1992) (in which Larry Belcher, 17yrs, 8 months and confined to wheelchair due to advanced muscular dystrophy, had a respiratory arrest. Larry's parents would not make the do-not-resuscitate decision without Larry's input. His doctors felt he was too immature to make such a decision. Larry was made DNR by the providers and died after a cardiac arrest. The court formally recognized the existence of a mature minor exception to the common law rule of parental consent). See, Penkower, J. (1996), 1181.

<sup>106</sup> 724 S.W.2d 739 (Tenn. 1987) (in which a 17 yr, 7 month old young woman sought relief from back pain. After complications from treatment, the parents sued for failing to obtain parental consent. The court ruled against the parents).

if religion is the basis of refusal (*In re: E.G.*)<sup>107</sup>; 10) whether the minor is well-enough informed to make an intelligent choice (*In re Long Island Jewish Medical Center*)<sup>108</sup>; 11) whether the minor has capacity to appreciate the risks of the medical procedure administered or withheld (*Belloc v. Baird*)<sup>109</sup>; and 12) whether the minor can assess the implications of his or her choice (*Belcher*).<sup>110</sup> Such a list of traits and circumstances is certainly more comprehensive than those attributes demanded of adults refusing life-saving medical treatment. As a result, it would seem that minors are held to a higher, even unfair, standard by the deciding judge.

Because adolescents' decision making capacity is not presumed – it is often not even imagined – reactions by family and providers to a teen's treatment refusal may understandably take different courses. The adolescent patient's reasons may not be explored, or may even be discounted. Instead of trying to discover the basis of the refusal, the teen may, quite literally, be forcibly required to submit to treatment. Such was the experience of Benito Agrela.<sup>111</sup> Benny, born with an enlarged liver and spleen, received a liver transplant when he was eight years old. Several months after his second transplant at age 14 he stopped taking his medication because he could no longer tolerate the side effects. He was forcibly removed from his parents' home by the Florida Department of Social Services and admitted to a Miami hospital. When he continued to

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<sup>107</sup> 549 N.E.2d at 322 (Ill. 1989). See *supra* text, *In re E.G.*

<sup>108</sup> 557 N.Y.S.2d 239 (N.Y. App. Div. 1990) (case of Phillip Malcolm, just shy of age 18, in which his refusal of blood transfusion for religious reasons, was overruled). See Chapter 2.

<sup>109</sup> 443 U.S. 622 (1979) Also known as *Belloc II* (in which the Supreme Court found 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.) See, Penkower, J. (1996), 1184.

<sup>110</sup> Penkower, J. (1996), 1210.

<sup>111</sup> Weir, R.F. and Peters, C. (1997). "Affirming the Decisions Adolescents Make about Life and Death." *Hastings Center Report*, 27, (6), 29-40.

refuse further treatment, his case was taken to circuit court where the judge, after meeting with Benny and his physicians, ruled that Benny had the legal right to refuse medications and return home. Before his death at age 15, Benny said: “I should have the right to make my own decision. I know the consequences, I know the problems.”<sup>112</sup> Benny’s case, among others, has blurred the distinction between the rights of adults and minors to refuse life-saving medical treatment.<sup>113</sup>

The judge’s application of ‘rights’ language in this case was a serious mistake. Ethical problem solving measures, such as referral to an ethics committee, are always preferable to adjudication. Unfortunately when a case like this enters the courts – as the final arbiter - the language of rights is legal currency. The experience Benny had with his life-long illness gives far greater credence to his refusal than the judge’s opinion that Benny has a ‘right’ to make such a decision. Although Benny’s refusal may have satisfied the cognitive elements of the informed consent doctrine, the judge ought to have instead acknowledged that Benny has been chronically ill since birth and is well aware of the burden of post-operative recovery and anti-rejection medications after liver transplant. An appeal to beneficence, rather than a misleading presumption of Benny’s autonomy, would have better guided the responses by parents, providers, and the state. His longstanding chronicity pointed to the real possibility that continued treatment posed far greater burden than benefit to Benny.

In looking closely at the case of *In re E.G.*, the 17 ½ year old girl with leukemia who refused blood transfusions because of her Jehovah’s Witness beliefs, Brewster argues that

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<sup>112</sup> Ibid., 30.

the court of final ruling, the Illinois Supreme Court, reached the wrong conclusion.<sup>114</sup>

He gives three reasons for his opinion, although he acknowledges that the common law analysis was correct. First, the court disregarded the State's interest in preservation of life. Second, the Court decision contradicted the fact that blood transfusions are clearly in a minor's best interests. Third, the decision erroneously extended the mature minor doctrine after failing to recognize the differences between the abortion cases referenced and this one. In the abortion cases, the United States Supreme Court focused on the minor's best interests in light of the minor's circumstances: burdensome responsibilities of motherhood and allowing parents absolute veto power. But, claims Brewster, the two situations are completely different. Permitting minors to have an abortion allows an affirmative act by a minor after which sequelae can be treated. But allowing minors to refuse blood transfusions may result in the end of their lives. Expanding the mature minor doctrine beyond the context of abortions essentially asserts that death may sometimes be in the minor's best interests, which is a suggestion that ought to comprise only rare consideration.<sup>115</sup> Once again, the misplaced emphasis on 'rights' language deals a disservice to the young person who is permitted to refuse a life-saving transfusion. Instead of the state protecting her future because she was a minor, the state associated her refusal with that of an autonomous adult.

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<sup>113</sup> Penkower, J. (1996), 1168.

<sup>114</sup> Brewster, W.D. (1990) "In re E.G., A Minor: Death over Life: A Judicial Trend Continues as the Illinois Supreme Court Grants Minors the Right to Refuse Life-Saving Medical Treatment." 771 *John Marshall Law Review* 23, pp. 779-784.

<sup>115</sup> Ibid., 785.

### **Ethical Rights and Responsibilities of the Sick Adolescent and of Others**

In our society, conceptually and practically, children are not autonomous persons but are instead dependents linked legally and daily to adults entrusted with their care.<sup>116</sup>

Children's dependency is situated in the sphere of family life, where parents stand between children and the state. Children's rights vis a vis their relationships with adults can take three forms of increasing rights authority for minors.<sup>117</sup> First, the state can invoke obligations, that are aptly named 'child protections,' by or in the name of the child. Such protections include state interventions to remove them from neglectful or abusive home situations, in addition to child labor restrictions, and restrictions on drinking and driving. The last set of restrictions is in sharp opposition to what might be considered rights of autonomous individuals.

A second conception of children's rights joins the child with the parent instead of squaring the child against the state or the state assisting the child to resist parental authority.<sup>118</sup> In other words, the child and parent are envisioned as partners, not potential adversaries. A third form of children's rights involves the state in suspending children's usual dependence on, and subjection to, parental authority. For example, Justice Douglas in his dissenting opinion in *Wisconsin v. Yoder* argued that the Amish children themselves ought to have a voice in determining whether they attend public high

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<sup>116</sup> Minow, M. (1989), 18.

<sup>117</sup> Ibid., 18-20

<sup>118</sup> Minow sees that In re *Gault* articulated the child's right to consult legal counsel in the context of juvenile court proceedings as a right of the child and parents, together. 387 U.S. 1,41.

schools.<sup>119</sup> In a second example, the *Danforth* ruling, giving minors the right to consent to their own abortions, rejects parental demands to have their power reinforced by the state. These possible permutations of children's rights offer a hint at why "children's rights" have been claimed for ostensibly conflicting conceptions of autonomy. Minow suggests that "rights represent the coinage of opposition to two kinds of power: the power of the parents and the power of the state."<sup>120</sup>

Liberal theory, primarily with reference to the work of John Rawls, holds that the highest priority in society is the protection of individual rights. The ability to promote and preserve personal autonomy is a fundamental attribute of a just society.<sup>121</sup> In contrast to the liberal view, communitarians tend to view the values of communities as having priority over the rights of their individual members. They critique the liberal view by noting that individuals do not fashion a personal conception of the good. Rather, individuals develop a conception of the good within the context of their community.<sup>122</sup> Others, though, see that the communitarian view treats the family itself as an intrinsic good, without reference to its instrumental role. The family, Binder argues, is valuable to the extent that it "enables individuals to develop autonomously and maintains the social framework within which individuals may pursue their own conceptions of the good, regardless of the origins of these conceptions."<sup>123</sup> Because of the exclusive primacy given

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<sup>119</sup> Minow, M. (1989), 20. 406 U.S. 205,241 (1972) (Douglas, J., dissenting).

<sup>120</sup> Ibid.

<sup>121</sup> Binder, N.S. (1994) "Taking Relationships Seriously: Children, Autonomy, and the Right to a Relationship." 69 *New York University Law Review* 1150, p.1152; Rawls, J. (1971). *A Theory of Justice*, Cambridge, MA: Harvard University Press, 407-16.

<sup>122</sup> Binder, N.S. (1994), citing Sandel, M.J. (1982) *Liberalism and the Limits of Justice*. New York: Cambridge University Press, pp. 59-65,179-83.

<sup>123</sup> Binder, N.S. (1994), 1153.



to the community, communitarians have shed light on the value of relationships and how these have not been adequately incorporated in liberal theory. Binder argues that “a child’s interest in, and right to, a relationship with her parent neither threatens the basic principle of family privacy, nor treats children as fully autonomous actors. By treating children as developing individuals, we can appropriately locate their interests not in the sphere of action, but in a family environment that allows for the development of the ability to act autonomously as adults.”<sup>124</sup>

*Rights and responsibilities with poor prognosis*

A policy of allowing adolescents to have the final say about life-sustaining treatment is discouraged by the triadic approach for adolescent life-and-death decision making. It is not hyperbole to suggest that the lives of seriously ill teenagers may be at risk from a society that holds an unsettled and undeserved respect for the autonomy of adolescents. Life-and-death decisions do not belong in the hands of teens facing life-or-death treatment. The beneficence-based triadic approach guides the adolescent, parents, and clinicians to consider prognosis, wishes, and values of the adolescent in forging a plan for acute or continued treatment of life-and-death illness.

A poor prognosis together with little chance of continued treatment affording significant survival paints a bleak picture of the adolescent’s prospects. Here professional guidelines about informing the teen of her situation and acting according to her decision are quite appropriate.<sup>125</sup> In this scenario, a beneficence-in-trust approach on the part of parents and providers recognizes that potential benefits and actual burdens are

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<sup>124</sup> Ibid., 1154.

best understood by the very sick adolescent who will experience them. This approach, though, does not entirely alleviate the potential for parent-child-provider disagreement because of the varied construals of poor prognosis among them. What is a poor prognosis for one person, or family, is, for others, a ray of hope. The teen must be informed that treatment options, if any, are limited. Those aggressive treatments available may, indeed, hold more burden than benefit. The adolescent is offered this information so that she might choose how she will spend the time remaining. Based on the tragic prognosis and her experiences of what treatment has been like, a therapeutic alliance between the adolescent, her parents, and clinicians is vital for discerning her best interests in the final stages of a chronic-inevitably-fatal or terminal disease. The alliance here is not 'therapeutic' in the sense of treating the disease, rather it is focused on symptom relief and meaningful communication.

An illustrative case is presented by a nurse who is frustrated by 'giving up' on a young patient.<sup>126</sup> A fifteen year old girl with acute lymphocytic leukemia had been diagnosed at age twelve. With intensive chemotherapy the patient had two remissions, but after the second relapse her disease was characterized as resistant and advanced. Her physicians suggested that another course of chemotherapy followed by bone marrow transplantation offered about a 20% chance of surviving another two to four years without disease. The girl refused further treatment much to the dismay of her parents who wanted everything done. The ethics committee was called to help mediate the impasse between the patient,

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<sup>125</sup> Committee on Bioethics, American Academy of Pediatrics (1994). "Guidelines on Forgoing Life-Sustaining Medical Treatment." *Pediatrics* 93, 532-6.

<sup>126</sup> Awong, L. (1998) "When an Adolescent Wants to Forgo Therapy." *American Journal of Nursing*, 98(7), 67-8, p. 67. Also see Chapter 2.

parents, and providers. Eventually the parents acceded to their daughter's wishes. A clinician's frustration that everyone was 'giving up' on this girl can often have the effect of mobilizing the entire health care team to dispute the family's wishes and provoke a legal action which can serve to antagonize all parties at a time when the young girl needs everyone's support. "Giving up" may convey the notion of abandonment to the family. But with good communication, it can also mean that all parties become convinced that aggressive treatment is no longer in the girl's best interest. A 20% chance of limited survival is not an optimistic prognosis, especially in light of the girl's past experience with the disease. Forgoing active treatment is appropriate, not because the girl refused it, but because doing so aligns with beneficent practice by providers and parental duty to protect their daughter's best interests in this case. "Giving up" on aggressive treatment should not mean that the girl will no longer receive comfort care.<sup>127</sup>

Weir and Peterson argue that chronically ill, critically ill, and terminally ill adolescents ought to be able to utilize advance directives to make their wishes known about the uses of life-sustaining treatment.<sup>128</sup> The authors ignore the ambiguous and scant psychological research on adolescent decision making capacity and suggest

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<sup>127</sup> Research shows that we fail to provide appropriate comfort care to dying children. See, Wolfe, J., Grier, H.E., Klar, N, Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S, Emanuel, E.J., & Week, J.C. (2000). "Symptoms and Suffering at the End of Life in Children with Cancer." *New England Journal of Medicine*, 342 (5), 326-33. Interviews of 103 parents of children who died of cancer revealed that 89% of children suffered "a lot" or "a great deal" from at least one symptom in the last month of life. Attempts to control the signs and symptoms of pain were often unsuccessful. We need to pay greater attention to the early and comprehensive provision of palliative care.

<sup>128</sup> Weir, R.F. & Peterson, C. (1997), 30. Advance directives for adolescents are not of focus in this dissertation. Rather the emphasis is on contemporaneous decision making about life-saving treatment, not life-sustaining treatment that is seen to prolong death. However, it is important to note that my position about chronically ill adolescents in the final throes of their disease is that they should have a major role in decision making, by virtue of their vast experience with the disease. For this reason, advance directives receive some mention here.

developing guidelines to utilize advance directives as instruments of moral persuasion. As such, Weir and Peterson submit they are not ‘legal documents’ rather they are used to convince providers, relatives, and others to carry out their wishes without legal threats. These nonstatutory advance directives, already used frequently with adults, are given probative weight. One state supreme court was willing to accept the oral directives of an adolescent as providing sufficient legal evidence of the ‘seriousness and deliberativeness’ of the patient’s views.<sup>129</sup> Weir and Peterson maintain a *moral* right for adolescents to make decisions about life-sustaining treatment. They urge that fourteen year olds and older also have the legal right to do so.<sup>130</sup>

Lainie Friedman Ross sees quite a different picture when viewing the prospect of adolescents having the right to make decisions about life-sustaining treatment.<sup>131</sup> She critiques the American Academy of Pediatrics’ recommendations<sup>132</sup> for assuming that decision making capacity can be defined or measured. Ross is particularly troubled by the Academy’s recommendation that if there is parental-child disagreement and the child is judged to have decision making authority, the child’s decision should be binding. After offering justifications as to why a child’s present-day autonomy ought to be limited, Ross offers pragmatic reasons to permit parents to override the present-day autonomy of competent adolescents. One reason comes back to the fact that no competency test

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<sup>129</sup> Ibid., 35. See, *In re Swan* 569 A.2d 1202 (Me. 1990) (herein the court deferred to a 17 year old’s life-sustaining treatment preference after a serious auto accident left him in a persistent vegetative state. He had earlier commented that he would not want to be kept alive in such a condition).

<sup>130</sup> Ibid.

<sup>131</sup> Ross, L.F. (1997). “Health Care Decisionmaking by Children: Is it in Their Best Interest? *Hastings Center Report*, 27,(6), 41-5, at 41-3. Ross’ comments combine concepts involving refusal of life-sustaining and life-saving treatment. Ross is opposed to allowing adolescents to refuse either.

<sup>132</sup> Committee on Bioethics, American Academy of Pediatrics (1995).

currently exists. A second reason is that many parents already recognize their adolescent's developing maturity and treat them accordingly. They may already voluntarily respect their mature child's decisions. Along this line of thought, Laura Purdy remarks: "It is plausible to think that children's maturity is not completely unrelated to parental good sense."<sup>133</sup>

Ross' third reason against respecting life-and-death decision making by minors is based on placing the notion of health care rights in context. If, asks Ross, a fourteen year old is granted decision making authority over life-and-death decisions, why may this same fourteen year old not buy and smoke cigarettes or drop out of school?<sup>134</sup> Indeed, Ross' question emphasizes the arbitrariness of legislators drawing a bright line at eighteen, which appears to be a traditional demarcation between the decision making abilities of minors and adults. In the case of medical decision making, the contrived bright line has also influenced judicial observation about impairment in adolescent judgment.<sup>135</sup> However, because of increasing pressure to respect adolescent decision making, the arbitrary line does offer appropriate legal protection in preventing adolescents facing life and death from becoming victims of their age. The bright line is a beneficent device for mitigating premature death that may result from appeals to adolescent autonomy in allowing respect for refusal. It is not ethically inappropriate to 'use' the bright line as an advantageous tool in protecting such adolescents, if doing so is consistent with beneficent action.

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<sup>133</sup> Purdy, L.(1992), 78.

<sup>134</sup> Ross (1997) fails to consider that in some areas, adolescents do have some rights – statutory rights that are given where, if affected teens were not to avail themselves of them, the society would bear a great burden. Interestingly, we give, and do not give rights, based on which has the biggest benefit to society.

*Correlative duties to others: Do seriously ill adolescents have responsibilities if they have rights?*

We have explored the concept of adolescent rights, how they are, or are not, conceived, and how the legal system objectifies them. A handful of judicial proceedings, as well as, professional guidelines ascertain that seriously ill adolescents do, and should, have the right to refuse life-saving or life-sustaining treatment. Whether that right is, from a moral perspective, a liberty right or claim right is unclear. A liberty right is a right to noninterference by others, whereas a claim right is a right to some good or service from particular others.<sup>136</sup> We generally believe that infants and young children do indeed have claim rights - even though they are incapable of claiming them - because parental care and supervision is owed to them for their own sakes. Liberty rights for children vary inversely with claim rights. As children grow and mature, parental authority is gradually relaxed as the child has less claim on the parents' duty to provide need-fulfillment.

