Adolescent Refusal of Lifesaving Treatment: Are We Asking the Right Questions?

Douglas S. Diekema MD, MPH*
Professor of Pediatrics, University of Washington School of Medicine; Director of Education, Treuman Katz Center for Pediatric Bioethics, Seattle Children’s Research Institute, Seattle, Washington

On November 28, 2007, Dennis Lindberg, a 14-year-old with leukemia, died after refusing to allow a blood transfusion. Dennis had recently been diagnosed with acute lymphocytic leukemia and undergone a first round of chemotherapy. With treatment, he would have a 70% chance of disease-free survival. When told he would require a transfusion for decreasing blood cell counts, Dennis refused, arguing that it would violate his faith as a Jehovah’s Witness. Dennis had been living with his aunt for the past four years, having been removed from the custody of his biological parents because of their illicit drug use. His aunt served as his legal guardian, was a Jehovah’s Witness, and supported his decision to refuse blood products. On hearing that Dennis and his aunt refused to authorize a blood transfusion despite the likelihood of death without one, his biological parents objected and contacted child protective services. A Skagit County superior court judge in Washington state, arguing that Dennis was sufficiently mature and understood that he would die without a transfusion, declared him a mature minor and held that he had the right to make the decision. Dennis died shortly after the court decision.¹

Dennis’ refusal of a blood transfusion and his resultant death was troubling to many, and it raised the question of whether an adolescent, even a mature one, should be permitted to refuse a lifesaving treatment. Whether adolescents possess the capacity to make medical decisions remains a contentious issue. In general, adolescents do not have the legal authority to consent to or refuse most medical interventions, with a few notable exceptions (usually involving birth control, pregnancy-related care, diagnosis and treatment of sexually transmitted diseases, and the treatment of substance and alcohol abuse). However, there are some who argue that mature adolescents ought to have their decisions respected,

*Corresponding author.
E-mail address: diek@u.washington.edu (D. S. Diekema).

Copyright © 2011 American Academy of Pediatrics. All rights reserved. ISSN
especially when that decision is supported by the adolescent’s parents or legal guardian.

Most jurisdictions would not allow a parent to withhold a potentially lifesaving blood transfusion from a minor in Dennis Lindberg’s situation on the grounds that it placed the child at significant risk of serious harm. Presumably that would have been the case had Dennis been younger, or if he had not displayed sufficient maturity that a judge would feel that his decision, independent of his aunt’s, should be respected. In life-threatening situations, whether and under what conditions a minor should be allowed to refuse a lifesaving intervention is an important question. Most would agree that age of majority “is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood.” However, the important question is whether most minors truly possess sufficient capacity to make life-altering medical decisions. Although a strict line may not exist, it is not clear that it lies on the younger side of the age of majority.

In this chapter, I address the issue of whether adolescents, as a rule, possess capacity of sufficient quality that it should be respected even in the case of life-altering medical decisions. I begin by reviewing the traditional approach to determining when adolescents should have their decisions respected, an approach that focuses on establishing capacity under a traditional informed consent model. I then review our evolving understanding of adolescent brain development, and explore the implications for adolescent decision-making capacity. I argue that a demonstration of understanding and mature reasoning abilities is not sufficient to establish decision-making capacity, and that most minors do not possess fully mature decision-making capacity. Finally, I suggest an approach to adolescent decision-making that is more reflective of the developing state of the adolescent brain.

