Section 1

Chapter 1

Core issues in clinical pediatric ethics

Pediatric decision-making: informed consent, parental permission, and child assent

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Case narrative

Osteosarcoma is a highly malignant bone cancer with a predilection for spreading to the lungs that primarily affects adolescents. Non-metastatic osteosarcoma has an approximate cure rate of 70%. Patients with osteosarcoma and metastases at the time of diagnosis are cured less than 20% of the time. Treatment consists of surgery and chemotherapy. Many children with cancer are treated according to clinical research trials.

Michael, a 15-year-old with metastatic osteosarcoma, has not responded to conventional therapy. For almost one year, he was treated on a therapeutic randomized clinical trial, which consisted of standard therapy (up-front chemotherapy, limb salvage surgery, and postsurgical chemotherapy). When his cancer responded poorly to up-front therapy he was randomized to receive additional “experimental” chemotherapy.

Michael has a very close relationship with his mother, and he has been an active participant in every treatment conference. For the most part, Michael tolerated the treatment; however, he struggled both physically and emotionally with the last 3 months of treatment. Michael's end-of-therapy scans confirmed that tumor was still present in both the bone and the lungs.

Michael's mother wants to proceed with an (unproven) experimental therapy in an effort to prolong his life. Michael, on the other hand, does not desire this intervention. Michael asks the physician not to administer the drug and to allow him to die on his "own terms." Michael's mother (emphatically) states that this is her decision to make and not his. She adds that if the physician is not willing to treat him, she will take him to a doctor who will.

Introduction to ethical issues

Decision-making in pediatrics presents numerous challenges for children, parents, and physicians alike. The related, yet distinct concepts of assent and consent are central to pediatric decision-making. While informed consent is largely accepted as an important ethical and legal principle in adult medicine, the limits of parental permission and the concept of assent continue to be mired in debate. This chapter will examine the issues of parental permission and assent, explore how to resolve disputes between children and their parents, consider the relationship between assent and consent, and offer an effective, practical, and realistically applicable decision-making model.

Ethical principles and discussion

Parental permission and surrogate decision-making

Parents have the legal and moral authority to make medical and other decisions on behalf of their children for several reasons (Diekema, 2004). First, unless proven otherwise, parents are assumed to care about their children, know the unique needs of their children better than others, and are invested in promoting their child's well-being. Second, the interests of family members may conflict, and parents are presumably more able than outsiders to balance the competing interests of family members in making a final decision. Finally, as caretakers, parents will have to contend with the consequences of the choices they make on behalf of their children.

Parenthood alone, however, does not qualify one as an adequate surrogate decision-maker. A parent or guardian must meet four preconditions in order...
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Assent is not consent

Informed consent is a process grounded in the notion of respect for persons. Autonomy is the right of a rational person to make his or her own decisions and provides a moral justification for the doctrine of informed consent. Capacity to consent requires the legal ability to enter into a valid contract and the psychological or developmental ability to make sound decisions. Hence, minors cannot give valid consent, but they may give assent. Consent for adults is based on the principle of autonomy, which in turn focuses on competence, a legal term. Assent on the other hand is better viewed as focusing on capacity, a developmental term.

Participation of children in non-therapeutic situations than healthy children or children whose parents have allowed them to make decisions. Children with poor health (often resulting in more experiences and a greater role in decision-making) or whose parents have allowed them to make decisions in exactly the same way, and each child's personal experiences with decision-making are unique. These experiences contribute to the child's unique capacity for decision-making. Children of varying ages possess varying abilities to synthesize information and to make decisions accordingly. In general, children 14 years and older appear to be as competent as adults in making informed treatment decisions (Weithorn & Campbell, 1982). Age alone, however, does not indicate a child's ability to understand. Knowledge, health status, anxiety, experience with decision-making, and each child's unique cultural, familial, religious background, and values all play a role in children's understanding of their situation and impact their ability to make decisions. Children with poor health (often resulting in more experiences and a greater role in decision-making) or whose parents have allowed them to make "life decisions," seem better equipped to appreciate that their choices carry certain consequences and thus, they may have a greater understanding of what is required to consent to participate in medical (and research) decisions than healthy children or children whose parents have insulated them from making decisions.