Allowing an adolescent to authorize a life-saving treatment refusal could mean that either or both liberty and claim rights are seriously considered by parents and providers. By not interfering with the adolescent's decision, we have given full weight to the young person's liberty interest and right to refuse. On the other hand, and perhaps simultaneously, we may see the adolescent claiming a good in appealing to parents and providers to respect her refusal of treatment. Since rights language is frequently employed in discussion of treatment refusal, I will utilize it for the sake of my argument here. That is, adolescents facing life and death have a claim right on their parents and

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<sup>135</sup> Hartman, R.G. (2002), 415.

health care providers to protect their future interests by overriding their refusal of treatment if warranted by the principle of beneficence-in-trust. In turn, chronically ill adolescents facing poor life prognosis hold a different claim right. The nature of that right is for their parents and providers to listen to their refusal and give it serious consideration, especially if further treatment would be far more burdensome than beneficial.

Many questions remain about whether adolescents faced with life-threatening illness or disease have any responsibilities and whether they, as ‘sick’ individuals, align to the ‘sick role’ as conceptualized by ‘sick role theorists’.<sup>137</sup> If it is acknowledged that receiving respect for one’s autonomy also means that the autonomy of all others is also respected, the expectations on a very sick adolescent become questionable. If we respect her right to make life-and-death decisions about herself, does she have a responsibility to respect a corresponding right among others who are morally and professionally charged to uphold her best interest? However, if adolescents have no decision making rights it is arguable whether they then have responsibilities toward others with interest in their welfare. If we agree that the adolescent may not have the ultimate authority in deciding on life-saving treatment for herself, we can still acknowledge that she should have significant opportunities to voice her views, fears, and questions. We can also expect that

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<sup>136</sup> Blustein, J (1982), 163. Citing Hohfeld, W.N. (1964) *Fundamental Legal Conceptions as Applied in Judicial Reasoning*. New Haven: Yale Univ. Press.

<sup>137</sup> Parsons’ well-known concept of the ‘sick role’ has four features: 1) the sick person has an inability to perform her socially approved roles that is not correctable by her will or actions; 2) the sickness is a legitimate excuse from performing role responsibilities; 3) the sick person shares the basic value assumptions as the rest of society; and 4) the sick person seeks the help of the identified authority and submits to that person’s regimen in order to get well. Discussed in Brody, Howard (1987). *Stories of Sickness*. New Haven: Yale University Press, 36. Whether the sick adolescent aligns with any of these

the ill adolescent should acknowledge and respect that others - her parents, her providers – will also have views to be voiced, which might be quite different from her own. The triadic approach addresses the exchange of values and information in therapeutic alliance that affords acting according to the principle of beneficence-in-trust on behalf of the adolescent.

### **Conclusion**

Encouraging adolescents' participatory inclusion in decision making about themselves is normative.<sup>138</sup> The teen's developing maturity puts her in the unique situation of wanting to know about her illness, wanting to be an active participant in conversations with health providers, but not necessarily being able to process the information with an eye to her future. It appears, then, that soliciting the adolescent's consent when cognitive elements of decision making capacity are evident is disingenuous if the refusal will not be honored. Perhaps to even talk about adolescent decision making autonomy in light of this discrepancy between accepting consent and not accepting refusal has us chasing up the wrong tree. The vocabulary of individual rights and autonomy is an 'ill-fitting' ethic for the family relationship in which the adolescent is a major player.

What is needed is to move the problem away from an obsession with adolescent autonomy and more toward an enveloping family mutualism. The central importance of relationship in the family without losing sight of the individuality of the parties is

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features, especially #2 (do they have any responsibilities usually?) and #4 (parents will seek out medical attention on behalf of their child) is questionable.

<sup>138</sup> Committee on Bioethics, American Academy of Pediatrics (1995).



captured by Thomas Murray's model of mutualism.<sup>139</sup> Murray's model of mutualism reflects the "relevant facts about parents and children: that the flourishing of parents and children is intertwined; that by doing what is loving for their child parents experience profound satisfactions and develop virtues that promote their own flourishing as well."<sup>140</sup>

The notion of flourishing connotes the fulfillment of intertwined obligations and responsibilities within the family. The additional notion of the "therapeutic alliance" supplements the intertwined obligations by adding those of health care providers. Their role is to forge communicative relationship based in beneficent practice.

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<sup>139</sup> Murray, T. (1996), 61. Murray sees the vocabulary of individual rights and autonomy as an "ill-fitting ethic" for the family.

<sup>140</sup> Ibid., 61.

## **CHAPTER 4**

### **Parental Rights and Responsibilities when an Adolescent Child**

#### **Refuses Life-or-Death Treatment**

The analysis in this chapter forms the second part of a triadic approach that examines the ethical considerations of an adolescent's refusal of life-saving treatment: parental rights and responsibilities. The first part of the decision making approach was examined in relation to the adolescent's decision making capacity, interests, rights and responsibilities in terms of making decisions, chapters 2 and 3, respectively. This chapter will query the extent to which parental interests, rights, and responsibilities are determinative in adolescent life and death decision making.

#### **Describing the Context**

A patient's refusal of recommended life-saving treatment is a disturbing and serious occurrence within the health care setting. Despite the presumed right to refuse medical treatment, refusals of life-saving intervention by capable adult patients may be viewed as unreasonable by health care providers and are not uncommonly challenged, ignored, or even overridden. Such events are fodder for the work of ethics committees that attempt to understand and offer suggestions for resolution of patient care dilemmas. Involving ethics committees in efforts to resolve problems related to a patient's refusal of recommended medical treatment suggests that respecting the presumed decision making capacity of autonomous adults is imperfect, at best. And even if decision making capacity were determined to be intact, other features of the patient's narrative may confound immediate respect for the adult patient's refusal. These include: wishes of the

family, such as spouse, children, and grandchildren, status of cognitive functioning, experience with the illness or disease and treatments already tried, and liability concerns of the clinicians. Health care providers may appropriately hesitate to respect the adult's refusal and seek to engage the patient and persons with moral standing in conversation to uncover the reasoning behind the refusal. Referral to the institutional ethics committee is another option in trying to resolve the ethical problem of refusal of recommended medical intervention. Such action may, in the long run, end up being beneficial for the patient by alerting the family, providers, and the patient herself to the seriousness of the situation. The patient, or surrogate, may reconsider the grounds claimed for treatment refusal and accede to the providers' recommendation with the hoped-for benefit of continuing to live a life within a family structure.

Refusal of life-saving medical treatment by an adolescent escalates the seriousness of the situation for all concerned. Just as an adult's refusal of treatment is enmeshed within a complex narrative, the adolescent's is often even more so. The adolescents' life story is, for the most part, only in its early chapters. It is primarily a story of dependence on parents, teachers, or other adults for the basics and the frills of living life as a growing teenager. The adolescent usually lives with one or two parents, may have siblings, an extended family, friends, even pets.<sup>1</sup> Family provides the adolescent with a home, a sense of belonging, and an identity intertwined with the lives of others. Parents,

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<sup>1</sup> For purposes of analysis, the 'ideal' family consists of at least one parent and one or more children living together

specifically, confer a background of values onto their children that continues its influence into adulthood.<sup>2</sup>

Within this expanded view of the adolescent's sphere, parents play a vital role in the teen's development into a young adult. As illness strikes, either at an early age or suddenly as a teenager, the parents are instrumental in seeking treatments - perhaps performing them<sup>3</sup> - in an effort to find a cure, or at least, relief for their sick adolescent.<sup>4</sup> Parents advocate for their child's treatments. They must often contend with the schools, the insurance companies, or the health care professionals to get what they feel their child deserves in the way of medical treatment or services. It is, then, illogical to suppose that these same parents would sit idly by the bedside of their child who is refusing life-and-death treatment, and deemed to be a capable decision maker, without 'making a fuss.' It

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<sup>2</sup> Granted not all adolescents are subject to the nurturing provided by a strong family environment. Some adolescents, sadly, are alone, without a family or parents who are supportive. If not physically alone, these adolescents may be emotionally abandoned. See *The Adolescent Alone: Decision Making in Health Care in the United States* (1999). J. Blustein, C. Levine, N. Dubler (Eds.), New York: Cambridge University Press. I will argue that even such "adolescents alone" should not be in a position to make life-and-death decisions without the participation of a supportive adult.

<sup>3</sup> Many chronic, inevitably fatal diseases of childhood and adolescence require continuous vigilance and the performance of active treatments on the part of parents and older siblings. For example, family members of children with cystic fibrosis are well-versed in the techniques of postural drainage and chest percussion, typically prescribed twice daily and lasting 45 minutes at a time, to clear the pulmonary tract of tenacious secretions.

<sup>4</sup> Seeking conventional treatment is conditioned by parental beliefs in mainstream health care. While the vast majority of individuals will pursue health care as made available by the current state of knowledge and technology, there are cases of parents whose religious faith (primarily Christian Scientist and Jehovah's Witness) impugns modern therapies for the sick. Such parents, unlike the indicting neglect or child endangerment accusations eventually filed against them, are generally preoccupied with employing all modalities for cure available within the confines of their religion. The American Academy of Pediatrics acknowledges the increasing use of complementary and alternative medicine among the pediatric population, especially in an effort to treat autism and related disorders (see *Pediatrics*, 107(e), 598-601). However, the use of faith-based therapies in the context of life-threatening illness becomes a contentious scenario, which is difficult for most providers to understand and permit. See *In matter of McCauley*, 565 N.E. 2d 411 (Mass. 1991) wherein the court applied the best interest test to determine that the child suffering from bowel obstruction should receive treatment over the parents' refusal on religious grounds.

is also unrealistic to suppose that these parents' input may be deemed inconsequential when their adolescent balks at, or refuses life-saving or -prolonging treatment.

The trend to regard the capable adolescent as the ultimate decision maker about her health care<sup>5</sup> appears to diminish the importance of the traditional parental activity of making decisions for their children. An overarching consideration appears to be whether parents should have a major role in assisting, or even making, life-and-death decisions on behalf of their adolescent. A further consideration is whether parents have rights or responsibilities to overrule their child's refusal of life-saving treatment, however sincere or misguided that refusal may be.<sup>6</sup>

### **The Argument So Far: Rights and Responsibilities of the Adolescent in Making Decisions about Treatment for Life-Threatening Illness**

An unsettling conclusion of Chapter 2 is that many early-to middle-adolescents<sup>7</sup> in our society may be viewed as capable decision makers according to guidelines in law and bioethics that emphasize cognitive abilities. This impression is reinforced by the presence of statutory legislation that has afforded adolescents numerous health care decision making opportunities. Such legal provisions for adolescent decision making

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<sup>5</sup> Bartholome, W.G. (1995) "Hearing Children's Voices." *Bioethics Forum*, 11(4), 3-6; Committee on Bioethics, American Academy of Pediatrics. (1995) "Informed Consent, Parental Permission, and Assent in Pediatric Practice." *Pediatrics*, 95(2), 314-7.

<sup>6</sup> The problem of medical treatment refusal by adolescents is a more remarkable scenario than is refusal by parents on behalf of their children. The latter is a generally settled ethical and legal position wherein the granting of a court order permits treating of the child with life-saving measures over and above parental refusal. The ethical and legal justification is rooted in a realization that simply because children are raised within their parents' religious beliefs, the children, as minors, have not internalized such beliefs into their own lives and therefore require protection. It may also be necessary to protect such children from undue influence or coercion by their parents.

<sup>7</sup> As described by the concluding report of the Carnegie Council on Adolescent Development (1995), early adolescence comprises ages 10 to 14. Middle adolescence covers ages 15 to 17, whereas late adolescence can stretch from age 18 into the twenties. *Great Transitions: Preparing Adolescents for a New Century*, Washington, D.C.: U.S. Dept. of Education, Office of Educational Research and Improvement.

authority are not necessarily justified by the adolescent's deemed adult-like cognitive capacities, but may rather stem from political expediency, societal utility, and creative judicial interpretation. The enthusiastic embrace of the principle of autonomy in clinical ethics has also increased the propensity to regard as capable any person who meets decision making criteria. Those decision making criteria, ambiguous at best, are not specifically designed for application to youth. A further complication is that many bioethicists and health care professionals who champion the ability of children to understand their illness, promote respect for adolescent decision making, maintaining that an adolescent's refusal of treatment ought to be essentially inviolable.<sup>8</sup>

Where Chapter 2 questions extrapolating adult decision making criteria into the adolescent arena, Chapter 3 examines the problems of applying adolescent rights and decision making autonomy to scenarios where the adolescent is in danger of dying without prompt medical intervention. The discomfort over this application to adolescents emerges from a shared intuitive impression that adolescents are known risk-takers, impulsive, and oriented to the present.<sup>9</sup> Additionally, adolescents have limited life experience, they have a limited context in which to place their own lives, and may as a result not be able to imagine themselves getting beyond the discomfort and fear they feel at present. A limited life context also means that adolescents rarely recognize their roles and responsibilities in the family structure. From their perspective, life is largely centered around themselves, their needs and desires, not necessarily those of their parents

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<sup>8</sup>See footnote 5 above. Also see, Midwest Bioethics Center Task Force on Health Care Rights for Minors (1995) "*Health Care Treatment Decision-Making Guidelines for Minors.*" *Bioethics Forum*, 11(4), A1–A16.

<sup>9</sup>See Scott, E. (1992). "Judgment and Reasoning in Adolescent Decision Making." 37 *Villanova Law Review*, 1607.

and family. These observations are not criticisms of adolescents, rather they serve as points of departure in acknowledging the realities of adolescent development. Handing adolescents rights, such as the right of refusal, with few commensurate responsibilities sets up troublesome dilemmas, possibly leading to the premature death of an adolescent who has been given the ‘right to make a mistake.’

Let us revisit the unfortunate 15 year old boys in the two exemplar cases running throughout this dissertation. AJ has cystic fibrosis, a chronic, inevitably fatal, disease that appears to have neared the end of its course. Without the aid of mechanical ventilation, complete respiratory compromise will occur followed by death. AJ does not want any further medical intervention, which includes intubation to sustain an airway. The second boy, BJ, is healthy and athletic. In contrast to AJ’s past medical situation, BJ had no experience with acute medical treatment prior to his recent diagnosis of synovial sarcoma. BJ does not want the life-saving, and probably curative, amputation of his leg. Both boys appear to meet the cognitive elements for decision making capacity which are: 1) possession of a set of values and goals, 2) understanding the information being presented, 3) appreciating the information for one’s own circumstances, 4) reasoning with the information, and 5) expressing a choice.<sup>10</sup>

The situations of these two boys as described are even more unfortunate if they alone are given full decision making authority for an irreversible decision, such that their refusal is the last word. Except in the unusual circumstance where the adolescent patient

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<sup>10</sup> Grisso, T. & Appelbaum, P.S. (1998). *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. NY: Oxford University Press, 20; President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). *Making Health Care Decisions, Vol. 1*. Washington, D.C.: U.S. Government Printing Office. See full discussion of these elements in Chapter 2.

has no support from a trusted family member or friend, the boys would not be alone.<sup>11</sup>

One or both parents would be involved with the adolescent in attempting to help sort out this gut-wrenching dilemma. But what ought to be the parameters of parental involvement in the decision to be made in AJ's and BJ's cases? An exploration of this question will lead into a discussion of the concepts of parental interests, rights, and responsibilities in the context of 15 year old boys faced with life threatening decisions.

### **Parental Interests in Decision Making for their Children: Buchanan and Brock**

In their authoritative book Deciding for Others: The Ethics of Surrogate Decision Making,<sup>12</sup> Allen Buchanan and Dan Brock set out a framework to describe the values involved in health care decision making on behalf of adults and children. They view decisions concerning the adult to center around two main values that may lie in dialectical tension: well-being and self-determination. Well-being deals with the preservation of goods and interests that sustain a person according to what she herself considers important in her own life. Exercise of self-determination is equally important to the adult deemed a capable decision maker who wants to make life decisions about herself. It becomes a derivative value when self-determination has never been demonstrated or achieved.

In health care decision making involving children, an additional third value contributes to the tension inherent in trying to balance often incommensurate values.

This third value is the interest of parents in making important decisions about their

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<sup>11</sup> See footnote 2. However, even an adolescent who is alone, should not be left to make an irreversible decision about life and death without the assistance of another, even if that person is a court-appointed advocate. This notion will be further developed as the chapter unfolds.

<sup>12</sup> Buchanan, A. & Brock, D. (1989) *Deciding for Others: The Ethics of Surrogate Decision Making*. New York: Cambridge University Press.



children's welfare. This value has great significance in scenarios involving parental refusal of life-saving or life-sustaining medical treatment for their infant children in opposition to providers' recommendations. Since the infant has no ability to contribute to an assessment of personal well-being and is not self-determinative, the parents are the sole representatives of the child within a setting of strangers. Although Buchanan and Brock illustrate the value of parental interests in decision making with scenarios involving infants, this same value has relevant applicability to the role of parental authority in decisions to be made about older children and adolescents, and will be developed herein.

Well-being and self-determination are the chief values at stake for both children and adults in ascertaining whether the adult or child patient will decide about his or her own treatment.<sup>13</sup> Buchanan and Brock point out that for the adult there are "typically no other-regarding values, which are thought to be decisive for the question of whether the patient is to be permitted to make his or her own decision."<sup>14</sup> But the situation is different for children in that parental interests in making important decisions about the welfare of their children have a role that is not generally present within adult health care. The determination of decision making capacity, which involves, in their view, only the patient-centered values of well-being and self-determination, cannot by itself resolve the problem of the child's decisional authority. Buchanan and Brock are correct in noting that the bioethics literature and health care practice have not adequately appreciated this crucial issue in describing informed consent and competence in minor patients. They

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<sup>13</sup> Ibid., 225-6.