THE CURRENT APPROACH TO ASSESSMENT OF CAPACITY IN ADOLESCENTS

When faced with an adolescent who refuses diagnostic testing or treatment, the health care professional may have to decide whether to respect that decision or act against the adolescent’s wishes. Parents are generally granted the authority to make medical decisions on behalf of minor children, including adolescents, and they are granted significant discretion in terms of the choices they can make as long as their choices do not place the child at significant risk of serious harm as compared to other alternatives. When the patient is an adolescent, however, the decision-making process may become complicated if the adolescent has independent views about accepting or rejecting a medical intervention or plan. If the adolescent is felt to be sufficiently mature, providers and legal authorities may be inclined to respect the adolescent’s wishes. This may include situations where the health or life of the adolescent is at significant risk and in which a parental refusal would generally be challenged as medical neglect.
There are 3 situations in which a minor has the legal authority to make decisions regarding his or her health care. First, state law designates certain minors as emancipated and grants these emancipated minors the right to make decisions, including health care decisions. Children who are legally emancipated may give consent for medical treatment. They may also refuse medical care. Although emancipated minor laws vary from state to state, most states recognize minors to be emancipated if they are married, a parent, economically self-supporting and not living at home, or on active-duty status in the armed services. Second, most states designate condition-specific exceptions to consent laws whereby adolescents of a certain age are granted the authority to provide informed consent. These condition-specific areas typically include the diagnosis and treatment of sexually transmitted diseases, pregnancy-related care, and the treatment of substance abuse. It is important to note that these condition-specific exceptions exist primarily for public health reasons, and not because legislatures believe that minors possess full capacity to make decisions related to those health conditions. Finally, most states have some mechanism whereby adolescents can be granted “mature minor” status. In most states, mature minors must be older than 14 years and have been formally recognized as sufficiently mature to possess decision-making authority. There is significant variation among states: Some states allow medical professionals to make a mature minor determination, others require a court determination, and states differ with regard to the minimum age at which such a determination can be made.

If a child is not an emancipated or a mature minor, then he or she has no legal authority to either provide consent or refuse medical care. However, lacking legal authority does not require a health care professional to force medical interventions on a minor. With regard to minor patients, the American Academy of Pediatrics Committee on Bioethics has argued that “there are clinical situations in which a persistent refusal to assent (ie, dissent) may be ethically binding.” There is general agreement that health care professionals should inform adolescents of the interventions that are being proposed, educate them about those interventions, and seek their agreement, at least informally. In those situations where the adolescent persists in a refusal to accept medical treatment, especially in situations where the treatment is for a life-threatening illness, however, there is less agreement about whether such a decision should be respected and under what circumstances.

When adults refuse potentially lifesaving therapies, they are generally assumed to possess the capacity to make that decision. The ethical basis for this stance rests in the principle of respect for autonomy. Unless an adult is found to lack capacity, their decision is respected, even if it results in death. Adolescents, on the other hand, are assumed to lack capacity unless they can demonstrate otherwise. If an adolescent can successfully exhibit adult-like decision-making capacity, however, the ethical principle of autonomy would seem to require that his or her decision be respected. The basis for determinations of capacity for adults and
adolescents tends to be the same. As a general rule, capacity to make a decision requires some combination of the following:

- The ability to evidence and communicate a choice
- An understanding of the information and facts relevant to the choice
- An appreciation of the situation and the consequences of the decision
- The ability to manipulate the information in a rational way

Although some have suggested that capacity also requires that the choice result in a "reasonable" outcome, others have argued that capacity should focus on the process by which the decision is made (i.e., the decision was reached after considering alternatives, rationally weighing them, and providing reasons for the choice), not by the outcome or choice itself.

Health care providers and legal authorities have used these criteria to establish whether a given adolescent should be allowed to refuse an important medical intervention. These determinations are influenced by several empirical studies that have concluded that by the age of 14, the ability of adolescents to make rational and reasonable health care decisions approximates that of adults. Perhaps the most widely cited of these studies was performed by Weithorn and Campbell, who used hypothetical treatment dilemmas and a scoring system designed to rate subject responses in terms of each of four tests of competency (evidence of choice, reasonable outcome of choice, understanding, and a choice derived from rational reasoning) at each of 4 age levels (9, 14, 18, and 21 years). Employing a rigorous methodology, these investigators demonstrated that although 9-year-olds appeared less competent than adults, 14-year-olds did not differ significantly from adults in terms of their ability to express reasonable preferences regarding medical treatment. These authors (like many of those who cite their work) concluded that the findings did not support the denial of the right to self-determination in treatment situations on the basis of presumed incapacity and that most adolescents possessed the capacity to make such decisions.

Mann, Harmoni, and Power similarly defined competence in decision-making in terms of cognitive processes, and concluded that adolescents aged 15 and older show a reliable level of competence in metacognitive understanding of decision-making, creative problem-solving, correctness of choice, and commitment to a course of action. Others have reached similar conclusions, noting that additional factors, such as experience with chronic illness, can further enhance the ability of children and adolescents to develop capacity to make health care decisions.