In contrast to informed consent, a less exacting capacity for decision-making is necessary for a child to meaningfully assent. Assent empowers children to the extent that they are capable. Meaningful assent requires an appreciation of the child's developmental stage and recognition of his or her basic preferences. Children should be included in medical decisions to the extent they are able to and want to be involved (Unguru et al., 2008). Children need to be encouraged by parents and physicians to communicate openly so that they may be active participants in the assent process. Shared decision-making empowers children to the extent of their capacity (Geller et al., 2003).

Assent differs from consent to the extent that, while the willingness of a minor to accept treatment is important, the minor is not the ultimate decision-maker. Treatment (based on a child's best interest) often may proceed against the minor's wishes if his or her parents consent. Thus, parental permission may trump assent and is legally binding.

Assent and decision-making capacity

Beyond a child's desire to make decisions, understanding or capacity is a critical component of assent. Capacity for decision-making is not a fixed phenomenon, but rather a process that matures with time and experience. Not all children experience life, health, or disease in exactly the same way, and each child's personal experiences with decision-making are unique. These experiences contribute to the child's unique capacity for decision-making. Children of varying ages possess varying abilities to synthesize information and to make decisions accordingly. In general, children 14 years and older appear to be as competent as adults in making informed treatment decisions (Weithorn & Campbell, 1982). Age alone, however, does not indicate a child's ability to understand. Knowledge, health status, anxiety, experience with decision-making, and each child's unique cultural, familial, religious background, and values all play a role in children's understanding of their situation and impact their ability to make decisions. Children with poor health (often resulting in more experiences and a greater role in decision-making) or whose parents have allowed them to make "life decisions," seem better equipped to appreciate that their choices carry certain consequences and thus, they may have a greater understanding of what is required to consent to participate in medical (and research) decisions than healthy children or children whose parents have insulated them from making decisions.
Barriers influencing a child’s ability to participate in decisions

For assent to be valid, it must be voluntary. A child’s freedom to choose may be influenced by many competing interests that call into question if a child is ever truly a voluntary decision-maker. Each decision or choice a person makes is ultimately influenced by and affects others, and children are no exception. It is useful to consider how children, especially sick children, see themselves and view their place within their larger social networks and how that may affect their ability to participate in decision-making. In their seminal work on informed consent, Faden and Beauchamp (1986) identified the concept of “role constraints,” which serve to limit a person’s ability for autonomous expression. They assert that the expectations associated with the role of a patient are constraining, and a unique feature of this role is to place the (child) patient in a passive position with authority figures, i.e., physicians and parents, who assume a more powerful and controlling position. Therefore, the ability of a child to voluntarily make a decision is limited by the child’s role as a hospitalized or an ill patient. Children are particularly vulnerable to influences in medical consent/assent situations because of their physical, emotional, and financial dependency upon adults (Grodin & Alpert, 1983) and because of their relative inexperience with health care-related decisions. Subsequently, minors may regress to dependency on significant others (Weithorn & Scherer, 1994) rather than achieving their potential as developing decision-makers. Although adolescents may possess the skills to make informed treatment decisions, they often lack perspective and life experience. As such, they are more likely to act impulsively and to focus on their current situation rather than the future.

Parents present another barrier to children’s involvement in medical decision-making. Many parents feel that decisions about a child’s health care belong to them alone, regardless of the child’s awareness or capacity (Bluebond-Langer et al., 2005). Some parents are not aware that it is acceptable to include their child in the decision-making process (Angst & Deatrick, 1996). Thus, it may become the physician’s responsibility to broach the topic of children participating in decisions about their care. Ideally, physicians need to do this relatively early in discussions with families and should revisit the point periodically to assure that a child’s increased decision-making parallels their developmental growth. For assent to be more than a mere symbolic gesture, it needs to be viewed as a process, rather than as a one-time event. This necessitates that assent be periodically revisited. As a child matures, gaining both life- and health-related experience, physicians must ensure that the information provided and issues discussed are commensurate with the child’s increased level of maturity and experience. Physicians need to continually remind themselves that a meaningful application of assent requires the involvement of the child, physician, and parents.