<sup>14</sup> Ibid., 226.

offer four strains of reasoning for why parental interests may play a necessary role in medical decision making about children: 1) parents will do the best job in ensuring their children's welfare is served; 2) since parents must bear the consequences of treatment choices for their children, they should have some control over them; 3) parents claim a right to raise their children under their own values and standards and to transmit those to their children; and 4) our society views the family as a valuable and significant source of intimacy for adults and the developing capacities of children.<sup>15</sup> Each of these purported parental interests in making medical decisions about their children will be expanded upon below.

*Parents are interested in decision making for their child because parents do the best job in ensuring their child's well-being is served*

Is it true that parents will do the best job in ensuring that their child's well-being is served? A partial answer to this question can not be generalized especially since cases of parents acting contrary to their child's well being and best interest confront us in the daily news. However, it is probably safe to say that the vast majority of parents very much have their child's welfare at heart.

Parental concern about the welfare, or well-being, of their child resonates with an established legal and ethical concern for the child's best interests.<sup>16</sup> American society defers, for the most part, to parents to represent and advocate for their young children's best interests. This presumed responsibility of parents was put to a test during the 'Baby Doe' era of the 1980's when the federal government challenged the accepted

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<sup>15</sup> Ibid., 232-234.

<sup>16</sup> See discussion of 'best interests' in Chapter 3.

understanding that parents act in their child's best interests and ought to make their health care decisions. Officials claimed that parents who chose non-treatment for an impaired newborn, when in fact a medical intervention was possible but often very burdensome, were not loving and caring, but, rather, were self-interested and were prejudiced against the handicapped. The desire to extinguish all considerations of 'quality of life' in making treatment decisions was a major goal of federal officials who were concerned about discrimination against disabled newborns. Although the Baby Doe regulations have been diluted in their force and ramifications for health care providers, they have left behind the question of whether parents are the best decision makers, especially for very young children.<sup>17</sup>

In addressing whether parents are the persons most interested in their child's well-being, Goldstein, Solnit, Goldstein, and Freud offer a response that remains controversial. The authors submit that no one has a greater responsibility, nor can anyone be presumed to be in a better position, than a child's parents to decide what course to pursue if medical experts disagree about the treatment or if the outcome of a certain treatment is better than no treatment at all. They ask the question, "how can parents in such situations be judged

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<sup>17</sup> The Baby Doe infants included several cases beginning in 1982 involving the birth of infants with varying disability and impairment. The case of Infant Doe involved an infant with Down's syndrome and tracheoesophageal fistula, requiring rather routine surgery in order to allow feeding. The case of Baby Jane Doe involved an infant born with microcephaly, spina bifida, and other handicaps. Parents refused surgery in both cases. The Department of Health and Human Services (DHHS) first implemented so-called Baby Doe Rules in 1983 to require treatment of all defective newborns. Due to widespread misunderstanding, these rules underwent revisions. In 1984, Congress amended its Child Abuse Prevention and Treatment Act to count non-treatment of handicapped newborns as child abuse. These regulations required that, except under certain specified conditions, all newborns receive maximal life-prolonging treatment. The United States Supreme Court heard the case of *Bowen vs. American Hospital Association* in 1986 ruling that the government had no authority to give unsolicited advice to parents, hospitals, or officials about difficult decisions concerning handicapped newborns (476 U.S. 610, at 611). See discussion in Pence, G.E. (1990) *Classic Cases in Medical Ethics*, NY: McGraw-Hill, 141-63 and Boyle (2005) "Newborns, Infants, and Children." In, J.C. Fletcher, E.M. Spencer, & P.A. Lombardo (Eds.), *Fletcher's Introduction to Clinical Ethics*, 3rd ed., 238-9.

to give the wrong answer when there is no way of knowing the right answer?"<sup>18</sup>

Goldstein and colleagues argue that parental autonomy must be recognized in such cases or the state should assume the full responsibility of treatment, care, and nurture of such children. Buchanan and Brock take issue with this argument for two reasons. They see that in suggesting there is no single correct answer, it does not follow that any answer will suffice. Rather, the decision making process ought to include constructing a range of reasonable options from which the 'best' option can be chosen. Buchanan and Brock also disagree with Goldstein and colleagues' approval of unilateral parental decision making. High stakes decision making must involve a deliberation process, which ensures fairness and consideration of relevant factors to the best extent possible. Buchanan and Brock suggest the institutional ethics committee as being the most promising mechanism in fostering an ethical process of decision making.<sup>19</sup>

Lainie Friedman Ross, a pediatrician and bioethicist, is critical of Goldstein and colleagues' willingness to allow parents the right to determine what 'a life worth living' is from the parents' perspective, rather than from the perspective of the child.<sup>20</sup> Although Ross claims the difference is obvious, her critique also begs the question of whether the young child, especially, has a perspective. She notes that parents ought to make difficult decisions about life-saving treatment for their young children from the child's own perspective and consider whether the treatment would promote the child's personhood.

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<sup>18</sup> Goldstein, J., Solnit, A.J., Goldstein, S., & Freud, A. (1996). *The Best Interests of the Child: The Least Detrimental Alternative*. New York: The Free Press, 130.

<sup>19</sup> Buchanan, A. & Brock, D. (1989), 258.

<sup>20</sup> Ross, L.F. (1998) *Children, Families, and Health Care Decision Making*. New York: Clarendon Press, 138-140.

If, Ross advises, parents are unwilling to accept such limitations on their decision making, they do not have the right to make such decisions.

Buchanan and Brock submit that the line of reasoning that claims parents are most interested in the child's well-being gives parents no independent right to decide or to enforce their choice if that choice, as determined by others, does not best serve the children's welfare. The crux of the claim emphasizes the child's welfare; no intervening interests exhibit more importance.<sup>21</sup> A fundamental shortcoming, though, of an argument based on asserting that parents know their child's best interests is that 'best interests' are difficult to know. They are to be interpreted in the context of the child, but may still remain essentially subjective. A young child is not capable of contributing a view, but an older child, a teenager, is. The adolescent may well determine his 'best interests' in reference to himself. However, a parent may unavoidably insinuate other considerations into what are the child's 'best interests,' such as a desire to not lose the child to death, an unwillingness to give up trying to find a cure, or an unremitting religious faith in a miracle. 'Best interests' is a slippery concept that contributes significant leverage in discussions about surrogate decision making but is inadequate for substantive understanding of parental authority in cases of critical life-and-death decision making for the adolescent.

*Parents have an interest in making decisions for their children because since they must bear the consequences of treatment choices for their children they should have some control over them*

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<sup>21</sup> Buchanan, A. & Brock, D. (1989), 233.

Buchanan and Brock submit that even if parents must bear some consequences of forced treatment, it is the child who bears them primarily, so parents may be permitted only limited discretion.<sup>22</sup> Although the authors essentially dismiss this strain of reasoning, it may actually have some basis for the older child and will be more fully developed in terms of its application to the adolescent. The scenarios involving the two boys are built on the chronological advantage both boys have over infants, and, in addition, an experiential advantage for AJ. AJ is experienced with his ever-worsening illness. He has lived with it his entire life, is savvy to the discomforts, annoyances, and expectations of medical treatment, and has an understanding of what a future connected to a ventilator holds for him. AJ is adamant about refusing any further life-saving medical treatment. BJ has no real experience of pain and suffering. He has only the recent experience and discomfort of testing, poking, and prodding in being diagnosed with a life-threatening illness. He also has the conviction that he cannot live without his leg, because he would be unable to carry on with his life as it had been. BJ is adamant about his refusal and he will not accept a potentially life-saving amputation of his leg.

Health care providers see two boys who 'know their minds.' Parents see two sons who will surely die without the necessary medical interventions which the boys have refused. As Buchanan and Brock point out, it is the boys who will die or primarily bear the consequences of forced treatment in the face of their overruled refusals.

However, there is another narrative in these boys' lives. It is that of their parents and family. If the parents insist on treatment, they must bear the potential consequences of

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<sup>22</sup> Ibid.

their sons despising them and making the family's lives miserable. If the parents allow their sons' refusal they must in turn bear the consequences of their sons' deaths and their own guilt. On the one hand, the parents' relenting to AJ's refusal for further treatment is understandable. He has lived a difficult life, is informed about his limited future, and is wise to the medical treatment required to save his life. On the other hand, the parents' acquiescing to BJ's refusal, is morally unthinkable for the parents and unethical for health care providers to permit. Parents must be the guardians of their children's welfare and the adolescent's potential. In allowing their child to become a victim of his own autonomy, in the case of BJ, the parents would bear consequences of inestimable guilt since they have not fulfilled their responsibility of protecting their child's welfare.

The child's potential ability to self-determine his future is protected by parents' stewardship of the child's 'rights-in-trust.' Such rights-in-trust are summed up by Joel Feinberg as the child's 'right to an open future.'<sup>23</sup> Feinberg maintains that since children have only developing autonomy, it is up to the parents, and by default, the state, to ensure that a child's prospects are left as unrestricted as possible so as to afford that child the ability to determine his own future. In the case of BJ, allowing him to refuse life-saving treatment, permitting him to die because that is his decision, clearly and severely limits his future prospects. Unlike the case of a capable adult who regrettably refuses recommended life-saving treatment, there is an opportunity to protect BJ from the irreversible consequences of his own ill-advised decision by allowing parents to protect

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<sup>23</sup> Feinberg, J.(1980) "The child's right to an open future." In, W. Aiken & H. LaFollette (Eds.), *Whose Child? Children's Rights, Parental Authority, and State Power*, 124-153. Totowa, NJ: Rowman & Littlefield.

their son's welfare. BJ ought not to bear the consequences of our wavering notions of adolescent autonomy and authority.

Richard Miller quite rightly points out that Feinberg's 'rights in trust' can cut in two directions. "They may restrict the authority of caretakers whose decisions may seriously handicap children's future options, or they may empower caretakers to exercise authority over children's conduct should those children make decisions that promise seriously to attenuate their opportunities as adults."<sup>24</sup> Respecting the autonomy of a capable adult to make his own decision is a highly prized ethical principle and ordinarily supercedes forced intervention against the patient's will. However, the autonomy of the adolescent is arguably incomplete and is complicated by decisional authority and responsibility held by parents. As compared to adults who, depending on their ages, have embarked on their future in some way, the prospect of the child's future self ought to have significant moral weight in determining our medical treatment of children.<sup>25</sup>

Feinberg's 'right to an open future' acknowledges that since a child still has the task of growing and developing left to complete, other adults in her life will do their best to ensure that her future retains as many options for her autonomous choices as are possible. Peter Brown proposes a principle of 'primary parental responsibility' that bears some similarity with Feinberg's notion of the 'right to an open future.' Brown writes that parental responsibility "consists in securing for children those primary goods that are necessary for successful participation in the central institutions of the society in which the

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<sup>24</sup> Miller, R.B. (2003) *Children, Ethics, and Modern Medicine*. Bloomington: Indiana University Press, 43.

<sup>25</sup> Ibid.



child can reasonably be expected to live as an adult,”<sup>26</sup> unless those institutions are seen to be morally objectionable. By appealing to John Rawls’ primary social goods, construed as things with which one may be more able to carry out one’s rational plans, such as rights and liberties, opportunities, income and wealth,<sup>27</sup> Brown holds that securing such goods, which may or may not be different for children, ought to be a paramount parental concern for their child’s future. Ross and Purdy supply a slightly different perspective in adding the parental responsibility of providing children with a protected period in which to develop “enabling virtues,” such as the habit of self-control, which advance life-time autonomy.<sup>28</sup> Ross evidently agrees with Brown in acknowledging that securing an open future for a child does not mean the child must be equipped to function with requisite skills in any social or community setting. However, Ross contends that parents ought to have flexibility in securing a threshold level of each primary good for their child.<sup>29</sup>

It is the parents’ responsibility to maintain the ‘right to an open future,’ by fostering in their child the cognitive, emotional, and physiologic capabilities to secure primary goods and develop enabling virtues. The right to an open future generates obligations on the part of parents to ignore children’s wishes if they seem harmful to their future interests.

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<sup>26</sup> Brown, P.G. (1982). “Human Independence and Parental Proxy Consent.” In, W. Gaylin & R. Macklin (Eds.), *Who Speaks for the Child? The Problems of Proxy Consent*, 209-222. New York: Plenum Press, 215.

<sup>27</sup> Rawls, J. (1971). *A Theory of Justice*. Cambridge: Harvard University Press, 92.

<sup>28</sup> Ross, L.F. (1995). “Arguments against Health Care Autonomy for Minors.” *Bioethics Forum*, 11(4), 22-6, p. 23; Purdy, L. (1992). *In Their Best Interest? The Case against Equal Rights for Children*. New York: Cornell University Press.

<sup>29</sup> Ross, L.F. (1998), 49-50.

A corresponding duty of beneficently focused pediatric providers is also to protect a child's welfare but to do so within a context of therapeutic alliance<sup>30</sup> with the adolescent's parents or guardians.

*Parents claim a right to raise their children according to their own values and standards, and to transmit those values and standards onto their children.*

The interest that parents have in making medical decisions for their children may have a basis in the parents' own faith beliefs, political tendencies, or broader sensibilities. Since, in American society, we accord the family a significant role in shaping the development of younger generations, it is reasonable to entrust parents with significant discretion over imparting their values to their children. In the context of adolescent life-and-death decision making there are two potential problem areas to address within this strain of reasoning about parental interests: 1) parents with religious beliefs that are incompatible with withholding or withdrawing non-beneficial or unwanted medical treatment and 2) parents who may have strong political sympathy with parental rights movements, which are often themselves inspired by faith-based constituencies.

The narrative scenarios of AJ and BJ can come to similar conclusions if the refusal of both boys is permitted - both will die. If both refusals are overridden, they will not die, although AJ will be subjected to further suffering in the face of an already grim prognosis. BJ may be cured of his cancerous disease, learn to adapt to a prosthesis and live a long life. Let us now suppose that both boys came from fervently vitalistic

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<sup>30</sup> Miller's (2003) term for the relationship forged by pediatric health care providers with the patient and parents. See Chapter 5 for further expansion of this concept.

religious families.<sup>31</sup> Parents are shaken and perceive themselves as spiritually inept that their sons would think of letting themselves die when, in their minds, further treatment is possible. In the parents' view it is God, not man, who determines when death will occur. The boys and the health care team are placed in the untenable situation of dealing with parents who may be unable to grasp the situation from any other than a narrow perspective. Such an inability is most assuredly unfortunate in AJ's case.

Up until now little has been said about the situation of AJ. It has been mentioned that respecting his refusal, acting beneficently in light of his experience with sickness and suffering, would be understandable, albeit distressing, for the parents and health care providers. The justification for such a perspective comes from considerations about his experience-enhanced decision making capabilities in terms of medical treatment, his recent and past ordeals with discomfort and suffering, the anticipated suffering to come, and the life-limiting course of his severe disease process. Further treatment to prolong his life can be viewed as more burdensome as compared to any benefit derived. Enter now parents who maintain that treatment must continue over and above their son's refusal. The son has had enough, but the parents claim that is not for him to determine. How much ought the parents' interests in raising their child according to their own values and standards count?

A partial answer would be to look toward the boy's own wishes, the opinions of the health care providers, and whether intervention, such as ethics consultation, may assist the parents to view the situation from alternative perspectives. Parents ought to have

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<sup>31</sup> A particular religious faith is not named here, nor is it necessary that a recognized faith group be acknowledged for this particular line of thinking to occur

some license in shaping their child's value system so that it reflects their own. However, parents are not permitted to require the enforcement of such values when they become detrimental to the child's well-being. Ethics and the law maintain that parents may not “make martyrs of their children before they have reached the age of full and legal discretion when they can make that decision for themselves.”<sup>32</sup> In this case, the ‘weak rule’ for clinical intervention as proposed by Pellegrino and Thomasma may be applicable in supporting action based in beneficence-in-trust. Herein, providers may act in the best interests of the adolescent patient by overcoming an impediment,<sup>33</sup> one in which the parents are not hearing and understanding their son’s values in his personal context. AJ’s providers should work to draw the parents into a ‘therapeutic alliance’ with the parents so as not to isolate them in their misunderstanding of their son’s situation.

The case of AM reported in the Canadian literature is instructive in how the parent of a refusing adolescent was given legal authority to make life-and-death treatment decisions that were not supported by health care providers. AM was diagnosed with renal failure at 12 years of age.<sup>34</sup> Her condition was complicated by repeated abdominal infections while on peritoneal dialysis and difficulties with vascular access while on hemodialysis. At 14 she received a cadaveric kidney transplant which showed signs of rejection within 6 months. AM could not remember a time when she had felt well. She

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<sup>32</sup> This oft-used phrase is from the decision in *Prince v. Massachusetts* (1944), 321 U.S. 158, at 170. The case did not concern itself with health care, rather it involved the distribution of religious material by children, in violation of child labor laws. However, the phrase has had important relevance to classic parent refusal cases involving blood transfusions and other life-saving interventions.

<sup>33</sup> Pellegrino, E.D. & Thomasma, D.C. (1988). *For the Patient’s Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press, 157.