Bioethicists have been persuaded by these empirical explorations of developmental ability. Sanford Leikin argued almost 30 years ago (on the basis of developmental psychology, particularly the work of Jean Piaget) that "... by age
14 years, many minors attain the cognitive developmental stage associated with the psychological elements of rational consent. . . . there appear to be no psychological grounds for the general assumption that minors 15 years of age or older cannot provide competent consent.” More recently, Weir and Peters argued that “. . . the presumption on the part of physicians and other health professionals should be that all adolescent patients between fourteen and seventeen have the capacity to make health care decisions, including end-of-life decisions, except when individual patients demonstrate that they do not have the necessary decision making capacity.” This conclusion was based in part on a review of the developmental evidence cited earlier. Other bioethicists have also concluded that some adolescents may be sufficiently mature that their decision-making capacity should be respected, even in cases where they refuse lifesaving treatment.

In Great Britain, the assessment of a minor’s capacity to consent to medical treatment, known as the “Gillick” test, has become the established legal standard. The Gillick test that requires a minor to demonstrate “a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.” Similar reasoning has been applied in several US legal cases. In Cardwell v. Bechtol, the Tennessee Supreme Court referred to the common law “rule of sevens,” which states that no capacity exists for children younger than the age of 7; lack of capacity is assumed for those between 7 and 14 years but can be rebutted with evidence of capacity; and, most pertinent to this discussion, a rebuttable presumption of capacity exists for those 14 years and older. Relying in part on the decision in Cardwell v. Bechtol, the Illinois Supreme Court found that a 17-year-old with leukemia who was a Jehovah’s Witness (her mother was also a Jehovah’s Witness and refused to consent to the transfusion) should have been allowed to refuse a lifesaving blood transfusion on the grounds that she was a mature minor.

Lainie Ross has pointed out that courts have moved in the direction of granting decision-making authority to adolescents who refuse lifesaving treatments, but usually only when parents concur with the adolescent’s decision. As if to illustrate Ross’ point, the state of Virginia, in response to a case in which a 15-year-old refused additional chemotherapy for his Hodgkin’s disease, recently passed a law that allows parents of a child at least 14-years-old to refuse recommended medical treatment when the decision is made jointly by parents and the adolescent, the adolescent is deemed sufficiently mature to have an informed opinion about the treatment, other treatment options have been considered, and the parents believe that their (and the adolescent’s) decision is in his or her best interest. Ross, whose stance differs from that of many bioethicists, argues that these kinds of laws may deprive a child of the opportunity to fully develop his or her decision-making skills, goals, and values: “Mature minor laws that permit refusals of effective life-saving treatments by adolescents alone (minor refusal) or in conjunction with their parents (family refusal) are morally unjustified.”
ADOLESCENT DECISION-MAKING: THE PROBLEM

Is Ross correct that mature minor laws are misguided, and that adolescents who are allowed to refuse effective lifesaving treatments are deprived of the opportunity to fully develop their decision-making skills, goals, and values? If so, what are we to make of the empirical studies cited previously that seem to suggest the opposite?

The conclusion that at least some adolescents are capable of making adult-like decisions, a conclusion shared by the Gillick test, the mature minor doctrine, and the arguments of many in bioethics and developmental psychology, all share an underlying model of decision-making capacity that focuses on assessment of the adolescent’s rational faculties—primarily assessments of understanding and reasoning. Using those criteria, many adolescents older than the age of 14 years appear capable of making rational decisions that approximate those of adults. They also appear capable of fulfilling the requirements of informed consent and demonstrating an understanding and appreciation for even complex medical decisions and the ability to make a voluntary decision on the basis of that information.

