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DECISIONAL CAPACITY AND MINORS

If you think that assessing adults' ability to make and take responsibility for decisions is challenging, keep reading. Children and adolescents present a whole other set of issues related to their emerging cognitive abilities, self-awareness, and moral authority. Because minors are usually considered incapable of assuming responsibility for their health care, conflicts about treating this vulnerable population will likely come before your ethics committee.

As discussed in chapter 2, the concept of decision-making capacity involves notions of autonomy and moral responsibility. Autonomy refers to self-governance, which requires that, at the very least, the individual has a *self* to govern. In this sense, autonomy implies a more or less integrated set of personal values and preferences that are recognizable and generally well-established. Moral responsibility refers to a person's capacity to be accountable for his actions and suggests qualities of stability, consistency, and foresight. These qualities develop as part of the maturation process that begins in young childhood and continues through adolescence into adulthood.

Children

III Timmy, a healthy 3-year-old child, is scheduled for a tonsillectomy this morning. His parents have done everything they can to prepare Timmy for the surgery, including reading him books about going to the hospital, "operating" on his stuffed rabbit, and packing all his favorite toys. Despite their presence and reassurance, however, Timmy becomes increasingly agitated. He resists all contact with any medical personnel, including the nurses, the surgeons, and Dr. Lewis, the anesthesiologist.

Although Dr. Lewis tries to explain what she is doing and what will happen, Timmy keeps screaming, "No! No!" He struggles to climb off the stretcher and spits out the Versed that the nurse tried to mask with apple juice. In order to proceed, Dr. Lewis must hold him down and sedate him with an injection. When Timmy is sufficiently sedated and offers no resistance, Dr. Lewis brings him to the operating room, where the surgery proceeds without incident.

Following surgery, Timmy is returned to the main recovery room and then to the pediatric ambulatory area, where his parents are waiting for him. He still screams when he sees clinical personnel but, except for continuous crying, there are no postoperative problems.

Anyone who has spent time with young children knows that they do and do not want things, sometimes loudly, often inconsistently, and almost always vehemently. The sincerity with which they voice their wishes, however, should not be confused with the judgment necessary for responsible decision making. Timmy genuinely does not want to be in the hospital and efforts by his caregivers or even his parents to reason with him will not change his mind. He is unable to appreciate the need for surgery or the prospect of feeling better once his tonsils are removed. He cannot be placated by promises of ice cream when the operation is over. He is incapable of thinking about anything except his current fear and his desperate desire to be elsewhere.

Because of their immaturity, young children lack the attributes associated with autonomy and self-governance—that is, they do not have decision-making ability. The same is largely true of older children, although they may have preferences that can and should be accommodated in treatment plans. The younger the child, the less problem we have in saying, "This is a person for whom most decisions must be made by others because he has not developed the cognitive ability, experience, or judgment necessary to reason or the opportunity to form values and preferences that will inform his decisions."

As noted in chapter 2, however, decisions run along a continuum from low to high risk. Certainly, even young children are able to make some choices—"Do you want to wear the red or the blue shirt today?"—and giving them opportunities to do so helps them develop decision-making skills. As the consequences of the decisions become more significant—selecting suitable television programs, eating nutritious food, using seat belts—the intervention of adults becomes increasingly important. The need for adults to act on behalf of young children becomes especially clear when the decisions have critical outcomes and long-lasting consequences, as in the health care setting.

Adolescents

III James Bell is a 16-year-old adolescent admitted to the hospital with pain in his right leg. He is a tall, good-looking young man who is an honor roll student and involved in numerous school and community activities. His main claim to fame is his prowess in several sports and he is hoping to get an athletic scholarship to college. He lives with his mother, with whom he appears to have a good relationship.

After examination and tests, a diagnosis of osteosarcoma of the right femur was made. The hematology-oncology and orthopedic doctors met with James and his mother two days ago to discuss the diagnosis, prognosis, and treatment options. All the professionals recommended amputation of the leg rather than local excision, because amputation has been shown to increase the survival rates. James and his mother were both shocked and distressed by the news. When the options were explained, Mrs. Bell asked many questions, but James was silent. Finally she said to James, "There doesn't seem to be any question that amputation will give you the best chance to beat the cancer. I know it will be hard, but I think this is what we have to do." James replied, "No way! No way they're cutting off my leg! I'll agree to the local treatment, but that's it." When the doctors and his mother tried to persuade him, he said, "I'd rather die with my leg than live without it! You can't make me do this!" He has remained adamant, despite several attempts to explain the important benefits of amputation.