<sup>34</sup> Doig, C. & Burgess, E. (2000). “Withholding Life-Sustaining Treatment: Are Adolescents Competent to Make these Decisions?” *Canadian Medical Association Journal*, 162 (11), 1585-8.

informed her health care providers and family that she did not want to return to dialysis when the transplanted kidney finally failed. AM's mother was emphatic about her continued treatment and was supported by hospital counsel, who advised that the mother had legal authority over AM because she was still a minor. In part because AM's providers disagreed with hospital counsel and her mother, AM was able to have many frank discussions about treatment options. AM did undergo a trial of dialysis, but was, in the end, permitted to discontinue treatment.<sup>35</sup>

In this case, the mother's disagreement with AM's treatment refusal was respected and legally authorized. While the authors attempt to attribute power-hungry control to the mother, I contend that the mother was correct in wanting AM to try dialysis again. Ultimately, AM was permitted to discontinue the life-prolonging treatment because "she did not believe that dialysis offered any opportunity for her to recover or get well but rather, that it would simply prolong her suffering."<sup>36</sup> By forging a therapeutic alliance, in spite of their initial disagreement with the mother, health care providers persuaded AM's mother that after AM's trial of dialysis, her refusal of continued treatment was based on further experience and realization that the life-sustaining dialysis was unacceptable to her. Pellegrino and Thomasma's intermediate form of beneficence-in-trust points to trying the life-saving treatment, but withdrawing it when it is no longer beneficial.

In contrast to AM's scenario where a parent opposed her treatment refusal, parents may choose not to subject their child to recommended life-saving treatment because doing so may be contrary to their values or religious beliefs. Parents or guardians, are in

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<sup>35</sup> Ibid., 1587.

<sup>36</sup> Ibid.

such cases, viewed by clinicians as placing the child's or adolescent's life in jeopardy by not duly considering her best medical interests. After all methods of discussion and persuasion prove intractable, court orders authorizing medical intervention can, rather effortlessly, be obtained by health care providers. If an older child is capable of registering a wish for life-saving treatment in opposition to parents, and the wish is consistent with the providers' assessment of best interests, the parents are overruled.

Another facet of this scenario worthy of mention arises when both parents and adolescent agree in refusing life-saving treatment. The case of E.G. discussed in Chapter 3 illustrates that parents are often successful in imparting their religious values onto their children, but even in doing so they were overruled by the courts.<sup>37</sup>

The politically volatile issue of legally protected parental rights poses a distressing claim on parents' decision making authority about their adolescent. The Parental Rights movement, which waxes and wanes in its political and popular support, is an area in which the demands of parents, who claim inscrutable authority over their children's lives, may impact the fates of AJ and BJ. Popularly supported parental rights legislation has received significant coverage in recent years. The Federal Parental Rights and Responsibilities Act (PRRA), brought before the House and Senate in 1995, sought to enact legislation that would remove from public jurisdiction all matters related to the rearing of children, including health care and education. The bills were met with

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<sup>37</sup> *In re E.G.* 549 N.E.2d (Ill. 1989).

resistance and although they never made it out of committee, the debates remain on record.<sup>38</sup>

Proposed legislation in the federal sector is mimicked in attempts in numerous states to amend constitutional or statutory provisions in the name of parental rights. The action in Colorado was most visible in the mid 1990's. Although it failed in a state-wide referendum in 1996, other states continue to pursue parental rights legislation in the form of amendments or statutory language.<sup>39</sup> The possible impact of such legislation in health care could mean the end of certain statutory protections for adolescents to seek medical treatment without parental consent, such as reproductive, substance abuse, and mental health treatment. Advocates of the movement maintain that parents ought to have complete authority over their child's medical care and their education such that the state may not usurp their authority. Implications of state intrusion on parental authority and the privacy of the family will be further discussed in Chapter 5.

*Parents have an interest in making decisions for their children because our society views the family as a valuable and significant source of intimacy for adults and the*

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<sup>38</sup> The PRRA was introduced in the House of Representatives in June 1995 by Congressmen Largent (R, OK) and Parker (D., MS). Virtually identical legislation was introduced in the Senate by Republican Senators Grassley (IO), Lott (MS), Helms (NC), and Cochran (MS). Lane, L.(1998). "The Parental Rights Movement." 69 *University of Colorado Law Review* 825, p.830; Woodhouse, B.B. (1996). "A Public Role in the Private Family: The Parental Rights and Responsibilities Act and the Politics of Child Protection and Education," 57 *Ohio State Law Journal* 393, p. 398.

<sup>39</sup> For example, Michigan, Kansas, and Texas retain familiar Supreme Court "fundamental right" language in state legislation indicating the fundamental right of parents to "determine and direct the care, teaching, and education of their children" (MCLA 380.10), "exercise primary control over the care and upbringing of their children in their charge" (KSA 38-141), and "to direct the education and upbringing of their children" (Tex. Gen. Laws 102 (1997)), respectively. Home School Legal Defense Association, "Why do we need parental rights legislation?" Retrieved Feb. 29, 2004 at [www.hslda.org/docs/nche/](http://www.hslda.org/docs/nche/) Recently the Utah Legislature's House passed two measures proposing to redefine parental rights in cases of alleged medical neglect. The legislation is prompted by the case involving a young Utah boy whose parents chose to remove him from the state rather than submit to treatment for his cancer. Bryson, A.J. (2004) "House OKs 'Parental Rights' Measures." *Deseret Morning News*, Feb. 28, 2004.

*developing capacities of children.*

In this final strain of reasoning outlined by Buchanan and Brock, parents are viewed as incomparable to any other social entity in fulfilling the necessary goal of raising children who will be adult contributors to society. Parents and families are envisioned as child-rearing units where intimacy and privacy are respected to the extent possible. In order to do the job of parenting, society confers rights upon the parents to clothe, house, and educate their children as they see fit providing their methods do not inordinately harm the child. However, intimacy and privacy are not inviolable and where parents are suspected of abusing or otherwise harming children, government has the right to intervene and remove those children from the environment. This fourth strain of reasoning regarding parental interests in Brock and Buchanan's framework is, in many ways, most comprehensive since it incorporates notions of parental rights, competing interests of the family, and parental authority.

Parental rights, and in turn, parental autonomy are over-used terms in pediatric health care to the frequent detriment of not acknowledging the voice of the older child or adolescent. The restrictions of our language or perhaps the dominance of particular concepts, such as rights, impoverish the notion of a parent-child relationship. In Thomas Murray's view, rights language is incorrectly used in reference to what parents must do as parents.<sup>40</sup> Even mentioning the notion of parental rights gives an unavoidable impression of ownership. Murray encourages avoidance of traditional references to parental rights or authority in the parent-child relationship. In contrast to the association

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<sup>40</sup> Murray, T.H. (1996). *The Worth of a Child*. Berkeley: University of California Press.



of authority with ownership, stewardship, or consent, Murray submits that parents require authority to the extent necessary to facilitate a loving and trusting relationship

### **‘Parental Autonomy’**

Unfortunately, Murray's ideal of parental authority remains underappreciated. The strains of reasoning that address parental interests in making medical decisions about their children contribute to an established, but poorly understood, concept of parental rights. Even more disturbing though is the prevalent usage of 'parental autonomy.' The concept is frequently used in the pediatric setting, especially in reference to very young patients, those who are too young to participate in any medical decision making discussions about themselves. What then is parental autonomy? Discussion about autonomy has, heretofore, expressly referred to the notion that adult patients who are presumed to possess decision making capacity have access to autonomous decision making about themselves, whereas adolescents are seen to have developing autonomy.

Autonomy is deemed to be a self-referential concept - meaning it refers to, and is about, the individual. Individuals make decisions for themselves based on several criteria which include their own interests, their values, the understanding of their prognosis, and perhaps the wishes and situations of important family members. If persons are unable to actively make decisions, then their surrogate decision maker is called upon to represent the patient. The surrogate, presumably knowledgeable of the patient's values and life circumstances, is entrusted to represent only the patient's wishes and is not permitted to

consider her own personal circumstances, especially if she will be the caretaker for the patient. Such a scenario, though, may not be what the patient actually intended.<sup>41</sup>

In the practice of decision making on behalf of adults who have never been capable decision makers, who have profound mental or neurological impairments, or have never expressed or demonstrated their decisional preferences, a designated legal guardian is required to make decisions in their 'best interests.' However, even these guardians are not permitted to make decisions about the patient based on circumstances that do not immediately impact the patient. A notion of 'surrogate autonomy' is clearly not part and parcel of adult decision making.

Where, then, does the concept of 'parental autonomy' arise? Making decisions about children is a completely different undertaking than with adults. Since infants and young children are unable to express their preferences - never have but surely will as they grow - their parents are in the best situation to represent them. Parents will not be representing their child's expressed values and interests, rather parents will represent their child to health care providers as an individual, as a person needing health care. Parents are understood to be their child's biggest and best advocates. Providers must ask permission of parents to carry out interventions on the young patient. Parents give or refuse

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<sup>41</sup> Continued efforts in the literature to include the family in medical decision making by and about an adult family member are met with brief interest but are not seriously incorporated into practice. Some bioethicists, writing from a communitarian perspective, recognize that the principle of individual autonomy is impractical in the clinical setting where the family is intimately involved in the life of the adult patient. See Hardwig, J. (1990) "What about the Family?" *Hastings Center Report*, 20 (2), 5-10; Kuczewski, M. (1996) "Reconceiving the Family: The Process of Consent in Medical Decision-Making." *Hastings Center Report*, 26(2), 30-7; Blustein, J. (1993) "The Family in Medical Decisionmaking." *Hastings Center Report*, 23(3), 6-13; Strong, C. (1993) "Patients Should Not Always Come First in Treatment Decisions." *Journal of Clinical Ethics*, 4(1), 63-5,75; Nelson, J.L. (1992) "Taking Families Seriously." *Hastings Center Report*, 22(4), 6-12.

permission based on their sense of whether their child would benefit. They do not have the option of giving permission based on other considerations, hence their 'autonomy' - and indeed that term is misappropriated - is located solely in the decision making for their child. This description of the ideal of parental decision making is unsurprisingly ambiguous in practice, especially since it does not encompass the notion of competing interests. Parents may have their own selfish interests in making decisions that are separate from their child (and this is what was feared in the Baby Doe period). However, parents may also have the best interests of the entire family or particular family members in mind when called upon to make medical decisions about one child.

Ross takes issue with Brock and Buchanan's 'best interests' conceptualization, in noting that parents must also accommodate family interests as a unit, considering not only the best interests of the child patient but also of other siblings and perhaps, themselves.<sup>42</sup> As long as other interests do not prevent parents from fulfilling their child's basic needs, their decisions in representing the family are justified. Ross takes note of the child's limited decision making capacities by advancing the model of constrained parental autonomy. This model is "based on parental autonomy and is constrained by the principle of respect for persons modified to apply to children."<sup>43</sup> In contrast to Ross' position, Brock and Buchanan submit that parents are the appropriate surrogate decision makers for their children and that parents should be guided by the child's well-being, the child's self-determination, and their own interests in being

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<sup>42</sup> Ross, L.F. (1998), 42-4.

<sup>43</sup> Ross, LF (1998), 50.

parental decision makers. Ross agrees with these points but sees that parents must also look to the larger interests of the family.

There are at least two problematic areas in these key divergences on parental autonomy. First, Ross' model retains the language of 'parental autonomy', where parents retain fallacious self-determination about decisions relating to their child, and for Ross, in the context of family needs. Second, in Brock and Buchanan's view, parents may make decisions in their child's best interests, but also due to their own interests. Whereas Ross looks to the interests of other family members, Brock and Buchanan confine parental attention to a specific child and themselves. Perhaps, this is too fine a hair to split, but it seems clear that Brock and Buchanan are not overtly looking to the interests of other members of the family. Ross quite rightly notes that parents must account for the health, transportation, educational, and other needs of all children in the family. If these needs can be neatly organized and met without substantial obstacle, the parents' interests are certainly met and may not impact decision making about their child. While Ross' argument may be appropriate for families that must balance the needs of multiple members in daily life, it does not resonate in the adolescent life-and-death decision setting. An adolescent confronting a life-threatening illness or culmination of long-standing chronic disease demands the full attention of parents and health care providers. Family interests cannot contribute to the parental role in the decision making process about the adolescent facing life-or-death.

Miller tempers a discontent about use of the term 'parental autonomy.' He notes that parental autonomy is the method through which family privacy is upheld. Respect for

family privacy presupposes the family as the unit principally responsible for the child's welfare. Miller is correct in noting that respecting parental autonomy differs from respecting autonomy in adult medical contexts. Parental autonomy is conditional and is constrained by the criterion of the child's welfare. Adult autonomy does not adhere to standards of medical welfare. When pediatric providers respect parental autonomy they are not respecting persons as in the adult setting. Rather providers are acting in therapeutic alliance with parents or guardians who must justify their actions as being beneficial, or at least not harmful. Both parents and providers are obligated to act in the interests of the child's welfare ideally facilitated through a therapeutic alliance.<sup>44</sup>

Miller's views come closest to the conceptualization of beneficence-in-trust that has been the focus for adolescent life-and-death decision making in this dissertation. Questions of autonomy, either the adolescent's or parent's, give way to forging a therapeutic alliance to ensure the enactment of the adolescent's best interests in a life-and-death scenario.

### **Adolescents Without Involved Parents in their Lives**

The problem of the adolescent without an involved parent or guardian is unfortunately not uncommon in the pediatric and adolescent health care setting. It would be insensitive and unethical to presume that if a teen faced with a life or death medical decision does not have an involved parent or guardian, she gains default decision making authority by virtue of the void in her life. Just as adolescents with parents are not to become victims of their own autonomy, the same ought to be true for adolescents alone.<sup>45</sup>

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<sup>44</sup> Miller, R. (2003), 40.

<sup>45</sup> Defined as "patients between the ages of thirteen and eighteen, without kin, who faced ethically significant medical decisions." In, Levin, Betty, W. (1999) "Adolescents and Medical Decision Making: Observations of a Medical Anthropologist." In, J. Blustein, C. Levine, N. Dubler (Eds.), *The Adolescent*

In an ethnographic study of an adolescent inpatient unit, Betty Levin observed medical care and adolescents' responses, as well as medical decision making by the adolescent and other adults. At a time when the rate of runaway or 'thrown away' children is rising, Levin found very few of the adolescents to be technically alone. When there were no legally authorized guardians, there were often extended family members, or other adolescents or adults who could be involved in discussions about medical care. Even when no family members were available, Levin noted that medical care was not compromised because the adolescent patient eventually agreed to treatment recommended by the health care providers. Levin sees such action being acceptable, acknowledging that the clinicians are often the only individuals who know the adolescent well.<sup>46</sup> In this case, despite the inability of fully complementing the triadic approach, a therapeutic alliance was forged between providers and the adolescent patient.

Levin's observations confirm recognition on the part of health care providers, and perhaps even the adolescent herself, that health care decisions with irreversible consequences ought to be sorted out among multiple parties with moral standing. Even a toughened, seemingly independent "street kid" deserves not to be abandoned to his decisional authority because no one else seems to care. Ironically, the street tough adolescent without adult parents or caretakers may be better served ethically in not having her refusal for life-saving treatment respected than will the homeless adult also without family whose decision, if capable, will be respected.

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*Alone: Decision Making in Health Care in the United States*, 160- 182. New York: Cambridge University Press, 160.

<sup>46</sup> Levin, B. (1999), 179.

The adolescent with loving parents is, of course, in the best possible situation. If BJ's situation were to befall her, her parents serve her and her 'open future' best by not permitting her refusal of life-saving medical intervention. Health care providers have an ethical responsibility to respect the parents' decisional authority if it satisfies the criterion of the adolescent's welfare, fostering, by way of a therapeutic alliance, the adolescent's compliance without manipulation or force.

### **Conclusion**

The application of familiar ethical concepts to children's health care is fraught with difficulties, among them the appropriation of autonomous decision making. The word 'autonomy' has been attached to 'parent' by default since much of the pediatric clientele clearly cannot speak for itself. But many can - as adolescents with developing autonomy - and may be thwarted or disregarded in their attempts to claim a voice in the discussion about themselves. The concept of 'best interests,' however subjective, is probably the most germane way to think about what parents must consider in making life-and-death decisions for or about their children, no matter their age. The older child may offer a substantial contribution in describing her own 'best interests.' These ought to be considered by the parent, who is still ultimately responsible for making the 'right' decision. The notion of protecting the child's potential, or the child's 'right to an open future', is the most persuasive interest that parents have in ensuring authority over adolescent decision making in life-and-death scenarios. Parental responsibilities as recognized by our law and societal mores can easily become misinterpreted depending on competing interests. For this reason, together with the ambiguity around the concept of

'best interests', a third spoke in the adolescent life-and-death decision making approach is articulated in the next chapter: the role and responsibility of health care professionals, representing the interests of the state.



## **CHAPTER 5**

### **Health Care Provider and State Intervention in Adolescent Treatment Refusal: Roles and Responsibilities of the State**

In this dissertation, adolescent life and death decision making is conceptualized within a triad of interests, roles, and responsibilities involving the adolescent child, the parents, and health care providers, as representatives of the state. Discerning the roles and responsibilities of the adolescent and the parents enmeshed in cases that involve seemingly capable adolescents who refuse life-or-death medical intervention has been the emphasis of the last several chapters. Chapters 2 and 3 have shown that adolescent maturity and decision making capacity are not adequately understood to allow for definitive respect of a teenager's refusal of medical treatment in life-and-death situations. In Chapter 4 the aim was to show that it is not clear that the parental role, and its inherent interests and responsibilities, give adequate direction in resolving the issue of an adolescent's refusal of life-saving treatment. This is especially true if parents are in support of an adolescent's refusal of treatment which is determined to be in the teen's best medical interest. In such cases, health care providers, as representatives of the state in the third part of the decision making triad, are left in the position of not only recommending the ultimate decision about what ought to be done in these kinds of cases, but also acting on the decision. Because the state tends to align with physicians' recommendations, the health care providers may be viewed as extensions of the state processes in implementing action to take when adolescents refuse life-saving treatment.

The task of this chapter, in developing the third element of the triadic approach for adolescent life-and-death decision making, is to uncover the roles and responsibilities of the state and the state's representatives. Two illustrative cases involving refusal of life-saving medical intervention by two 15 year old boys serve as focal points of analysis. These cases - refusal by an adolescent (AJ) well-acquainted with his inevitably-fatal disease and refusal by an adolescent (BJ) newly diagnosed with a fatal disease – are relatively uncomplicated if we consider the direction of the discussion thus far. I have shown that bioethical and legal elements of decision making capacity among adolescents incorrectly rely on cognitive components which may be met by many adolescents. They are generally insufficient for justifying decisions that have life-and-death consequences for the teen.