There are 3 problems with this understanding of decision-making capacity, however. First, middle and older adolescents have the ability to make adult-level decisions, but frequently do not use that ability optimally, resulting in decisions that differ from those most adults would make. Although capable of adult-like decision-making, adolescents often do not perform at a level commensurate with their cognitive abilities. The emphasis on intellectual and rational criteria in establishing capacity may ignore other elements of decision-making that remain deficient in the adolescent as compared to the adult. For example, adolescents are more affected by the influence of peers, less future-oriented, more impulsive, and differ in their assessment of risks and rewards as compared to adults. Psychosocial factors appear to interact in important ways with the cognitive elements of decision-making. This would suggest that a model of capacity assessment that rests on the adolescent’s ability to understand and reason is incomplete. Second, although studies indicate that adolescents are more likely than younger children to rely on analytic processing, this does not establish that analytic processing is their primary means of decision-making. Finally, the empirical studies that have demonstrated adult-like rational capacity in adolescents have been conducted apart from the social and emotional context of real-life medical decision-making. Having established the ability to exercise rational judgment in the confines of a pen-and-paper exercise in a laboratory setting fails to establish whether those capacities would be exercised similarly in a health care crisis of the kind faced by Dennis Lindberg.

THE ADOLESCENT BRAIN

More recent neuroanatomical and neuropsychiatric evidence suggests that the traditional understanding of adolescent decision-making capacity, based on a handful of studies that measured understanding and reasoning ability using
hypothetical situations in a setting that does not approximate that of real-life decision-making, is inadequate.

It used to be thought that most brain development and growth occurred during the first 3 years of life. We now know, however, that the human brain undergoes a second period of rapid change during the pubertal and adolescent years. These changes include an increase in frontal lobe gray matter during preadolescence followed by a decline during postadolescence, synaptic pruning within the frontal cortex (allowing for more efficient and rapid information processing), increased myelination within the peripheral regions of the cortex, and increased connectivity between the prefrontal cortex and other regions of the brain. In addition to these neuroanatomical changes, neurochemical changes are also occurring, particularly with regard to dopamine, a neurotransmitter associated with motivating behavior and reward seeking.

Final brain maturation tends to occur from “back to front”, with the prefrontal cortex—that part of the brain associated with high-level reasoning, executive function, weighing of consequences, planning, organization, emotional regulation, and rational decision-making—being among the last to mature. This process of maturation occurs about a year earlier in females than males, but extends well into the 20s for both genders, suggesting that 18 years or even 21 years may not accurately reflect the point at which the human brain becomes “adult.” During this period of rapid change, the adolescent brain is quite different than the mature adult brain, differences that help explain why adolescent decision-making differs from that of mature adults.

TWO BRAIN SYSTEMS

Although middle adolescents are more likely to rely on analytic processing than early adolescents, this is not their primary method of decision-making. Several investigators have hypothesized that decision-making relies on dual systems within the brain, a socioemotional system composed largely of limbic and paralimbic structures (ie, the amygdala, ventral striatum, medial prefrontal cortex) and a cognitive control system composed of prefrontal and parietal cortical structures. The amygdala is essential for processing and responding to information with survival importance, including potential threats and stimuli that evoke an emotional response (fear, anger, sorrow). The ventral striatum is thought to influence behavior through reward seeking. This socioemotional system tends to involve rapid, automatic processing that is often reactive, intuitive, and unconscious, picking up patterns before an individual may be consciously aware of them and motivating behavior change through feelings and autonomic responses. Behavioral responses are often based on first impressions, or a “thin-slice” of available information and a rapid response to that information. The cognitive control system, on the other hand, tends to be consciously controlled, volitional, deliberate, reasoned, analytic, and reflective, and requires more time and conscious effort.
These two systems mature along different trajectories, with the socioemotional system maturing around the time of puberty and the cognitive control system maturing in later adolescence. Integration between the two systems (which may be important for the cognitive control system to exert control over the socioemotional system—sometimes referred to as “top-down” control)—also matures in later adolescence.