Determining the validity of a child’s decision

For a decision to be valid, it must be voluntary and informed. No universally accepted standard defines decisional capacity. Whether a person possesses decisional capacity depends on the type of decision and the risks and benefits involved. Capacity is linked both to developing cognition and to prior life experiences.

Decision-making capacity by children requires that the child possess the freedom to make a choice. The choice must be both reasonable and rational, and the child must understand information that is relevant to that choice. Thus, prior to soliciting assent from a child, it is crucial that the physician assess the child’s level of understanding of the details of the proposed diagnostic and treatment plan (including potential risks and benefits). This is one way to assure that assent is significant and meaningful. However, assessing understanding alone is not sufficient. The process of obtaining a child’s assent requires several steps (American Academy of Pediatrics, 1995): the physician must (1) help the patient achieve awareness of their condition; (2) tell the patient what they can expect regarding diagnosis and treatment; (3) assess the patient’s understanding; (4) assess factors influencing patient responses (i.e., undue pressure); and (5) solicit the patient’s willingness to accept care.

Balancing children’s, parents’, and caregivers’ goals

Children typically want to be involved in decisions that concern their bodies and health. They also generally recognize their role in decision-making as intertwined with that of their parents and appreciate and respect their parents’ input (Rossi et al., 2003; Unguru et al., 2010), particularly when they perceive a situation to be more risky (Geller et al., 2003). Most children do
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not expect to make decisions on their own, but wish to be involved in the process and have their opinions respected. Shared decision-making helps children to clarify values and preferences (Geller et al., 2003). Although most children prefer joint decision-making with their parents, many do not believe that decisions made by parents or physicians should be absolute (Levenson et al., 1982; Dunsmore & Quine, 1995; Snethen et al., 2006; Unguru et al., 2010). This emphasizes the importance of parents helping children to recognize their abilities and responsibilities as part of the process that constitutes meaningful assent.

The AAP encourages pediatricians to evaluate each child’s capacity for assent on an individual basis. Based on their development, children are encouraged to “provide assent to care whenever possible” (American Academy of Pediatrics, 1995). The AAP views assent as a process that ideally incorporates joint decision-making by all parties. The Academy endorses the view that discussion leads to the development of a meaningful relationship between a child and physician and it is this aspect of assent that is paramount in the process.

Clinicians should make every effort to provide parents with the tools to allow their children to think independently. Doing so enables children to make reasoned and valid, age-appropriate decisions knowing that they can rely on their parents to support these decisions. Children learn to make good, sound decisions with practice and by relying on those they trust. Parents and children may not be in a position to fully recognize the extent to which their relationship may serve to limit a child’s ability to make free or voluntary decisions. Thus, it is the physician’s responsibility, as the child’s advocate, to serve as a facilitator and to assure that this process occurs.

Suggestions for a practical decision-making model with appropriate roles for children, parents, and physicians

A strategy that accounts for a child’s developmental level as well as his or her unique medical background and history of decision-making combined with familial preferences is most appropriate. A tangible model of assent gives children of all ages choices (King & Cross, 1989). As children age and gain experience with decision-making they ought to be involved to a greater extent in decisions. Parents and physicians should evaluate a child’s decision-making prowess and then designate a role that not only allows the child to make appropriate decisions but which concurrently challenges his or her abilities.

This strategy results in one of three decision-making roles determined by the child’s capacity and the gravity of the decision to be made. Some decisions will be made exclusively by the child with minimal to no parental input; some decisions will place the parents in a more central role while children will be “consulted” for their preferences; and finally, some decisions will be made exclusively by parents and children will be asked only to ratify the decision. For example, (1) a child might have decisional priority for choosing how blood is to be drawn (i.e., right or left arm; with or without a local anesthetic); (2) the child could decide at what time of day a medication is taken, but not refuse to take it; (3) the child could approve of a life-saving intervention, but not be permitted to refuse it. Allowing children a developmentally appropriate role in decision-making respects them as persons with developing autonomy, it allows them to learn from the decisions they make and to improve upon future decisions, and it provides them with a sense of control and ownership that comes with making decisions related to one’s health.