Teens should regularly be invited by their parents and health care providers to contribute their perspective in discussions that involve their medical treatment. In cases involving life-or-death treatment, the adolescent's participation, to the extent they are willing, consists of providing input into the discussion. The teen should not be viewed as an autonomous decision maker for a decision of such magnitude, nor should the teen be handed the authority to make such a decision. Rather, a beneficence-based decision making approach grounds the discussion about life-and-death treatment for the adolescent in active consideration of the teen's best interests, from a variety of perspectives. For example, an adolescent in AJ's position brings a perspective that is well-versed in the daily discomfort and suffering of a long-standing chronic-inevitably-fatal disease. Such an adolescent, despite being a legal minor, deserves to have the reasons for his refusal

acknowledged. Listening to the adolescent's perspective, and considering it in the context of required beneficent intervention, is afforded by parents and health care providers, as representatives of the state.

Whereas the state maintains a common law interest in protecting the lives of its citizens, the interests of health care providers in protecting patients are based in a professional ethics incorporating beneficence and nonmaleficence. Within the triadic approach, these complementary ethical obligations of the clinicians join with parental responsibilities toward their child and with the adolescent's expressed interests. Ideally, a therapeutic alliance aimed at achieving an enactment of beneficence-in-trust is forged.<sup>1</sup> As Richard Miller points out, the forged relationship is an alliance "in the sense that health care providers are summoned first to discharge their responsibilities in concert with those of the family."<sup>2</sup> If parents fail to meet their appropriate obligations toward their child who refuses life-or-death treatment, a therapeutic alliance is in jeopardy. At such a time, health care providers, on behalf of the state, will have the responsibility to act with beneficence in order to rescue some adolescent patients not only from the vagaries of their irreversible health care decisions about themselves, but also from the parents who support their child's fatal decision.

For the most part, family intimacy and privacy are viewed as near inviolable precepts within American society. The ability of family, as represented by parents or guardians, to

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<sup>1</sup>As has been discussed in the previous chapters, the concept of 'therapeutic alliance' among health care providers, parents or guardians, and the pediatric patient is described in Richard Miller's 2003 book, *Children, Ethics, and Modern Medicine*. Bloomington: Indiana University Press. The concept of beneficence-in-trust is from the work of Pellegrino, E.D. & Thomasma, D.C. (1988) *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press

<sup>2</sup> Miller, R. (2003), 36.

raise children as they see appropriate is highly-regarded. There is generally an expectation that neither the state, nor those in authority representing the state, will overrule parental practices in childrearing unless there is broadly recognized child neglect or abuse.<sup>3</sup> Not surprisingly then, cases reported through the media, in which the courts have determined parents to be acting or making decisions contrary to the child's 'best interests,' prompt reconsideration of the parental role vis a vis the role of the state.

### **A Brief Return to AJ and BJ**

The discussion to this point has featured the composite cases of two adolescents, 15 year old AJ and BJ. AJ has had life-long experience with cystic fibrosis of a rapid progression and is presently refusing mechanical ventilation to sustain his failed lungs. Such treatment will likely prevent his death in the short term, but it likely also will be burdensome with no chance of regaining his former, very limited health status. BJ has been healthy and physically vigorous his entire life, until being recently diagnosed with synovial sarcoma, a potentially deadly cancer, for which likely cure involves an amputation of the lower leg. BJ is refusing the life-saving, curative amputation. Both boys are deemed to be capable according to decisional capacity criteria.<sup>4</sup> Neither is

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<sup>3</sup> See, for example, landmark court cases such as *Yoder vs. Wisconsin*, 406 U.S. 205 (1972) or *Parham vs. J.R.*, 442 U.S. 584 (1979) that serve as precedent-setting expressions of the perceived rights of parents to determine private child-rearing matters. The right to determine such matters is dependent on the harm, if any, conveyed onto the children. Many argue that decisions in both *Yoder* and *Parham* conveyed inestimable harm by limiting life opportunities, in *Yoder*, or diminishing due process appeals, in *Parham*.

<sup>4</sup> Criteria indicating capable decision making are seen to be cognitively based. The comprehensive listing of criteria used throughout these chapters includes 1) possessing of a set of values and goals, 2) understanding the information being presented, 3) appreciating the information for one's own circumstances, 4) reasoning with the information, and 5) expressing a choice. These criteria are distilled from the work of Grisso, T. & Appelbaum, P.S. (1998). *Assessing Competence to Consent to Treatment: A Guide for Physicians and other Health Professionals*. NY: Oxford University Press, 20; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). *Making Health Care Decisions, Vol. 1*. Washington, D.C.: U.S. Government Printing Office.

refusing medical intervention due to religious reasons. AJ has had much experience with disease and illness in his short life. He knows that mechanical ventilation is not a cure for him, but will impact the quality of his remaining life and could well prolong his discomfort. AJ has become acquainted with others who have shared his same disease and knows that his prospects of long-term survival are slim to nonexistent. BJ, on the other hand, has never been inside a hospital until now. He has never been ill, other than the usual childhood sicknesses, and has never known anyone with debilitating illness. He is an all-around sports star in his community. BJ refuses the life-saving amputation because he claims he cannot, and will not, live without his leg.

At this juncture, and for the purposes of this chapter, the responses of the two boys' parents may vary, qualified by their own insight as parents, but also by the type of input received from their sons or health care providers. The parents may oppose their sons' decisions, but also be impressed by the seeming maturity of the boys' reasoning. The parents are reluctant to have such a major disagreement fuel the emotional reality of the life-and-death dilemma, but believe that they, as parents, have the final authority to overrule their sons' decision. Indeed, societal understanding of parental autonomy and family privacy maintains that parents are in the position to make decisions on behalf of their minor children.

A potentially different scenario is that the parents support their sons' decisions to forgo life-saving or -sustaining treatment. In supporting them, the parents feel that they are granting their sons a final gift of respect for their decisions. The parents acknowledge that their sons will die without the treatment, but see the boys' refusal as a very personal

matter about which they are old enough to decide. Because the boys have different illnesses that confronted them at different times of their lives, the parents' responses are tempered with the acknowledgement that experience and knowledge of illness color the perspective the boys have about their treatment.

Witnesses and facilitators to the decision making dynamics between the boys and their parents are the health care providers. They know AJ well. He has impressed them with his clarity of thought and his understanding of his disease, especially within recent years. The health care team recognizes that although intubation and mechanical ventilation will save AJ's life in the short term, the intervention is a very temporary measure that will not cure him, but may instead prolong his suffering from the disease, and thereby severely limit the quality of his remaining life.<sup>5</sup>

The health care team acts with attention to beneficence and nonmaleficence in considering AJ's refusal of life-saving intervention. AJ's refusal of intubation and mechanical ventilation forces the health care team, the parents, and AJ to carefully deliberate between the withholding of ventilatory support that would be tantamount to his certain death, and the possibility of withdrawing the support after it has been tried but found to be overly burdensome by AJ. A therapeutic alliance is crucial in communicating truthfully about the consequences of withholding treatment now or

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<sup>5</sup> A highly subjective concept, quality of life, is seen to incorporate the consideration of moral judgments relative to medical indications for treatment decisions. Determining what kind of, or extent of, treatment should occur will invariably require thoughtful consideration of what will benefit a patient in the context of the kind of life they may live after a medical intervention. See Beauchamp, T.L. & Childress, J.F. (2001). *Principles of Biomedical Ethics*, 5<sup>th</sup> ed. New York: Oxford Univ. Press, 135-9.

possibly withdrawing mechanical ventilation after it has been tried.<sup>6</sup> An ethics committee consultation is helpful in the deliberation if communication is hampered. The important point to be made here is that AJ's perspective is fully considered by those with moral standing in the case. His cumulative illness, including past experience with mechanical ventilation, allows parents and health care providers to consider all aspects of the decision so that appropriate action is based in beneficence-in-trust.

BJ's situation poses a more challenging dilemma. The health care team has never met BJ until his recent admission to the hospital. He is dreadfully frightened and shocked by what has happened to him. He uses high level vocabulary as he reiterates his treatment refusal. He will not subject himself to the life of a cripple, he says, and cannot be forced to undergo a mutilating surgery he does not want. The case of BJ is especially worrisome because of his lack of reference to illness and pain, but also recovery. The situation becomes even more distressing if parents agree with their sons' refusal. Providers should try to persuade the boy patient, together with his parents, to accept the recommended intervention as an ethically required treatment for saving BJ's life.<sup>7</sup> Persuasion encompasses Pellegrino and Thomasma's first rule of intervention: reversing an impediment to competence. Even though restoring 'competence' is not the goal for BJ, because of his young age, efforts to educate him and his parents about the aftermath of

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<sup>6</sup> Beauchamp and Childress conclude that the distinction between withholding and withdrawing treatment, because it can result in action to address fears about overtreatment or undertreatment, is 'morally untenable.' "Decisions about beginning or ending treatment should be based on considerations of the patient's rights and welfare, and, therefore, on the benefits and burdens of the treatment, as judged by a patient or authorized surrogate." Beauchamp, T. & Childress, J.F. (2001), 122.

<sup>7</sup> The paramount bioethical tension is captured in this struggle of health care providers to respect persons and their autonomy while also serving the principle of beneficence, to do good. Health care providers recognize the life-saving abilities of both treatments for both boys, and may, at a minimum, highly recommend the treatment for BJ: below the knee amputation. The viable options for working through this struggle will be explored in the text.

the curative surgery, perhaps meeting another adolescent in rehabilitation after amputation surgery, can make the decision less isolating.

Failing persuasion, clinicians will be in the position of considering Pellegrino and Thomasma's second rule – the intermediate form – to justify beneficent action. According to the authors, “physicians should always act to reverse trauma or illness in spite of contrary expressions until the condition is judged irreversible and hopeless, or until the patient's current wishes are demonstrated as antedating this new event and perduring the present.”<sup>8</sup> Unfortunately, amputation is the treatment for BJ's fatal illness. It cannot be ‘stopped,’ or withdrawn, if the cancer proves to be very aggressive and further compromises BJ's health. More importantly, the second rule for beneficent intervention has limited applicability to a situation of acute diagnosis with a very good chance of cure.

In the case of AJ, pursuing the third rule of paternalistic intervention – the hard form – becomes necessary. The health care providers will anticipate the unwelcome prospect of obtaining a court order to countermand BJ's parents' decision to support their son's refusal. Pediatric health care providers know that judges to whom they appeal almost always take their side in a treatment dispute. Judges recognize that they themselves have no special medical expertise which can help them frame the interests of the state which they must uphold. Consequently, they rely on the accurate portrayal of the situation, together with recommendations, by medical providers. For this reason, and for the purpose of discussing state interests, the roles of the state and health care providers are

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<sup>8</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.



parallel, even though individual health care providers may possess independent interests or views about preserving life, respecting refusals, or protecting the ethical integrity of the professions.<sup>9</sup>

### **Interests of the State in Intervening in Adolescent or Parental Refusals of Treatment**

The countervailing interests of the state – preserving the sanctity of life, preventing suicide, protecting the rights of third parties, and upholding the ethics of the medical profession – are generally not seen as strong enough to limit the right of capable adults to refuse life-sustaining medical treatment.<sup>10</sup> These interests, so articulated in the *In re E.G.* opinion, describe competing interests of the state that have overruled a minor's refusal of life-saving treatment. The case began when Ernestine Gregory, at age 17 ½ years old age, refused, with her mother's support, a life-saving blood transfusion because her Jehovah's Witness religion did not permit transfusion.<sup>11</sup> An inherent problem in on-going discussion concerning adolescent refusal of life-saving treatment is the scarcity of relevant case law. Aside from the most recent opinions involving the adolescent's active religiously based refusal - *In re EG* in 1989 and *In Re Long Island Jewish Medical Center* in 1990 - other cases involve minors in conditions of persistent vegetative states whose

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<sup>9</sup> Rosato, J.L. (1996). "The Ultimate Test of Autonomy." 49 *Rutgers Law Review* 1, see footnote 288; this merger of the interests of the state and health care providers is iterated in the *Stamford v. Vega* opinion regarding the religiously-based refusal of blood transfusions after the birth of a normal baby: "The hospital's interests are in preserving the life of its patient and protecting the ethical integrity of the medical profession. Those interests are intertwined. Hospitals exist, and doctors are trained, in order to provide care and treatment for sick and dying patients. 'The preservation of life is not only a laudable goal for . . . the physicians and for the health care facilities to aspire to, it is a compelling one.' *St. Mary's Hospital v. Ramsey*, 465 So. 2d 666, 668 (Fla. App. 1985). Vega's life could be saved by the administration of treatment that most people would consider routine. The hospital and its doctors quite understandably did not wish to stand by and see a healthy young woman die." *Stamford v. Vega* 236 Conn. 646, (Conn. 1996) p.665.

<sup>10</sup> Rosato, J.L. (1996), 67. These interests are itemized in *In re E.G.*, 549 N.E.2d(Ill. 1989), 327.

<sup>11</sup> See earlier discussions of *In re Gregory* in previous chapters. *In re E.G.*, 549 N.E.2d(Ill. 1989)

prior wishes were considered in parental refusals of life-saving and life-sustaining treatment on their behalf.<sup>12</sup>

Exploring countervailing state interests for intervention in treatment refusals by AJ and BJ will be the emphasis in this section. Their refusals are not rooted in religious proscriptions, begging the question, even in the case of adult refusals, whether refusal justified on the grounds of religious values does have or should have greater ethical validity.<sup>13</sup> For the purposes of this project, a religious basis to adolescent refusal of life-saving treatment has little bearing on the problem it presents to parents (if they disagree) or health care providers. The tension between respect for autonomy and beneficence in the adult context of treatment refusal for religious reasons is significantly minimized in the context of legal minors, in part because well-developed autonomy is not a recognized characteristic of minors.

*Preserving the sanctity of children's lives*

In treatment refusals involving adults, the interest in sanctity of life is framed as a general interest in the preservation of life and does not ordinarily outweigh the patient's right to self-determination. However, the interest is much more compelling when children's lives are at stake. Two aspects of the state's interest are implicated when

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<sup>12</sup> One exception, not resulting in a judicial opinion, but involving a contributing adolescent, The case of *In re Rena*, 705 N.E.2d 1155 (1999) involved a 17 year old girl, with the pseudonym of Rena, who, with her parent's support, refused a blood transfusion for religious reasons after sustaining a lacerated spleen requiring surgery. A court ordered transfusion, but on appeal the trial judge was severely chastised, following *In re E.G.*, for failing to consider whether Rena was a 'mature minor.' The finding was considered moot and vacated when Rena was discharged a day after the refused transfusion. See further discussion in Harvey, M.T. (2003). "Adolescent Competency and the Refusal Of Medical Treatment." *13 Health Matrix* 297, 302-3.

<sup>13</sup> Do treatment refusals based in religious objections comprise a more sympathetic challenge to American understanding of self-determination law and protection of religious freedom than those refusals based in the autonomous patient's desire to not go forward with a particular recommended medical intervention? Although this question cannot be addressed herein, it does merit future consideration and research.

treatment is refused by a minor or on behalf of a minor by parents or guardians: 1) the *parens patriae* injunction to protect a child's health and life and 2) the imperative of protecting a child's future on behalf of society.<sup>14</sup> The first aspect involves the state soundly invoking its traditional role as *parens patriae* to further protect the child's health and well-being.<sup>15</sup> Such protection is summoned when the state perceives that the actions of a parent or guardian are inconsistent with the child's best interests, requiring state intervention to protect the child. For example, parental refusal of professionally recommended life-saving treatment of the adolescent may invite protection by the state. The state's *parens patriae* power serves as an indisputable reminder that although family privacy is highly valued, it is not inviolable.

Although the *parens patriae* protection diminishes conceptually as the child matures in his or her decision making ability,<sup>16</sup> it is nonetheless implicated when, as a minor, a child is in danger of sustaining great harm that is preventable. The state's *parens patriae* interest may also be weighed more stringently the more the procedure in question is expected to restore health and well-being. Even in jurisdictions where mature minors are recognized (Virginia is not one of these), the state's interest in protecting the minor from him or herself is compelling and determinative if a full, or reasonable, recovery is expected.<sup>17</sup> The state's countervailing interest in AJ's case, in which mechanical ventilation would arguably prolong his dying process, is likely to be insubstantial.

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<sup>14</sup> These aspects are also delineated in Rosato, J.L. (1996), 69.

<sup>15</sup> *Parens patriae* is the philosophy that the government should be proactive in protecting the welfare of minors. Hartman, R.G. (2002). "Coming of Age: Devising Legislation for Adolescent Medical Decision-Making." 28 *American Journal of Law and Medicine* 409, p. 412.

<sup>16</sup> See *In re E.G.*, 549 N.E.2d 322 (Ill. 1989) "The *parens patriae* power fades, however, as the minor gets older and disappears upon her reaching adulthood," pp. 326-8.

<sup>17</sup> Harvey, M.T. (2003), 305.

However, where BJ has a very good chance of being cured, the state has a substantial interest in overriding the adolescent's treatment refusal. If the parents are in agreement with their son's decision, and refuse on his behalf, health care providers would likely intervene by bringing the case before a judge to override the refusal of BJ's parents. In doing so they appeal to the third rule for paternalistic intervention based in beneficence-in-trust.

As has been discussed in Chapter 2, adolescents' demonstration of decision making capacity is subject to the realities of their youth, as well as the ambiguities of how decision making capacity is understood. Typical adolescent characteristics of inexperience, risk-taking, and focus on short-term consequences<sup>18</sup> contribute to the courts' approaching adolescent decisions with the skepticism worthy of the irreversible nature of a 'bad' decision. Even Jennifer Rosato, a staunch advocate of adolescent autonomy and decision making rights, admits that when children's lives are at stake, "the state's interest may be strong enough to circumscribe even a mature minor's right."<sup>19</sup> Rosato's hedging about adolescent decisional authority in life-and-death situations illustrates how supporters of adolescent decision making rights are uncomfortable with those same teens making the ultimate decision that may end their lives.