Not only has the part of the brain associated with executive control and reasoning not fully matured during adolescence, but an “imbalance” of sorts develops, with the maturation of the “emotional” areas of the brain occurring earlier than the cognitive-control system. In other words, those areas of the brain responsible for emotion-arousal, reward orientation, and sensation-seeking may be fully engaged at a time when the regulatory functions of the prefrontal cortex are not yet fully matured. This may lead adolescents to rely more heavily on their instincts and impulses when confronted with stressful or emotional decisions. Although their brains may be capable of adult-like decision-making, adolescents may have difficulty engaging the “cooler,” more rational parts of their brains under certain conditions. The relatively automatic responses of the limbic system may overpower the response inhibition function of the prefrontal cortex. In the words of Laurence Steinberg, this “may well create a situation in which one is starting an engine without yet having a skilled driver behind the wheel.” Put another way, the adolescent’s accelerator (subcortical systems) may overpower the adolescent’s brakes (prefrontal control system).

This relative imbalance between the emotional and cognitive areas of the brain (combined with still developing integration between the two) manifests in several well-described behavioral implications during adolescence. First, the ability to regulate and understand emotions corresponds with the maturation of the cognitive areas of the brain and the tracts that connect those areas with the limbic areas. Second, susceptibility to peer influence and the ability to delay rewards tends to decrease with the maturation of cortex and prefrontal cortex and the increases in regional interconnectivity that occur during late adolescence. Third, these changes are also correlated with the increased vulnerability to risky behavior that occurs during adolescence.

Adolescents and young adults are more likely than adults to engage in a variety of risky behaviors (binge drinking, cigarette smoking, casual sex, violent or criminal behavior, and dangerous driving behaviors). The increased risky behavior seen among adolescents does not appear to be the result of deficits in logic or reasoning. Adolescents are similar to adults in terms of their ability to perceive risk, evaluate risk, and estimate their vulnerability to it. However, they may weigh risks and benefits differently under certain conditions and react more impulsively, perhaps ignoring that “little voice” warning them of danger. In addition, adolescents may consider some forms of risk in certain contexts to represent a positive thing (offering an immediate reward in terms of excitement or a way to maintain or
enhance social status), whereas an adult might perceive the same risk as a negative thing (focusing more on the potential future losses). Steinberg has postulated that this increased risk behavior is social and emotional, not cognitive—the result of a more assertive socioemotional system (which leads the adolescent to seek immediate rewards) and a still developing cognitive control system (which helps regulate these reward seeking impulses and orient toward future consequences). Under conditions of emotional arousal and heightened sensitivity to social rewards (ie, peer pressure, approval, or presence), the cognitive control system may have difficulty regulating impulsive and risky behavior. Adolescents appear to focus more on the immediate benefits than the future costs of risky behaviors, a finding that is exacerbated when in the presence of peers. Resistance to peer influence appears to gradually increase beginning at about age 14 until about age 18. In one investigation performed with the subject in an fMRI scanner, a driving decision task (involving assessments of risk) demonstrated the use of a wide variety of brain systems, including the prefrontal cortex, when the adolescent was alone. However, in the presence of peers, significantly increased activity in brain regions associated with the socioemotional network accompanied riskier decision-making among adolescents.

Psychosocial maturity (which includes impulse control, aggression suppression, future orientation, consideration of others, and responsibility) also increases gradually throughout adolescence and young adulthood (and peaks earlier in females than males). By middle adolescence, general cognitive functions are similar to those of adults, but adolescent psychosocial functioning, even at 18 years of age, remains less mature than that of adults in their middle to late 20s. These findings almost certainly have implications for decision-making, with decisions made under conditions of high arousal, in the presence of peers, and/or under real-life conditions resulting in different decisions than might be made under hypothetical conditions characterized by low arousal and no peers.

Although we should not assume that all adolescents develop at the same rate, or that no adolescent younger than 18 years of age is ever capable of making a reasonable and mature and authentic decision about significant medical issues, the data are fairly clear that in general, adolescents (and to a certain extent young adults), although capable of applying cognitive skills in an adult-like manner, frequently differ in the way they make decisions, and may be prone to underutilize the cognitive aspects of decision-making under certain conditions. In emotionally charged situations, decisions made under stressful conditions, or decisions made in the presence of peers, adolescents may rely on their more mature limbic systems than their less mature prefrontal control system. In addition, adults may be more able than adolescents to resist social and emotional influences and focus on long-term goals.