Children, parents, and physicians need not be equal in status when it comes to medical decision-making, but it is vital that each party have the opportunity to voice his or her desires and concerns (Bluebond-Langer et al., 2005). Parents need to understand the importance of listening to their child’s voice and consider what the child says as meaningful. Children need to appreciate that decision-making is a joint endeavor and while their input will be factored into the final decision, it is not theirs alone to make, nor will it necessarily be binding. Thus, by establishing ground rules and intervening where appropriate, the physician is able to shoulder some of the burden and ease what is a potentially contentious and stressful time for both children and parents.

Conclusions and practical suggestions

Since children do not, in general, have the ability to protect their own interests, they must rely on others to do so. Parents provide that function as the legal decision-makers for their children. The process of assent serves a different function. Assent gives children a voice in decisions, showing respect for their developing autonomy. Physicians are in a unique position to educate
parents and the child about the child's condition and options, and to help parents and children understand each other's role and responsibilities. Parents need to know that their authority will be honored, but that they must consider their child's opinions. Children must be given a range of choices. This will enable them to be involved in the assent process and provide them with a sense of control and empowerment. Children also need to know that while they will be allowed to participate in the process, their decisions may be overridden and the reasons for this should be revealed to them. Effective communication is a prerequisite for shared decision-making and shared decision-making is a strong foundation on which to base assent.

Case resolution
As a 15-year-old, Michael is sufficiently mature to understand the issues related to his treatment and to participate in decision-making. His experience with his disease and past treatment regimens has also resulted in a level of maturity that exceeds his age. Michael understands the nature of the proposed treatment, including its risks and expected benefits. He has voiced the opinion that he does not wish to proceed with an experimental regimen, an opinion not shared by his mother. Given his level of maturity, failure to respect his wishes, especially regarding an experimental treatment regimen that is unlikely to significantly alter the course of his illness, would be profoundly disrespectful and potentially harmful, leading to feelings of isolation and distress (American Academy of Pediatrics, 2000). Situations like this one do not lend themselves to easy solutions. By helping to facilitate, clarify, and resolve areas of contention, pediatricians can be extremely helpful. The challenge for pediatricians is to do so in a way that is both sensitive and respectful of the child's, parents', and providers' needs, needs that are often in conflict with one another. In many cases, simply by providing a space where Michael and his mother can speak freely about their choices and the reasons for those choices will lead to a solution that is acceptable to both. Michael needs his mother to hear what he is saying, and the physician's role in this case is not simply to override his desires, but to facilitate the opportunity for his mother to understand what he needs in this difficult situation.

References


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Chapter 7

Case narrative

Daniel Hauser was a 13-year-old boy from Sleepy Eye, Minnesota who, in early 2009, was diagnosed with stage IIB nodular sclerosing Hodgkin disease. Doctors determined that the cancer was readily treatable with chemotherapy, predicting an 80–95% chance of complete remission after 5 years. Daniel was prescribed six cycles of chemotherapy followed by radiation to treat the cancer. Daniel's parents initially consented to the course of treatment, but abruptly refused to continue treatment after only one round of chemotherapy because of side effects (e.g., fatigue and nausea). The Hausers sought opinions from five other physicians, including three pediatric oncologists, who all strongly recommended continued chemotherapy.

Despite a bleak chance of survival without chemotherapy and radiation, Daniel and his parents refused to continue the prescribed treatment and decided to use alternative therapies. Specifically, Colleen Hauser sought to treat her son with dietary changes and ionized water that would "starve the cancer" from his body. The Hausers justified their refusal of further chemotherapy by claiming it would violate the family's and Daniel's religious beliefs. Although the Hauser family was not of Native American descent, the family subscribed to the beliefs of Nemenhah, a Native American religious organization. Nemenhah doctrine advocates the use of Native American holistic medical practices, and a central tenet is the principle of "do no harm." Colleen Hauser, in particular, believed that "God intends for the body to be healed in a natural way." As such, the Hausers viewed chemotherapy as self-destructive and poisonous. Daniel, himself, asserted that he was a Medicine Man in the Nemenhah tradition, and that use of chemotherapy would violate his religious beliefs and status.