The content of serious decisions with significant repercussions, such as death, made by adults or adolescents may not differ,<sup>20</sup> but ought to be attended to quite differently.

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<sup>18</sup> Scott, E. (1991) "Judgment and Reasoning in Adolescent Decisionmaking," 37 *Villanova Law Review*, 1642-52.

<sup>19</sup> Rosato, J.L. (1996), 69.

<sup>20</sup> A reference to the well-respected Weithorn & Campbell study, which found that adolescents aged 14 years and above demonstrated a level of competency equivalent to that of adults. Weithorn, L.A. & Campbell, S.B. (1982). "The Competency of Children and Adolescents to Make Informed Treatment

Whether or not the state or health care providers, as the state's representatives, agree with the competent adult's decision is largely immaterial as to how and whether the decision is enacted. Ethical and legal precedent allow for the refusal of life-saving or life-sustaining medical treatment by capable adults regardless of their experience with personal or observed illness.<sup>21</sup> However, health care providers and family members may find the adult's refusal more compelling if illness experience augments the adult patient's rationale for refusing life-or-death treatment.

For both legal and ethical reasons, honoring the refusal of life-saving treatment by an adolescent ought not be justified because the teen 'seems' capable or experienced with illness. Adolescent decision making capacity has been shown to be unreliable. Additionally, personal or vicarious experience does not fully supplement the poorly understood and misrepresented concept of adolescent decision making capacity. Instead, an adolescent's refusal of life-and-death treatment is subject to a beneficence-based consideration of the adolescent's best interests, parental duties of protection, and health care providers' obligations to preserve the sanctity of children's lives. The outcome of deliberation may well be that the burden of life-and-death treatment does not offer reasonable benefit to the adolescent. In the triadic approach, such a decision is the result of an understanding of best interests by the adolescent, parents, and clinicians. It is not based in the concepts of adolescent or parental autonomy, rather the decision illustrates

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Decisions." *Child Development* 53, 1589-98. See Chapter 2 herein for further discussion on adolescent capacity.

<sup>21</sup> See the 1960 precedent-setting case of *Natanson v. Kline* in which the Kansas Supreme Court specifically addressed the refusal of life-sustaining treatment: "Anglo-American law starts with the premise of a thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery." 186 Kan. 393, p. 406, 350 P. 2d 1093, p. 1104 (1960).

the concept of beneficence-in-trust. The adolescent's inappropriate assessment of her best interests need not be belabored with an adolescent who sees his or her refusal of treatment as the final act of power in a heretofore powerless situation. It is important to establish that overruling the adolescent's refusal in favor of medical intervention is not a denial of his or her worth, character, or personhood. Rather it is the action necessary to realize what appears to be a viable future for the adolescent.

The refusal of life-and-death treatment by adolescents with significant illness experience ought to receive full attention in a discussion between the adolescent, parents, and health care providers. Beneficence-based, or beneficence-in-trust, decision making calls for recognition of the perspective the adolescent brings to the life-and-death situation.<sup>22</sup> Questions for consideration include: is intubation as a life-and-death intervention, but a non-curative measure, in A.J.'s best interests? What are AJ's parents' responsibilities in protecting him from further suffering that will not improve his situation? What are the health care providers' and the state's obligations in preserving AJ's life? Perspectives brought to a life-and-death scenario by adolescents with varying illness experiences ought to influence how 'best interests' are determined

AJ has been mechanically ventilated in the past and has additionally witnessed the treatment of other peers suffering from chronic respiratory disease. His wishes, though not recognized as autonomous, are nonetheless crucial contributions that must be considered by those with moral standing in AJ's case: his parents, his health care providers, and himself. AJ's struggle with cystic fibrosis, as well as Benny Agrelo's

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<sup>22</sup> Pellegrino, E.D. & Thomasma, D.C. (1988).

repeated liver transplants count as experience that place the adolescent's refusal in a relevant context for serious ethical consideration. In other words, life-prolonging intervention for AJ or Benny does not afford the prospect of a future that is, on balance, less burdensome than the lives they are already living.

For a moment, let us expand BJ's situation into one where he is newly diagnosed with a life-threatening disease, but also suffers from Crohn's Disease, a chronic inflammatory disease of the bowel. He has undergone multiple hospitalizations, including surgeries, for the painful exacerbations of his Crohn's Disease and has recently sustained a colostomy which may end up being permanent. Upon hearing the diagnosis of cancer that could be cured with amputation, BJ tearfully refuses to submit to the mutilating surgery, claiming that he has had enough.

For parents and health care providers to claim to respect his refusal based on his 'experience' is a disservice to BJ. Chronic diseases, such as Crohn's or diabetes mellitus, offer significant life challenges but are not inherently associated with eventual intervention that may be more burdensome than beneficial. BJ deserves the chance for a future, it is in his best interests to begin treatment for the cancer since the possibility of cure is high. Pellegrino and Thomasma's first rule of intervention should always precede other paternalistic actions. Herein, efforts are made to educate BJ and his parents about the cancer treatment perhaps by meeting other young persons who have sustained curative amputations because of cancer. Should BJ and his parents be unconvinced and continue refusal, the providers initiate steps to act in BJ's best interests. Appealing to the third rule for paternalistic intervention, via court order if necessary, is appropriate

because the amputation cannot be ‘withdrawn’ once carried out, as the second rule suggests. Should his prognosis and condition deteriorate with burdens far exceeding hoped-for benefits, invoking Pellegrino and Thomasma’s second rule of intervention is justified and guided by BJ’s best interests which may include discontinuing follow-up cancer treatment that was earlier refused.<sup>23</sup>

The notion of securing a future for the adolescent is the second aspect implicated in the state’s interest in preserving the sanctity of the child’s life. If the state permitted that adolescent refusal of life-saving treatment be honored as a matter of course, society may well see that minors’ lives are not important enough ‘to fight for’. The symbolic nature of the unrealized potential of young persons within a society is that they are the hope of society’s continued existence and improvement.<sup>24</sup>

Acknowledging the symbolic nature of the child’s life should not, however, require the state or health care providers to preserve a chronically ill adolescent’s life merely because of what it represents, without a regard to quality of that life.<sup>25</sup> In returning to the scenario of AJ, individuals with a moral stake in his life ought to recognize that his refusal of life-saving treatment is an important perspective he contributes. AJ is suffering from an incurable disease which has reached the culmination of a prognostic downward spiral. If parents and health care providers are successful in persuading AJ to submit to

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<sup>23</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.

<sup>24</sup> Rosato, J.L. (1996), 68-9.

<sup>25</sup> The vitalists’ perspective that life, as life itself, must be preserved at all costs is not compatible with either state or health care provider approaches. As discussed in Chapter 1, numerous cases of adult refusal of life-saving treatment in the courts clearly show that the autonomous adult’s right to refuse medical intervention is a compelling right which the state generally chooses not to override, unless other competing interests outweigh the adult’s right to refuse. See the third competing interest – protecting the interests of third parties – in a subsequent section of this chapter.



the respirator with the option of withdrawing it later should he find it unduly burdensome, they are obligated to respect his later wishes. The state is unlikely to insist on initial or continued intubation and mechanical ventilation for this young person, largely because the health professionals are unlikely to bring the case to the state's attention. The state's unwillingness to pursue forced medical intervention, reflects a high regard for the providers' professional integrity and ethical mandate to diminish suffering.<sup>26</sup> Additional discussion on the state's upholding of professional integrity in the face of treatment disputes appears under the fourth and final countervailing interest.

### *Preventing suicide*

The state's second competing interest in intervening in patient refusals of life-sustaining treatment is suicide prevention. In cases involving adults, courts have agreed that the adult patient is not seeking to commit suicide.<sup>27</sup> Rather the adult is viewed as attempting to fulfill an autonomous desire to refuse further medical interventions. Although death is generally the result of such refusals, the courts recognize that it is not

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<sup>26</sup> Both nursing and medical professional associations issue position statements relative to the care of patients at the end of life. See for example: "Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care," "Decisions Near the End of Life." Policy H-140.966 of the American Medical Association; also, "When the restoration of health is no longer possible, the focus of nursing care is assuring a comfortable, dignified death and the highest possible quality of remaining life," "American Nurses Association Position Statement on Pain Management and Control of Distressing Symptoms in Dying Patients," effective December 5, 2003. Retrieved at [www.ama-assn.org/apps/pf\\_new/pf\\_online](http://www.ama-assn.org/apps/pf_new/pf_online) and [www.nursingworld.org/readingroom/position/ethics/etpain.htm](http://www.nursingworld.org/readingroom/position/ethics/etpain.htm) respectively.

<sup>27</sup> See *Brophy v. New England Sinai Hospital*, 497 N.E.2d (Mass. 1986) and *In re Browning*, 568 So. 2d 4 (Fla. 1990) as examples of both alert and no longer alert adults who were refusing on-going medical treatment. As a sharp contrast, see the case of Elizabeth Bouvia, an intelligent young woman with profound cerebral palsy, who requested pain relief as she died from the refused continuation of tube feedings. *Bouvia v. Superior Court*, 1979 Cal. App. 3d 1127, 225 Cal. Rptr.297 (Ct. App. 1986). After an odyssey through multiple hospitals and courts, Bouvia found relief with the opinion holding that the goal of her refusal "was not to hasten death, though its earlier arrival may be an expected and understood likelihood..."

the chief desire of the individual and comes as an undesired, but anticipated, consequence of the refusal.

The case of AJ parallels the scenarios of adult patients who have refused life-sustaining treatment and have been allowed to do so. AJ, having lived with his disease for a lifetime, is aware of its limitations and prognosis. His refusal of further treatment is compatible with exemplar cases involving adults. Yet, neither parents, health care providers, nor the courts can know AJ's true intention in refusing life-saving treatment. Because such information is unknown, his refusal and reasons for it ought to be subject to extensive conversation within the beneficence based triadic decision making approach. Conversation with AJ can satisfy the state's interest in prohibiting suicide by affirming among AJ, parents, and providers that life-or-death treatment is overwhelmingly more burdensome than it will be beneficial in light of AJ's medical history. By deciding on no further treatment, the triad of stakeholders acknowledges that the consequence of the decision is AJ's death. It is a decision based on AJ's best interests and does not incorporate the specter of suicide. Health care providers will not be sympathetic to forgoing life-and-death treatment if the intention of suicide is implicated for either an adolescent or adult patient.

If an adult patient refuses life-saving treatment, health care providers tend to seek an assessment of the individual's psychological state. Generally, a psychiatrist is consulted to perform a psychiatric evaluation.<sup>28</sup> One reason for seeking consultation is to ascertain

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<sup>28</sup> Features of a psychiatric evaluation for the purpose of determining decision making capacity in an adolescent may include assessing the history of the past and present illness, family history, psychosocial, and developmental history. Additionally a mental status examination (including assessment of physical appearance, manner of relating, orientation, central nervous system functioning, quality of thinking and

whether the patient is capable of issuing an informed refusal given that it may be in his or her best medical interests to receive the treatment. A second reason is to rule out suicidal thoughts that would invalidate the refusal in the eyes of many providers.<sup>29</sup> A third reason is to avoid legal repercussions that may ensue if a capable patient is forced to receive medical treatment after such intervention has been refused.

In turning back to BJ, we have established that his refusal of life-or-death treatment deemed to be in his best interests would not be acted upon since he is a 15 year old teenager. Therefore, obtaining a psychiatric consultation, for the purposes of determining his capacity to refuse, is disingenuous, since his refusal will not be permitted. However, a psychiatric consult to assess and treat his mental state relative to the required life-saving, but mutilating, surgery is certainly in order. Obtaining a psychiatric consult for AJ is also indicated, again, not to verify his decision making capacity, but rather to evaluate his state of mind and assess for suicidal thoughts.<sup>30</sup>

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perception, fantasies, affect, judgment and insight, self-esteem, and adaptive capacities) provides contextual information. There is no defined set of features to assess since the type of evaluation is dependent on particular circumstances. Lewis, M. & King, R.A. (2002). "Psychiatric Assessment of Infants, Children, and Adolescents." In, *Child and Adolescent Psychiatry: A Comprehensive Textbook*, 3<sup>rd</sup> ed. (M. Lewis, ed.), 525-43. Philadelphia: Lippincott, Williams & Wilkins. "The clinician uses his or her clinical judgment to determine what to look for and how fast and in what detail to proceed," p. 531.

<sup>29</sup> The conceptual argument of whether suicide ought to be an autonomous right finds some legitimacy among adults with presumed decision making capacity. Since the argument here is that adolescent's capacity is suspect, intervention in an adolescent's action that may resemble a suicide attempt, such as refusal of life-saving treatment, is justified in weak paternalism (intervention on grounds of beneficence or nonmaleficence only to prevent substantially nonvoluntary conduct). See extensive discussion of these points in T.L. Beauchamp & J.F. Childress (2001), 181, and generally 179-191.

<sup>30</sup> See position statement by the Committee on Adolescence, American Academy of Pediatrics (2000) reporting a substantial rise in the rate of suicide attempts and completions among adolescents. Between 1950 and 1990, the suicide rate among the 15 to 19 year old age group increased by 300%. Certain chronic or debilitating physical disorders also account for a higher risk of suicide. "Suicide and Suicide Attempts in Adolescents." *Pediatrics* 105, (4), 8714.

Ethical codes of professional practice for health care providers prohibit the assistance of suicide.<sup>31</sup> Such prohibition has particular relevance in the era of Dr. Kevorkian and his success in bringing physician assisted suicide into the public debate.<sup>32</sup> Although many health care providers can appreciate the reasons why individuals may pursue the option of assisted suicide, providers may be averse to the notion of complicity in a suicide. Seeing their roles as focused on affirming and saving lives, providers themselves may refuse to participate in actions they see as tantamount to assisting in suicide.<sup>33</sup>

### *Protecting the interests of third parties*

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<sup>31</sup> See ANA position statement on Assisted Suicide, for example: "The moral objection to the nurse's participation in assisted suicide does not diminish the nurse's obligation to provide appropriate interventions throughout the process of dying." At 4, effective date: December 8, 1994 retrieved at <http://www.nursingworld.org/readroom/position/ethics/etsuic.htm>; "AMA policy on Physician Assisted Suicide" (H-140.952), for example: "Physician assisted suicide is fundamentally inconsistent with the physician's professional role." Reaffirm: Res.237,A-99, retrieved at [www.ama-assn.org/apps/pf\\_new/pf\\_online](http://www.ama-assn.org/apps/pf_new/pf_online). It is important to note that only physicians who are AMA members must uphold the AMA Principles of Medical Ethics as a condition of membership. The policy above is a position statement generated by the AMA Council on Ethical and Judicial Affairs. Nurses are arguably more closely tied to the tenets of the ANA professional codes than are physicians to the codes of the AMA. The ethical guide to medical practice best known to physicians, and recited at many medical school ceremonies, is the Hippocratic Oath. Herein, assisted suicide, is expressly forbidden. Because most oaths and codes are administered by voluntary associations and not by regulatory agencies (such as the state agencies that issue licenses to practice medicine), the most serious disciplinary action these voluntary associations typically can take is to expel the member physician from the association. See also <http://www.ama-assn.org/ama/pub/category/5105.html#policy>.

<sup>32</sup> Dr. Jack Kevorkian began his physician assisted suicide activities in 1990 with Janet Atkins, a 54 year old woman with Alzheimer's disease, who was not terminally ill nor yet debilitated. Kevorkian's renegade approach to assisting suffering patients with options at or near the end of life is criticized for its lack of validation with another physician, and the lack of relationship developed with the patient. After assisting in over 100 deaths, Kevorkian remains in a Michigan prison. See also <http://www.pbs.org/wgbh/pages/frontline/kevorkian/chronology.html>

<sup>33</sup> Most states have passed legislation criminalizing assisted suicide on the part of health care providers in the face of Dr. Kevorkian's activities. Professional ethical codes and position statements also proscribe assisted suicide. Commonly referred to as physician assisted suicide, health care providers are cognizant that physicians are not the only clinicians able to assist in a suicide. For example, a survey study questioned nurses about their involvement in assisted suicide, see Asch, D. (1996). "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide," *New England Journal of Medicine* (21), 1374-9.

The state's third countervailing interest in intervening in treatment refusal involves protecting the interests of third parties who may be adversely impacted by the patient's refusal. Courts have considered the impact of an adult patient's refusal of life-saving treatment on close family members who were dependent on the patient financially or emotionally, but have not generally found this dependency interest to be sufficiently compelling to override the patient's decision.<sup>34</sup> Such cases are predicated on applying the *parens patriae* power to the abandonment principle.<sup>35</sup> Adolescents, with few exceptions, are not burdened with dependents. In their world they are largely themselves dependent on the responsible adults in their lives for care, comfort, and support.<sup>36</sup>

The issue of adolescents with dependents suggests a hypothetical scenario on which to test the triadic approach involving a pregnant teenager in a situation similar to that of either AJ or BJ. While many chronic-inevitably-fatal diseases do not lend themselves to pregnancy for a variety of reasons, the possibility cannot be dismissed. We acknowledge that AJ has expansive experience with his disease and resultant burdens of symptoms and their treatment. The triadic decision making approach involves considering AJ's views

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<sup>34</sup> A number of courts have examined the issue of whether an adult's right to refuse life-saving treatment may be overridden if the subsequent death resulted in abandonment, either financial or emotional, of the patient's minor children. Rosato's analysis shows that no court in recent history has found such an abandonment issue to exist. Rosato, J. (1996), 74.

<sup>35</sup> Recent cases involving the refusal by parents of life-saving treatment, such as blood transfusions, discount third-party interests. Examples of such cases include: *In re Osborne*, 294 A.2d 372 (D.C. 1972) (finding no abandonment where patient's wife and family had sufficient financial resources to meet children's needs and relatives were willing to help raise the children); *St. Mary's Hospital v. Ramsey*, 465 So. 2d 666 (Fla. Dist. Ct. App. 1985) (also finding no abandonment where patient's minor daughter had a fixed living arrangement and a small annuity).