A recent study on cosmetic procedures among teens illustrates the changing nature of perceptions and decision-making during the adolescent years. Of all
age groups, teens are the most likely to be dissatisfied with their appearance, and they tend to be very sensitive to how others look and what others think. More importantly, satisfaction with body image improves with age and peaks at 18 years. Many individuals experienced a change in their body image and attitudes as they approached adulthood, leading to changes in their views about the desirability of cosmetic surgery, and presumably whether or not they would choose to undergo a cosmetic procedure (or even get a tattoo). In the words of Laurence Steinberg, “Some things just take time to develop, and like it or not, mature judgment is probably one of them.”

**IMPLICATIONS FOR ADOLESCENT DECISION-MAKING**

The point of the previous discussion is not that one brain system is better or more important than the other, but that both are essential to good decision-making. Adults use both brain systems when making difficult decisions and moral judgments. Good decision-making requires that both systems be intact and integrated. Either system in isolation is likely to lead to serious errors during some decision-making tasks. Decision-making that occurs in the presence of damage to one or the other system is commonly flawed in significant ways.

Adolescents, even older adolescents, are not the same as adults neurologically or psychologically. Despite the fact that teens are capable of rational and intelligent decision-making, it is unwise to conclude that they always do so, or that they make decisions in the same way that adults do. Adolescents, even those at the age of majority, have a relatively underdeveloped prefrontal cortex, particularly those regions concerned with functions essential to good decision-making: high level reasoning, impulse control, assessment of future consequences, planning, strategizing, organizing, inhibition of inappropriate behavior, adjustment of behavior when a situation changes, priority setting, and estimating and understanding probabilities. The communication between the cognitive control regions of the brain and the emotional reactive regions of the brain are also not fully developed. The result is a situation where the prefrontal cortex is often not fully engaged, allowing the more fully matured, but more reactive socioemotional system of the brain to dominate, particularly under conditions of high stress or emotion, peer presence or pressure, and perceived short-term benefit. The ability to think about the future, plan ahead, and anticipate future consequences increases gradually through adolescence, but does not peak until well into the 20s. Impulsivity decreases on a similar timeline. These findings do not suggest that adolescents lack capacity to make all decisions or that they should not be involved with discussions about their preferences in the health care setting. These findings should, however, raise serious concerns when an adolescent makes a decision that appears to pose a significant threat to his or her future well-being.

One might ask why these implications do not apply to those “adolescents” who are over the age of majority. The current age of majority (18 to 21 years of age
depending on the state) is not supported by empirical data, and the data reviewed here suggest that brain development relevant to decision-making does not fully mature until the mid-20s. It may well be that the age of majority should be reconsidered; however, such a discussion is beyond the scope of this chapter. For purposes of this discussion, the data establishes fairly clearly that most adolescents younger than the legal age of majority have not yet attained a level of brain maturation that justifies treating them like adults with respect to significant health care decisions.

Health care providers do have ethical duties to adolescents, but those duties are not encompassed by the principle of respect of autonomy. Rather, health care providers have a duty of beneficence: to seek the good of the adolescent patient and to minimize harms. Beneficence recognizes the need to respect adolescents and encourage their involvement in decision-making tasks (because it enhances their well-being), but also seeks to protect (by preventing serious harms that might result from an unchecked decision).

Adolescents should be involved in discussions about their health care, and should be offered the opportunity to participate in discussions and voice their feelings, opinions, concerns, and fears. Their developing capacity should be honored, and they should be provided with reasonable opportunities to make choices and have those choices respected. In many cases, a successful therapeutic plan requires the adolescent patient to cooperate, and involving their participation and respecting their views is an important component of a therapeutic alliance. But the desire to respect adolescent decisions must be coupled with the recognition that decision-making, even of mature adolescents, may occasionally be flawed. Health care providers should recognize that under certain conditions (stress, high emotion) or in certain situations (where the presence or pressure of peers, family members, or even spiritual community members may play a role), adolescent decision-making is often less than optimal. In those cases, adolescents may need to have limits placed on the kinds of decisions they are allowed to make. For example, a 15-year-old with recently diagnosed cancer who becomes upset and says she doesn't want chemotherapy may be driven more by the short-term consequences (I will lose my hair and, along with it, my social standing) than the long term consequences (I will die without chemotherapy). She should gently be told that she must undergo treatment and provided the support she needs to face the challenges that result from that treatment.