General ethical and legal issues in decision-making for adolescents

This chapter will discuss the ethical and legal issues involved in adolescent medical decision-making. It focuses on treatment decision-making and does not address the specific requirements for adolescent participation in research protocols. We start below with a general discussion of the issues, including adolescent autonomy, capacity, and the scope of parental authority. We then outline the situations in which adolescents are legally authorized to make medical decisions without parental involvement. The final section applies the key points to the case study described above.

Adolescent autonomy and decision-making capacity

Autonomy

The principle of respect for autonomy remains a fundamental hallmark of modern bioethics. Autonomy has been defined as "at a minimum, self-rule free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice" (Beauchamp & Childress, 2001, p. 58). This conception of autonomy requires two elements: liberty (freedom from controlling influences) and agency (capacity for self-rule) (Beauchamp & Childress, 2001, p. 58). This conception of autonomy requires two elements: liberty (freedom from controlling influences) and agency (capacity for self-rule) (Beauchamp & Childress, 2001, p. 58). This conception of autonomy requires two elements: liberty (freedom from controlling influences) and agency (capacity for self-rule) (Beauchamp & Childress, 2001, p. 58). Decision-making capacity develops during the adolescent years, raising questions about how to deal with minors' emerging autonomy. During this time, parents wield enormous control over their minor children both directly and indirectly.
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through the values and beliefs they instill. Adolescents are usually socially and economically dependent on their parents, both of which challenge the notion of freedom from controlling influences. This raises a particularly difficult conflict in the pediatric setting—we must simultaneously recognize the limits parental influences place on adolescent autonomy, and also that in some cases the minor may be making certain choices as a way of rejecting parental influence. Autonomy in the adolescent context is thus a fluid concept. As a result, adolescents fall into an ethical and legal gray area, where the contours of decision-making capacity and autonomy are imprecise and frequently determined on a case-by-case basis.

Capacity
As noted above, autonomy requires both liberty and agency, or capacity. Key elements of capacity include the “degree to which an individual has the ability to understand a proposed therapy or procedure, including its risks and benefits, and alternatives; to communicate relevant questions; and to arrive at a decision consistent with his or her values” (Cummings & Mercurio, 2010). The fields of law and medicine have struggled with identifying a particular age or uniform standards to determine when adolescents develop sufficient decision-making abilities. The result has traditionally been a blanket legal presumption that patients who have not yet attained the age of majority (which may vary between 16 and 18 years old, depending on the state in question) lack capacity, with a few exceptions discussed below.

A more nuanced approach, but one that still relies on generalities, is the “Rule of Sevens.” Minors under the age of 7 years are presumed to be lacking the relevant capacities, minors aged 7–13 years old are presumed to be developing capacity and decisions may be made on a case-by-case basis, and minors 14 years and older are presumed to have capacity to make medical decisions, unless evidence is provided to the contrary (Cardwell v. Bechtol, 1987). The Rule of Sevens is supported by growing medical evidence. For instance, several sources (Weithorn & Scherer, 1994; Hartman, 2000) have identified the age of 14 as a developmentally relevant watermark for decision-making capacity. Based on their research, Weithorn and Scherer have noted that “the cognitive functioning of a fourteen year-old clearly appears sophisticated enough and sufficiently grounded in reason to meet legal criteria of competency to consent to most types of treatment” (1994, p. 152). This view is not without its drawbacks. It still groups minors by age, and may not accommodate vast individual differences based on actual development or experience. The approach also fails to take into account the maturity required for different types of decisions (e.g., simple versus complex, life-sustaining versus routine treatment). Furthermore, although minors 14 years and older may have greater decision-making capacity than younger minors, “competent children are not similarly situated to their adult counterparts” due to a shortage of life experience (Ross, 1997, p. 166). Finally, the most recent data on brain development suggest that some abilities crucial to medical decision-making (such as the capacity to appreciate long-term risks) may not fully develop until the mid-twenties—far beyond even the legal age of majority.