<sup>36</sup> Exceptional cases include those adolescents who are parents or those who are, in some way, contributors to the family's livelihood. In the first case, non-adopted children of adolescent parents are commonly cared for by the maternal or paternal grandparents, giving little validity to the abandonment issue. In the latter case, the adolescents' illness has already greatly impacted the flow of financial resources brought in by the teenager. Abandoning dependents is unlikely for adolescents without a stable home life. However, this unfortunate group deserves mention simply because they themselves may have no one upon whom they are dependent.

of life-and-death intervention in light of a poor prognosis. A pregnant adolescent, whose circumstances mimic those of AJ, ought to also be accorded full contribution to conversations by the triadic stakeholders. If the pregnancy is advanced, in deference to the fetus' viability, parents and health care providers may strongly encourage a trial of intubation and ventilation, with the option of stopping the intervention if it is excessively burdensome to the adolescent girl.<sup>37</sup> This approach aligns with the second, or intermediate, rule of intervention, where treatment is undertaken until the condition is judged irreversible and hopeless.<sup>38</sup> In the beneficence-based framework the needs and interests of the pregnant adolescent AJ ought to ultimately take precedence.

A case presentation involving a pregnant girl whose situation is similar to BJ's is more likely and is subject to intense deliberation by the stakeholders involved in the triadic decision making. In some states a pregnant minor may legally be viewed as emancipated, however not in Virginia.<sup>39</sup> As such, the pregnant adolescent is considered to be under the care and protection of her parents or guardians and subject to the beneficent actions of pediatric health care providers. She is not deemed to be a capable decision maker (perhaps her pregnancy confirms this) and ought to be treated in accord with her best interests. In this instance, as in previous variations of BJ's case, the third

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<sup>37</sup> Ethical guidance for cases involving maternal-fetal relations addresses priority for the wishes of the pregnant woman. Statutory provisions allow adolescents to seek reproductive health care and seek abortion with parental notification. In addition, court rulings have found that the pregnant woman's wishes should be controlling "in virtually all cases." See especially *In re A.C.*, 573 A.2d 1235 (D.C. App. 1990); Beauchamp & Childress (2001), 314-5; and, M.V. Rorty, J.D. Pinkerton, & J.C. Fletcher. (1997). "Reproductive Issues," in Fletcher, Lombardo, Marshall, & Miller (Eds.), *Introduction to Clinical Ethics*, 2<sup>nd</sup> ed., pp. 205-25, see pp. 213-5.

<sup>38</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.

<sup>39</sup> Virginia Code 16.1-333. In Virginia 3 conditions apply to enable order of a minor as emancipated: 1) a valid marriage, 2) active duty in the United States military services, and 3) living separate and apart from parents or guardian and fully self-supporting.

rule, or hard form, of clinical intervention applies. Parents and clinicians should act in accordance with Pellegrino and Thomasma's principle of beneficence-in-trust to provide life-saving medical intervention regardless of the adolescent's wishes to the contrary.<sup>40</sup> Parental authorization and providers' provision of life-saving treatment in the face of her refusal is morally sound, especially since her refusal does not reflect her own or the fetus' best medical interests. Saving the life of the pregnant adolescent ought to be viewed as the priority, with secondary consideration given to the fetus regardless of viability.<sup>41</sup>

Cases involving maternal-fetal relations pose difficult ethical challenges for families and health care providers. One major reason is that the pregnant individual and fetus are often viewed as two patients, subject to two sets of ethical consideration. These considerations come into play if a decisionally capable pregnant adult were to refuse medically-indicated intervention. The triadic approach to adolescent life-and-death decision making appears to meet the challenge posed by a 'pregnant' BJ. The added complication of pregnancy does not alter the need for providers and parents to override her refusal. Let us now move back to the more plausible circumstances of dependent, non-pregnant adolescents facing life-and-death decisions about medical treatment.

The typical minor's dependent-free legal status means the adolescent is an integral part of an intimate 'web' of interdependent relationships within a family unit. The

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<sup>40</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157-9.

<sup>41</sup> In saying this I appeal, in part, to the rule of double of effect, which despite having its critics can be useful in reflecting on cases such as this where one action may have both an intended and unintended effect. Such might be the case for a pregnant girl acutely diagnosed with synovial sarcoma which requires amputation followed up with chemo- and radiation therapy. Although the treatment has an excellent chance of saving her life, and perhaps curing her disease, it could be harmful to the fetus. Parents and providers ought to address the life-saving needs of the adolescent primarily. See Beauchamp & Childress (2001), 130-2 for additional commentary on the rule of double effect and its irrelevance to many pressing issues in biomedical ethics.

adolescent's mere presence has a significant bearing on the family's identity as a unified community of individuals wherein the adolescent in question has been sick for a very long time, or just recently diagnosed with a fatal illness. The boys in our scenarios, have been nurtured, loved, cared for, and worried over. It is inconceivable to the family that BJ would consider refusal of life-saving medical treatment. AJ's situation, on the other hand, is well understood by the family. The family understands AJ's health status as a part of its own family narrative.

### Third party protection of the family by the state

As was discussed in the previous chapter, parents have responsibility and great interest in preserving and facilitating their child's future autonomy. Doing so is imperative to maintaining the cherished role of family as a unified community.<sup>42</sup> As family members, each has a duty to exercise benevolence, care and concern for others and can, in turn, claim the right to be on the receiving end of such duties. John Ladd points out that in a community such duties of imperfect obligation are linked to specific persons.<sup>43</sup> The unified community of a family provides the opportunity for family members to give care or help to each other because of the needs and qualities each member exhibits as an individual. Each family member has a moral stake in ensuring such obligations are fulfilled.

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<sup>42</sup> Jeffrey Blustein interpreting G.W. Hegel's idea that "it is only in the children" that the family becomes a unified community. Blustein sees that a man and woman will love their children, biological or otherwise, as expressions of the love they have for one another. Blustein, J. (1980) "Child Rearing and Family Interests," in O. O'Neill and W. Ruddick, (eds) *Having Children*. New York: Oxford Univ. Press.

<sup>43</sup> Houlgate, L. (1988). *Family and State*. Totowa, NJ: Rowman & Littlefield. Citing John Ladd's (1972) important article differentiating community and organizations, in "The Idea of Community", *I New England Journal*, (1), August.



While parents do, ideally, guide the family as a unified, intimate community, their rule must not be overbearing in terms of making all important decisions for each family member. This feature of an ‘organic model’ of the family, wherein individual rights are subordinated to the desires of the family unit, finds favor with those holding the orthodox conception of adolescent autonomy. Proponents of the orthodox view adopt one of two strategies: either they cast serious doubts on the decision making capabilities of all adolescents or they grant, that while adolescents may demonstrate decision making capability, few significant decisions are made by the adolescent without substantial parental input.<sup>44</sup>

In her argument for constrained parental autonomy, Lainie Friedman Ross points out that the family, as an ethically integrated unit, offers intrinsic value in its emphasis on intimacy and family autonomy.<sup>45</sup> Family autonomy promotes the interests and goals of both the children and parents such that “families can continue to pursue family goals which may compete with the individual goals of family members, even of competent family members.”<sup>46</sup> Ross’ view of the family as an organic entity denies that a decisionally capable adolescent should be permitted to function autonomously within the family. Since parents serve as ultimate arbiters of intrafamilial conflicts they have the ‘right and responsibility’ to choose the family’s goals.<sup>47</sup> In this view, maintaining family integrity and the parents’ right to control the upbringing and decisions of minor children

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<sup>44</sup> Harvey, M.T. (2003), 310.

<sup>45</sup> Ross, L.F. (1998). *Children, Families, and Health Care Decision Making*. New York: Clarendon Press, 61-3.

<sup>46</sup> Ross, L.F., 62.

<sup>47</sup> Ibid.

are strong reasons for the state to intervene in protecting third parties from being adversely affected by a minor's refusal of treatment.

Significant traumatic loss must be shown to affect third parties before courts interfere with the adult patient's right to self-determination. As such, the case of a young child losing her parent due to a treatment refusal should not be considered the equivalent of a parent losing his or her child to death resulting from refusal of life-saving treatment. Because the courts have not found abandonment in the former cases, they would undoubtedly find no merit in the latter.<sup>48</sup> But while there may be no legal basis for finding the parents abandoned by their child who was allowed to authorize refusal of life-saving treatment, the emotional effects can last a lifetime.

The parents may never resolve the grief over the loss of a child. If they were to allow their child to refuse medical treatment that is deemed to be in the child's best interests, the parents will feel guilty for failing to prevent the child's death. Rosato's radical conception of adolescent autonomy<sup>49</sup> views such guilt as an unintentional consequence of the adolescent's self-determination in refusing medical intervention. The guilt feelings that Rosato describes, however, are greatly minimized by employing the deliberative triadic approach to decision making about the adolescent. The teen should be part of a deliberative process with parents and providers that allows an expression of her views and an explanation of why, in her best interests, her views can or cannot be upheld.

Parents and providers have an ethical responsibility to not permit the adolescent to make

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<sup>48</sup> Rosato, J. (1996), 76.

<sup>49</sup> Harvey, M.T. ( 2003) labels supporters of the 'treat equals equally' ideal of respecting adolescent decision making capacity as having a radical conception of adolescent autonomy. Another supporter of this view is Rhonda Gay Hartman.

the ultimate decision about refusing life-saving medical treatment if it is not in her best interest to do so.

The importance of the family in the adolescent's life, particularly a teen who is or has been sick, cannot be underestimated. Supportive parents and ethically sensitive health care providers can do much to diminish the turmoil of emotions surrounding an adolescent's refusal of treatment by working together to forge a therapeutic alliance to benefit the adolescent. Proactive medical professionals, together with assistance from an ethics committee, are crucial factors in the ethical resolution of AJ's and BJ's refusal of medical intervention.

*Upholding the integrity of the health care professions*

Finally, the state has an interest in upholding the integrity of the health care professions. This interest extends beyond the licensing, regulatory, and scope of practice aspects of the health care professions that are within the state's statutory purview. The state has a stake in maintaining and promoting the public's high level of trust and confidence in its health care providers and the institutions in which they practice. A health care institution's reputation in the community is a crucial attribute in today's highly competitive, tightly constrained health care market and is built upon the professional competence, proficiency, and integrity of its health care employees and affiliated practitioners. Hence, it has much to gain by ensuring that from an

organizational standpoint, clinicians are permitted to function within their job descriptions and contours of their professional codes of ethics.<sup>50</sup>

Professional practice by health care providers is taught in professional schools, modeled by teachers and mentors, guided by their relevant codes of ethics, and regulated by state oversight bodies.<sup>51</sup> Particular emphasis herein will be on codes and ethics position statements developed by professional membership organizations for use by physicians and nurses. These are the clinicians in closest, and most constant, contact with acutely ill adolescents. Insofar as the ethical codes are not statutory provisions, but rather guidance for practice, both nurses and physicians are presumed to act in a manner that respects persons and their dignity.<sup>52</sup> Both professional organizations additionally specify responsibilities in respecting the patient's refusal of treatment, as well as respecting the law. The American Academy of Pediatrics (AAP), in an influential

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<sup>50</sup> Organizational ethics committees are gaining in visibility within health care institutions. Conceptualized as administrative or clinical bodies that seek to resolve ethical problems that may arise as a result of organizational constraints on patient care and safety, accrediting organizations (such as JCAHO) are increasingly requiring an institution to support such bodies. See for example, Hall, R.T. (2000). *Introduction to Healthcare Organizational Ethics*. NY: Oxford Univ. Press. Professional codes of ethics exist for every health care profession functioning within an institution and licensed by the state. Although those published by the American Nurses Association and the American Medical Association are most prominent, professions such as respiratory therapy, social work, and physical therapy all have codes of ethics constituted within their professions. Again, as noted in footnote 35, to the extent that ethical codes are codified in the law, health care professionals do not have particular requirements to abide by ethical codes generated by professional membership organizations.

<sup>51</sup> For a more intimate perspective on the learning of 'good doctoring,' see Mohrmann, M.E. (2005) *Attending Children: A Doctor's Education*. Washington, D.C.: Georgetown University Press. Mohrmann emphasizes that the many encounters with sick children and their parents, "the daily experiences of being in the presence of suffering and strength, of being called to meet vital needs, of being expected – trusted – to rise to that call, were transforming," p.7.

<sup>52</sup> American Nurses Association Code of Ethics for Nurses with Interpretive Statements (2001). Provision 1: "The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems." Retrieved at <http://www.nursingworld.org/ethics/code/ethicscode150.htm#1.2>. The American Medical Association Principles of Medical Ethics (1957, rev. 2001) Principle I: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights." Retrieved at [http://www.ama-assn.org/apps/pf\\_new/pf\\_online](http://www.ama-assn.org/apps/pf_new/pf_online).

position statement, recognizes that although the process of informed consent and refusal is to be undertaken with patients, the developmental and legal status of children precludes ‘informed consent’ in the typical sense.<sup>53</sup>

Pediatricians are further advised that decision making involving the health care of young patients should flow from responsibility shared by physicians and parents, such that children participate by giving assent and parents give permission.<sup>54</sup> “If physicians recognize the importance of assent, they empower children to the extent of their capacity.”<sup>55</sup> Adolescent patients are asked for their willingness to accept the proposed care, with their solicited views to be taken seriously as guidance for implementation.

Within this background of professional guidance, health care providers confront numerous challenges in resolving impasses between the adolescent, parents, and clinicians in refusal of treatment scenarios. In the cases of AJ and BJ, the challenges may be mitigated by health care providers through serious consideration of influential elements. These elements include: 1) evaluating and communicating the likelihood of cure or significant alleviation of symptoms, 2) stewardship on behalf of the state’s *parens patriae* power, and 3) early referral to the ethics committee. The influence of these elements is conditioned by on-going, open communication among all parties with moral standing. Proactive communication with the adolescent and parents is indeed one of the most important activities that health care providers can perform.

#### Evaluating and communicating the likelihood of cure

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<sup>53</sup>Committee on Bioethics, American Academy of Pediatrics (1995) “Informed Consent, Parental Permission, and Assent in Pediatric Practice.” *Pediatrics*, 95(2), 314-7. Retrieved at <http://www.aap.org/policy/00662.html>.

<sup>54</sup> *Ibid*, 5 of 14.

<sup>55</sup> *Ibid*, 6 of 14.

One element conditioned on the expertise of health care providers is a consideration of how likely a medical intervention will lead to cure or a significant relief of symptoms. The bad news for AJ, in light of his progressively poor prognosis, is that this hospital admission might finally be the one where he is too sick and functionally impaired to ever again be free of the respirator. The medical intervention of placing AJ on a respirator is life-sustaining treatment. It serves to prolong life without reversing the underlying medical condition.<sup>56</sup> In considering the likelihood of continued suffering with no possible cure, in the face of a lifetime of burdensome illness, all moral stakeholders in AJ's case recognize that AJ's refusal ought to be ethically respected, on the grounds of honoring beneficence on his behalf. In doing so, health care providers in the acute care setting initiate a palliative care approach with AJ and his family. In working with AJ and his family over the years, health care providers would have been ethically remiss had they not at an earlier admission initiated a discussion about the approaching end of life. Health care providers may have also suggested that AJ, together with his parents, consider completing an advance directive to document his wishes for medical intervention near the end of his life.

Statutory law in Virginia does not provide for advance directives to be completed by, or more importantly, honored for those less than 18 years of age. There is great interest among advocates of self-determination for adolescents who are impacted by an inevitably

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<sup>56</sup> American Medical Association Policy Finder, H-140.966 "Decisions Near the End of Life." Retrieved at [http://www.ama-assn.org/apps/pf\\_new/pf\\_online](http://www.ama-assn.org/apps/pf_new/pf_online)

fatal disease to document such directives.<sup>57</sup> In practice, advance directives for adolescents, especially for AJ, might be a hindrance as life-sustaining treatment is refused. As is well known, advance directives are often second guessed on behalf of adults. Doubts enter, such as whether the individual was a capable decision maker when he instituted his directive; did he or she anticipate the current situation; is this situation finally 'it' or can it be overcome by short term intervention? What is indisputably helpful for AJ, is less the presence of a prepared advance directive document, and more the on-going conversation with his family and health care providers as his condition deteriorates.<sup>58</sup> If his thoughts about his dim prognosis and his views on his death are known by loved ones and those providers who have grown to care for him, a refusal of life-saving treatment will be viewed as a central consideration for parents and providers in developing a plan for supportive care as death ensues.<sup>59</sup> Another positive aspect to an on-going conversation with AJ is that, should he lose his ability to continue to communicate, his wishes are known and may be considered after he becomes unresponsive.<sup>60</sup>

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<sup>57</sup> See for example, Hawkins, L.A. (1992) "Living-Will Statutes: A Minor Oversight," 78 *Virginia Law Review* 1581; Leikin, S. (1993) "The role of adolescents in decisions concerning their cancer therapy," 71 *Cancer Support* 3342; Rosato, J. (1996); Weir, R. & Peters, C. (1997) "Affirming Decisions Adolescents Make about Life and Death," *Hastings Center Report*, 27 (6), 29-40; Hartman, R.G. (2002) "Coming of Age: Devising Legislation for Adolescent Medical Decision-Making," 28 *American Journal of Law & Medicine* 409.

<sup>58</sup> See Weir, R. & Peters, C. (1997). An acknowledgment of the non-statutory advance directive, either oral or written, whose primary status is as an instrument of moral persuasion; "the persons who sign, compose, or verbalize these directives do so because they want to convince physicians, relatives, and any other persons to carry out their expressed preferences without legal threats," p.35.

<sup>59</sup> It is important to note, that although clinical ethics has made a clear distinction between life-saving and life-sustaining medical intervention, the words used make little difference to family members who are faced with losing their loved one. To them, such treatment is invariably viewed as 'life-saving.'