In most situations, adolescents should not be allowed to refuse treatment that is likely to be lifesaving, even when supported by a parent. It appears that courts and physicians are more likely to support a decision to refuse life-sustaining treatments when both parents and adolescent agree.76 Dennis Lindberg's decision to refuse a blood transfusion was supported by his legally authorized decision-maker. If Dennis had been a young child, his aunt's decision would almost certainly have been overruled on the grounds that it placed the child at
significant risk of serious harm. Because Dennis agreed with his aunt, however, the opposite decision was made. It is not clear that simple agreement between a parent or guardian and the adolescent should carry additional weight. There are data that suggest that adolescents are quite deferential to parental desires, and more deferential than young adults.\textsuperscript{77,78} In addition to the concerns raised here about brain development and decision-making maturity, this raises additional concerns about whether an adolescent’s expressed wishes can be considered voluntary when they may feel pressure from parents. In fact, when an adolescent’s decision to refuse a lifesaving intervention reflects the stance of important figures in his life (such as his parents, peers, or church), this “peer pressure” is likely to represent a far greater influence on the adolescent than it would on an adult. As a general rule, minors should not be permitted to refuse lifesaving interventions that offer a reasonable probability of success. If the parental decision to refuse a medical intervention would be challenged on behalf of a younger child, then it should also be challenged for an adolescent.

Exceptions to this general rule may exist, but they should be extremely rare, reserved for adolescents who can demonstrate not simply the ability to understand and reason, but also a high level of psychosocial maturity. This requires minimally an assessment of the adolescent’s ability to project meaningfully into the future, express a relatively settled set of values and beliefs, and demonstrate that his or her decision is driven more by long-term interests than short-term concerns. Likelihood of a good outcome, the burden of proposed interventions, and the duration and frequency of the proposed interventions are also relevant considerations. Prior “lived” experience with illness and treatment may also be an important determinant in whether an adolescent’s decision to forgo a potentially lifesaving intervention should be honored. An adolescent considering treatment for relapsed leukemia or the option of a second or third transplant because of rejection should be granted more decision-making authority than those making decisions early in an illness.

Finally, having established that an adolescent does not possess capacity to refuse life-sustaining treatment does not necessarily imply that they should be physically forced to endure it. Forcing an adolescent to undergo treatment may ultimately cause greater harm than forgoing treatment or may ultimately undermine the goal of a successful outcome. The use of physical force is rarely justified, particularly if it is required repeatedly. In these situations, a health care provider may decide to forgo lifesaving interventions simply because the harm done by using force may not be justified, particularly in a setting of long time therapy that requires the cooperation of the adolescent.

Although Dennis Lindberg likely displayed a level of maturity greater than most 14-year-olds, the data reviewed here would suggest that his decision-making capacity was not fully matured. The level of immaturity in his brain’s ability to make decisions, the recent diagnosis, his reliance on his aunt, and the “peer”
pressure from his religious community all converge in ways that should cast doubt on his status as a mature minor. The decision to withhold lifesaving interventions from adolescents should not be premised on the notion that the adolescent is capable of fully mature decision-making. Issues of practicality and beneficence remain valid considerations: Can a successful intervention be achieved if the adolescent and his or her family will not cooperate, and will the likely benefit of the unwanted intervention(s) ultimately justify the harms of the intervention (including the harms of disrespect and psychological trauma that might result from forcing an unwanted intervention)? The answers to these questions ought to determine whether an attempt is made to obtain a court order in cases where adolescents refuse effective lifesaving interventions. These decisions should not be made on the basis of an incomplete model of adolescent decision-making capacity.

References

2. In re E.G., 549 N.E.2d 322(Ill. 1989)
7. Doig C, Burgess E. Withholding life-sustaining treatment: are adolescents competent to make these decisions. CMAJ. 2000;162:1585–1588
25. Gillick v West Norfolk and Wisbech A.H.A. 1986 A.C. 112 at 189
28. Cardwell v. Bechtol. 724 S.W.2d 739 (Tenn. 1987)
30. VA Code 63.2-100 (2007)