Parental authority – source and limits
Parents are legally authorized to consent to (or refuse) medical treatment for their minor children. We assume that parents are best able to ascertain their children's interests and act in accordance. This parental right is deeply rooted in ethical and legal traditions. The Supreme Court of the United States has long recognized the right of parents to the care, custody, and nurture of their children as a protected liberty interest under the Fourteenth Amendment (Meyer v. Nebraska; Pierce v. Society of Sisters; Wisconsin v. Yoder). Parents have wide latitude to direct their children's upbringing, from schooling to religious training to reasonable corporal punishment. This right has been expressly extended to include the right to make medical decisions for their children. Parents' status as decision-makers has a practical component as well. When a patient makes an informed decision, he or she must be prepared to live with the attendant consequences. Parents are responsible for caring for their minor children, including any corresponding financial obligations. Thus, a parental role in decision-making seems necessary and appropriate.

A parent's right to make medical treatment decisions for a minor is limited. Under certain circumstances, the state and courts will intervene in the decision-making process. Laws pertaining to child abuse and medical neglect may restrain parents from refusing beneficial medical treatment for their children. The propriety of state intervention often depends on balancing the potential harm of refusal (including whether the harm is life-threatening or irreversible) against the strength of the preferences and values of the minor
and the parents. The vast majority of refusals of medical care, made by parents and/or minors, are based on religious objections. Although religious freedom is a highly protected constitutional right, religiously motivated treatment decisions are not immune to being overridden when a child's welfare is at stake. Religious objections to medical treatment are frequently upheld on legal grounds, but some professional associations have called for an end to such exemptions when children are denied therapeutic treatment (Committee on Bioethics, 1997). As the Supreme Court famously stated in limiting religious freedom, “Parents are free to become martyrs themselves. However, it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves” (Prince v. Massachusetts, 1944, p. 170).

**Legal authority of minors to make decisions**

The law recognizes certain situations in which the balance between a minor's autonomy and parental authority has been resolved in favor of allowing adolescent decision-making. Every state has laws identifying circumstances in which an adolescent's consent alone is legally sufficient to obtain medical care. In addition to the exceptions described below, there are specific legal rules in two other areas, which we will not discuss in this chapter. The first, adolescent decision-making for abortion, varies from state to state and may require judicial involvement. The second is the general emergency exception to informed consent, which functions for both adults and minors, allowing treatment in the absence of any decision-making by either the patient or the patient's family. The exception applies only in the case of true emergencies, when there is no time to elicit consent.

**Public health exceptions**

The majority of minor consent laws are rooted in public health policy. The laws primarily address: (1) access to contraception and family planning services (not including sterilization or abortion); (2) diagnosis and treatment of sexually transmitted infections (STIs); (3) mental health treatment; and (4) substance abuse treatment. All states have enacted minor consent laws in some or all of these areas, but there remains little uniformity regarding the prerequisites to consent. Age and status requirements, types of treatment permitted, and other limitations on consent vary considerably. The public health exceptions to the parental consent requirement were enacted for two reasons. The primary reason is based on community public health needs rather than on the recognition of adolescent autonomy or capacity. Minors will be encouraged to seek certain treatments if they know it can be done confidentially, thereby reducing the spread of STIs, the incidence of unplanned teenage pregnancies, substance abuse, and teenage suicide. Legislators acknowledge that minors will not seek access to these treatments if parental consent is required (Jones & Boonstra, 2004). This reasoning is especially apparent in the case of STIs. Every state has a law allowing minors to consent to STI diagnosis and treatment. Forty-one of these states permit all minors to consent to any age, highlighting the public health imperative to reduce community infections regardless of minors' capacity to make informed decisions. States have made this policy determination not because they believe adolescents are more capable of making these decisions, as opposed to general medical treatment decisions, but because minors would not seek treatment at all if parental consent or involvement was required (Rosato, 1996). The second reason for minor consent laws in the particular treatment areas noted above is the recognition that adolescents have a limited constitutional right to privacy. This right has been most robustly developed in the area of reproductive health care decision-making, with a limited focus on public health consequences. Thus, laws allowing adolescent consent to contraception may be a product of both public health reasoning and legal recognition of autonomy in the reproductive context.