<sup>60</sup> See court cases where articulated statements from teens who became comatose were honored and life support was removed. For example *In re Rosebush*, 491 N.W.2d 633 (Mich. Ct. App. 1992); *In re Swan*, 569 A.2d 1202 (Me. 1990).

For BJ, in light of the likelihood of cure, his situation is less tragic than is AJ's. BJ's disease as presented herein has an excellent chance of being entirely eradicated. Upon determining that likelihood, health care providers convey a highly positive prognosis to BJ and his parents. Clinicians are right to be confident of a cure. In the interest of beneficence-in-trust, the curative intervention should be recommended to parents, discussed with BJ, and performed, consistent with the third, or hard, form of intervention proposed by Pellegrino and Thomasma.

Let us suppose that BJ questions the clinicians' statistical presentation of intervention and cure. Perhaps he refuses treatment because he fears being in the 10% of those not cured and does not want to 'fight' the disease. Clearly, BJ requires significant education and support about his chances, especially since his refusal has no practical merit in our decision making framework. Such education comprises the weak rule for justifying necessary medical paternalism from the standpoint of beneficence-in-trust.<sup>61</sup> By working with BJ to help him recognize why the life-saving intervention is ethically required, parents and providers may reverse his refusal. Because the curative treatment of amputation is not reversible and BJ is not acting in his best interests, the third rule, or hard form of paternalism, is indicated. In progressing to this point, BJ continues his adamant refusal, however he is told that the intervention will take place since a cure is likely. If his condition deteriorates and his prognosis becomes unfavorable, BJ's views regarding refusal for continuing treatment become of more pressing relevance.

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<sup>61</sup> Pellegrino, E.D. & Thomasma, D.C. (1988), 157.



Let us further suppose that the chances for cure are far less than 90%, perhaps only 30-40% or even less. In such a scenario, where a disease is newly diagnosed, providers ought to again firmly recommend and insist on treatment consistent with the hard form of intervention. Beneficence-in-trust requires providers to work with the patient and parents in providing treatment with the possibility of cure or alleviation of disease. If, down the road, BJ's disease is deemed incurable, such that further treatment is essentially prolonging his death, and his refusal of treatment becomes legitimately based in burdensome experience with illness, pain, and suffering, parents and health care providers may elevate the extent to which BJ's refusal of medical intervention is considered. At such a time, BJ's scenario becomes one similar to that of AJ with its associated recommendations.

#### Stewardship for *parens patriae*

As noted earlier, health care providers' interests in beneficent practice overlap with the interests of the state in protecting its citizens. The health care providers caring for an adolescent refusing treatment are viewed as stewards for *parens patriae*. Stewardship may include evaluating the adolescent's comprehension of what has been presented to him, especially if it is life-changing information, and inviting discussion of the adolescent's choices and desires.<sup>62</sup> Serious consideration of the adolescent's views promotes collaborative interaction between the teen, the parents or guardians, and the clinical team. In the case of AJ who is refusing treatment, health care providers engage in an on-going dialogue to assess his patient skills for imagining palliative care activities,

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<sup>62</sup> See Hartman, R.G. (2002), 447.

for processing his concept of dying, for discovering psychological or emotional barriers that prevent AJ from processing information and confronting dying, and for optimizing his ability to describe his best interests.

The health care providers' actions relative to AJ are aimed at discovering his views and wishes relative to any further life-saving medical intervention. If AJ's providers have prevailed in forging a therapeutic alliance comprising of dialogue and disclosure, AJ's parents will also be in agreement with AJ's wish to forgo further medical intervention. However, if the parents adamantly demand continued life-saving treatment, providers are in the position of employing their communication skills to persuade the parents of their son's perspective, with which the clinicians also agree.<sup>63</sup> Early referral to the ethics committee is highly recommended in order to avert a strained relationship between those the adolescent must rely on for emotional support.

Health care providers' stewardship is especially called upon when the adolescent refuses life-saving medical intervention that has a chance of being curative, as in the case of BJ. Regardless of BJ's demonstrated decision making capacity, his refusal cannot be honored. Here the pediatric clinicians' and the state's interests merge. The state aims to preserve a minor's life; the clinician's objective is to provide beneficial treatment and protect the adolescent from his harmful decision. Although BJ presents as a seemingly

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<sup>63</sup> Hartman's study (2001) of physician perceptions of adolescent decision making capacity found that among her responding group of 110 pediatric physicians, almost two thirds reported that they have not honored adolescent patient wishes about life-threatening conditions when confronted with conflict by a parent or guardian. "Adolescent Decision Autonomy for Medical Care: Physician Perceptions and Practices," 8 *University of Chicago Law School Roundtable* 87, p.113. Such results give pause to considerations of whether adolescents who refuse life-sustaining treatment, must often be subjected to it if their parents are unable to deal with their inevitable deaths. Interestingly, if the life-threatening condition is removed, two thirds of physicians would honor their adolescent patient's decision despite conflict with the parent or guardian. See p.111.

autonomous decision maker, there is enough vagueness about what capacity means in adolescence, to implore the clinicians to function from the vantage of the principle of patient-centered beneficence. Respecting BJ's questionable decision making capacity will result in a premature and preventable death. Health care providers, acting in concert with the state's interests, are compelled to overrule BJ's refusal in order to preserve his life and afford him future opportunities to actualize ethically and legally-recognized autonomy.

If BJ's parents agree with their son's decision to refuse the life-saving intervention, health care providers should work with them to persuade them otherwise. The parents may be very amenable to the weak rule for intervention. That is, providers, in forging communication with the parents, can be successful in convincing the parents of their misappropriated agreement with their son. Again, early referral to the ethics committee may afford the parents and the adolescent patient the opportunity to understand that their decision is not ethically defensible in a situation where cure is possible.

The health care providers' role as stewards of *parens patriae* ought not diminish the role of parents or guardians. As the persons who best know the adolescent and have always in the past given permission or made decisions on their child's behalf, the parents are not to be sidelined.<sup>64</sup> Clinicians have a great responsibility to maintain the relationship of trust and collegiality – a therapeutic alliance - in helping parents direct

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<sup>64</sup> Hartman, R.G. (2001). Of 153 physicians queried, almost 90 percent reported that they believe adolescent patients benefit from consultation with a trusted adult when deciding their medical care. In fact, the same number said that they would encourage adolescents to make decisions about medical care only after consultation with a parent or guardian.

their energies toward AJ's dying or BJ's unwanted – but required - intervention and rehabilitation.

For adolescents without a parent or guardian figure in their lives, the recommendations previously given are no different. An adolescent who has no adult in his life to agree with or dispute a treatment refusal is not, by default, more or less decisionally capable. Just as with a supported adolescent, an adolescent alone may be refusing because of an inadequate understanding of the facts, or out of fear or panic. For the adolescent alone, refusal may buy time for more attention and certainly further dialogue. Adolescents alone who refuse life-saving treatment may need more patience and support than other adolescents because of their prior history and lack of trust.<sup>65</sup>

#### Early referral to the ethics committee

Throughout this section, the ethics committee has been appealed to as an extremely useful resource to health care providers who are faced with treatment disputes. One of the first steps taken by the ethics committee is assisting in the determination of who, among all those with moral standing in the case, ought to be making the decision before the committee. Where very young patients are involved, the parents are in the position to make decisions in the best interests of their child, unless the state holds a compelling best interest to the contrary. The involvement of adolescent patients who appear to demonstrate decision making capacity becomes complicated and often too emotional for those at the bedside to examine the case with objectivity. Seeking out a judicial opinion

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<sup>65</sup> Blustein, J., Dubler, N. & Levine, C. (1999). "Ethics Guidelines for Health Care Providers." In, J. Blustein, C. Levine, & N. Dubler (Eds.), *The Adolescent Alone: Decision Making in Health Care in the United States*, 251-270. New York: Cambridge University Press, 261.

is discouraged, not only because of the likely hostility it may engender, but due to express prior statements by the courts requesting that such private cases remain at the bedside.<sup>66</sup>

Members of an ethics committee, unlike a judge, approach ethical dilemmas from an inherently individual and value-based perspective. They are able to facilitate conversations from the vantage of the family's narrative, which is far more personal and meaningful than a confrontational atmosphere in front of a judge.<sup>67</sup> If health care providers have been able to forge a therapeutic alliance with the adolescent patient and parents, consultation by an ethics committee may be unnecessary. However, if there is disagreement among parties and a therapeutic alliance holds little promise, health care providers ought to consult early on with an ethics committee.<sup>68</sup>

Early consultation with the ethics committee cannot be overemphasized as its intervention will be crucial in defusing the appearance of 'forced' treatment on a refusing adolescent, perhaps in the case of BJ. Neither clinicians nor parents will be emotionally inclined to impose treatment on a kicking and screaming adolescent. A life-and-death situation does not offer much extra time to persuade the adolescent to recognize his refusal cannot be honored. Thus, a proactive ethics committee referral can offer

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<sup>66</sup> *In re Rosebush*, 491 N.W.2d at 638 and *In re Doe*, 418 S.E. 2d 3. Courts in both cases refer to recommendations by institutional ethics committees. Since the ruling in Karen Quinlan's case by the New Jersey Supreme Court highlighted the role of ethics committees in resolving medical treatment conflicts, state courts have encouraged ethics committee intervention. Hartman (2002) wonders how much deference by the courts is appropriate since ethics committees utilize bioethical values instead of legal concepts in their deliberation.

<sup>67</sup> Hartman, R.G. (2002), 450.

<sup>68</sup> The necessity for extensive discussion is underscored in the case of adolescents who present with life-threatening illnesses and have few adults, if any, to depend on for support. Although ethics consultation is not mentioned by name, its usefulness in facilitating such discussion and deliberation is presumed. Blustein, J., Levine, C., & Dubler, N. (1999), 261-5.

significant assistance in resolving the dilemma of adolescent treatment refusal involving no prior relevant experience with illness. For a case like AJ's, early ethics committee involvement can be critical for building a therapeutic alliance between AJ, his parents, and health care providers in order to foster understanding of AJ's views about no further medical intervention, together with his best interests. Ethics committee involvement can play a crucial role in promoting a therapeutic alliance directed toward development of a beneficence-based course of action.

## CHAPTER 6

### Concluding Reflections

This project has indicated a crucial need for more research on adolescent and adult medical decision making. The shortcomings in understanding decision making capacity and considerations of informed refusal in adults are only amplified when adolescents enter the picture. Among the authors cited in this dissertation, even those with a radical approach to adolescent autonomy and decision making,<sup>1</sup> there appears to be consensus that adolescents who refuse life-saving medical intervention, in the face of a high probability of cure, are to have their refusals overridden.<sup>2</sup> These authors reluctantly and briefly admit a conditional limitation on adolescent decision making in life-and-death cases. Their admission comprises only several lines of text and is eclipsed by voluminous arguments for general adolescent decision making rights.

This dissertation has proposed a direct approach in not permitting adolescent refusal of life-saving treatment in cases where medical intervention is extremely, or even somewhat, promising. The refusal of treatment is not an option to be presented to the adolescent or considered by parents or health care providers when medical intervention is deemed, in dialogue among the adolescent, parents, and providers, to be in the adolescent's best interests. This proposal is a departure from growing concessions to the adolescent's developing autonomy and subsequent respect for life-and-death decisions she makes for herself. The triadic approach for decision making permits consideration of

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<sup>1</sup> Harvey, M.T. (2003). "Adolescent Competency and the Refusal of Medical Treatment." *13 Health Matrix* 297 delineates authors who propose arguments for either radical or orthodox conceptions of adolescent autonomy, 307-13.

<sup>2</sup> Ibid. Included here are writings by Jennifer Rosato, Rhonda Gay Hartman, and the American Academy of Pediatrics, Committee on Bioethics.

the adolescent's perspective about medical intervention in the context of an on-going conversation with parents and providers. Longstanding experience the adolescent has had with disease and suffering is a compelling talking point within the conversation. With the adolescent, parents and care providers consider the adolescent's best interests in arriving at a plan for proceeding with medical treatment. Such consideration may be assisted by the ethics committee. Determining, and acting upon, the adolescent's best interest forestalls the current inclination of adhering to a misconstrued respect for adolescent autonomy.

Perhaps it appears counter-intuitive to the work of ethics committees to deny respect for an adolescent's apparent informed refusal. This is a concern especially in light of the progress the clinical ethics movement has made in teaching that informed consent is meaningless without informed refusal. If adolescents can, and ought to, give informed consent, advocates ask, why then are they not able to give informed refusal about medical interventions that will have a significant impact on their immediate, and future, lives? Whether adolescents are capable of giving informed consent and refusal has been the troubling problem through much of this dissertation. Because they are adolescents, teens exhibit qualities that place their ability to truly appreciate a life-threatening situation in doubt. Although these qualities do not knowingly impact our current cognitively-based criteria for decision making capacity, suspecting they do ought to make it very difficult to allow an adolescent to make that ultimate decision that could effectively end their lives.

The triadic approach for deliberating about the problem of an adolescent refusing life-saving treatment draws many considerations into a culminating resolution. Advocates of



unrestricted adolescent autonomy in medical decision making argue that a bright line of 18 years of age unfairly discriminates against those teens shown to express full decision making capability. The triadic approach for adolescent life-and-death decision making, reflecting the counter-arguments, maintains a bright line of 18 years and allows adolescents who are shown to display decisional capacity at such an age to have their decision respected, as would be the case for any adult. Our review of literature shows that older adolescents, those 18 and above, continue to retain qualities apace with inexperience, risk taking, and focus on the present. However, since the age of 18 is legally viewed as the age of majority, health care professionals and the state have no compelling moral interest in not honoring the wishes of a legal adult. To put this in another way, clinicians and the state can morally justify protecting an adolescent from a refusal with life-threatening consequences only up until the age of 18 years, when society has agreed that presumed capacity allows individuals to express their self-determined preferences as they see fit. In short, until further research affords greater reliability in capacity measurement, we must use the legal bright line to protect adolescents from irreversible decisions about life-saving medical treatment. Overriding an adolescent minor's refusal - that is based in under-developed decisional capacity - in order to permit a future opportunity for capable refusal as an adult, is a beneficent action not subject to regret over disrespect for autonomy.

The triadic approach for adolescent life-and-death decision making can be viewed as a triangle of varying contour depending on the circumstances the adolescent faces. In a scenario such as that of AJ, the triangle may be equilateral. All parties – adolescent,

parents, and health care providers – may assume an equal role in deliberation. At the other extreme, the triangle reflecting the triadic approach in BJ's scenario takes on a very different configuration. Although BJ is to be kept informed about his condition and treatment options, and his perspective is known, his contribution to the final decision making is minimal. Since he does not recognize his best interests in being treated, his side of the triangle is short in comparison to the other two sides. Where the triangle is not equilateral, health care providers retain the longest side, parents the second longest, and the adolescent the shortest. This image conveys that it is the health care providers who are responsible for fostering a therapeutic alliance with parents in order to help them best fulfill their duties of protection toward their child. It is also the health care providers, as representatives of the state, who must seek to override parents who wish to either initiate burdensome treatment without benefit or support their child's refusal of life-saving treatment that has a reasonable chance of cure.

The team of clinicians is in the best position to advocate for the best interests of the adolescent who is facing life-sustaining treatment without a chance for cure: AJ's case. Open communication with the teen and parents can best foster an enhanced mutuality between parents and their dying child in the context of a therapeutic alliance amongst the triadic stakeholders. The clinicians' role, together with parents, is in providing comfort measures and supporting a 'good death.' Where clinicians or parents are in disagreement, the ethics committee may be instrumental in facilitating understanding among those with moral standing about the adolescent's predicament and how to best serve his best interests. If, failing the efforts of the ethics committee, the case is brought to the courts,

it is the responsibility of the state to recognize the expertise of clinicians in evaluating the dim prognosis facing the teen.

In contrast to the specter of poor prognosis, health care providers have the ethical responsibility to promote life-saving treatment with a chance for cure, especially in the face of refusal by an ostensibly capable adolescent. Here again, open communication is crucial in conveying that refusal is not an option. Honest, on-going conversation with the adolescent and with parents or guardians is necessary to convey clinicians' responsibilities, but also parental responsibilities in securing a highly feasible future for their child. Failing a strong therapeutic alliance, the ethics committee may be helpful in attempts to persuade the adolescent to willingly accept a required intervention. If judicial action is sought on behalf of the refusing adolescent, responsible judges will recognize the expertise of clinicians in determining the degree of successful, curative treatment. Even a low chance of cure warrants proceeding with the third rule of medical intervention. Parents and providers ought to consider beneficent enactment of the second or intermediate rule of intervention if, after the curative procedure is performed, the prognosis deteriorates and further treatment becomes unduly burdensome.

The 'hard' cases involve careful consideration of the adolescent's best interests in circumstances where the adolescent is confronting very low chances of treatment success especially in the face of on-going, challenging illness and suffering. Although the adolescent signals refusal for further treatment, the triadic approach fosters decision making from a patient-centered best interests perspective. Beneficence-in-trust requires listening to, and acknowledging, the adolescent's views in deliberating about his best

interests. A strong therapeutic alliance that affords communication and trust is able to bear more uncertainty than is a weak or absent relationship.

The symbolic meaning of youth to our society invokes a responsibility not to abandon teenagers to their questionable autonomy. Health care providers for adolescent patients are best positioned to fulfill an ethical imperative to include adolescents, with the parents, in discussions about their medical status and their treatment options. Adolescent participation in decision making, to the extent they are willing and capable, is viewed by health care providers as vital to the success of any treatment regimen. However, adolescent refusal of beneficial life-saving medical treatment is not an option. Intervention based in beneficence-in-trust, on the part of providers and parents, is ethically justified when it occurs with sensitivity toward the adolescent's views and sensibilities. Ethical action continues to require active communication with the adolescent and family in order for all to understand the prospect of living a different kind of life than previously imagined, but a life, nonetheless, with a future.

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