**Emancipated minor exception**

The emancipated minor exception authorizes adolescents who have reached specific life milestones to make their own medical treatment decisions. There is little uniformity across the states, but typical laws designate marriage, joining the armed forces, bearing a child, graduating from secondary school, living apart from one's parents, or managing one's own finances as relevant life experiences. Essentially, these life experiences serve as proxies for determining decision-making capacity and maturity. Emancipated minor laws grant broader decision-making authority to adolescents than public health exceptions or mature minor determinations (discussed below). If an adolescent is found
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Mature minor exception

Mature minors are minors by virtue of their chronological age. However, because of their ability to understand the risks and benefits of a proposed medical treatment, they are granted limited decision-making power. Under this exception, a court may extend the right to consent to or refuse medical treatment if the minor demonstrates that he/she can “appreciate the consequences of her actions, and [...] is mature enough to exercise the judgment of an adult.” (In re E.G., 1989, pp. 327–328). One court stated that the consent of a minor will be effective if the minor is capable of appreciating the “extent and probable consequences of the conduct consented to, although the consent of a parent, guardian or other person responsible is not obtained or is expressly refused” (Cardwell v. Bechtol, 1987, p. 746).

Relevant factors to be weighed include the age, ability, life experience, education, and degree of maturity of the minor (Cardwell v. Bechtol, 1987). In comparison with the emancipated minor exception, mature minor determinations focus on actual decision-making capacity rather than attainment of specific life experiences. The mature minor exception has garnered support from the medical and academic communities (Committee on Bioethics, 1995). The Institute of Medicine has even promoted using the mature minor standard in obtaining adolescents’ informed consent to research (Institute of Medicine, 2004).

A primary benefit of the mature minor exception is that it acknowledges emerging adolescent autonomy and is based on a fact-specific review of the minor’s decision-making abilities. Despite its utility, the mature minor exception has several disadvantages. As an initial matter, the maturity determination must be conducted on a case-by-case basis because there is no uniform objective scale to evaluate a minor’s maturity. Although judges may have general criteria to guide them, some determinations may come down to mere instinct. The case-by-case nature of the determination can also prove problematic when time is of the essence. Judicial rulings take time for deliberation, during which the health of a minor refusing treatment could significantly deteriorate. A final disadvantage is that a court may simply be reluctant to find a minor “mature” if the result would be the adolescent making a decision that poses a substantial risk to his or her health. For example, a judge may otherwise find a minor mature, but believe that the minor’s refusal of life-sustaining treatment is evidence itself of impaired decision-making. Thus, the court may be willing to grant a mature minor petition more readily when the adolescent’s proposed decision comports with some external perception of what is in the minor’s best interests. The problem lies in the potential assumption that an “unwise” decision is the product of faulty or impaired decision-making, focusing on the choice we think the minor should make rather than the minor’s capacity to make the decision at all. This highlights a disadvantage shared by all of the minor consent exceptions: they are tailored mainly to an adolescent’s right to consent to treatment, not the corollary right to refuse.

Conflicts between adolescents, parents, and clinicians

In all situations adolescents should be involved in decision-making to the extent they are capable. This both recognizes their developing autonomy and has the practical effect of involving them in their care. Similar to the reasons proffered for encouraging informed consent from adult patients, adolescents need to be prepared for the consequences of treatment choices and to sometimes actively engage in their own treatment. Involving adolescents in medical decision-making can facilitate this. Even where parents retain ultimate legal authority for consenting to or refusing treatment, adolescent patients will likely play some role in the decision-making process. While a formal concept