Can adolescents be considered to have the capacity to make health care decisions, especially those with serious consequences? Who does or should make health care decisions for adolescents? What else would be important to know about James' decision and reasoning? What is the relationship between consent and assent? Should surgery proceed over James' continued objections?

As anyone who has ever been or known an adolescent is aware, these issues become dramatically more complex during the teenage years. Along the decision-making continuum, adolescents occupy a position that is legally and ethically ambiguous. By the age of 14, the normal child demonstrates a capacity to reason, including the ability to understand the causes and effects of illness, that is both as good and as flawed as it will be in adulthood. It will come as no surprise, however, that adolescent capacity to make autonomous decisions is enormously variable, partly because it is tied to the growing ability to make authentic statements about values and commitment. As the individual develops in experience and judgment, he edges closer to assuming control of and responsibility for his own decisions and correspondingly greater weight is given to his values and wishes.

The challenge in evaluating this ability is to consider the relevant factors and skills in their appropriate context. The law, as a crude instrument, makes blunt distinctions necessarily based on somewhat rigid and arbitrary standards. Thus, we have those eagerly awaited milestone ages at which people are finally allowed to drive, vote, drink, and serve in the armed forces. Likewise, determining the ability to make decisions that

provide *legally* binding consent is based on easily defined characteristics, such as the age of majority, marital or parental status, or economic self-sufficiency.

In contrast, the ethical analysis of adolescent decision-making capacity is more complex, multifactorial, and nuanced. In assessing the capacity of an adolescent to make decisions that will be given *moral* weight, it is necessary to look beyond cognitive skills to consider

- personal values
- patterns of decision making and behavior, including risk taking
- biological and emotional maturity
- life experience, including health care and treatment experience
- appreciation of cause, effect, and consequence
- notions of the future, including life plans

While both adult and adolescent decision making combine these factors, adolescent decisions are typically the product of greater uncertainty and insecurity, less experience, more volatile emotions, immature self-image, unrealistic appraisal of risks and consequences, susceptibility to peer pressure and the desire to conform, and greater focus on the present than the future. These characteristics have direct implications for the capacity to make decisions, especially those with high stakes consequences. For example, an adolescent patient with chronic or serious illness may exhibit greater knowledge and more mature judgment about treatment decisions than would be displayed by a peer who has not had the same debilitating experience.

James has been presented with a prospect that would devastate a person twice his age. He is forced to confront his own mortality decades too soon. If that were not enough, he is asked to accept a drastic alteration in body image and the loss of what makes him special—his athletic prowess. No wonder he's reeling. As a newly diagnosed cancer patient, he is doing what many adults initially do in his situation—rejecting more unwanted information.

At 16, James is approaching adulthood. He may very well have the cognitive ability to understand his situation and consider his treatment choices. What he may not have is the experience and judgment necessary to make decisions with long-term consequences. To the extent possible, he should be given the opportunity to be an active participant in planning his care. His involvement will be critical to the success of his treatment and recuperation, as well as rebuilding his body image and sense of self-determination.

To assess his ability to participate, James' caregivers will need to know much more about his maturity, his ability to solve problems and consider alternatives, and his experience with illness and loss. It is not uncommon to hear people, especially adolescents, reject something by saying, "I'd rather die" as a way of expressing the strength of their feelings. Most often, however, they have little or no real sense of death or the implications of such a choice. It is also important to clarify James' reasons for refusing.

If he does not understand or believe the seriousness of his condition, he needs further explanation. If he is looking at short-range issues, such as his appearance, his popularity with his friends, his altered athletic ability, he may benefit from spending time with other adolescents in his situation.

A history of other illness and treatment will also affect his ability to deal with his current situation. For example, a 16-year-old who has lived for years with chronic and debilitating illness, endured rounds of unsuccessful radiation and chemotherapy, or rejected one or more transplanted organs may be well positioned to say, "Enough. I know what this is about and it's not the way I want to live for whatever time I have left." In contrast, James is newly diagnosed with an illness that has the potential for remission or cure. Despite the significant burdens of the proposed amputation, they may be vastly outweighed by the long-term benefits.

Perhaps James has been exposed to others—his father, other relatives, or even friends—in similar situations. If so, their clinical outcomes and successful or unsuccessful coping strategies will likely influence his response to his illness. If not, his lack of preparation for this unexpected assault will complicate his ability to absorb the implications of his diagnosis, prognosis, and treatment options.

Ideally, James, his mother, and his caregivers will be able to collaborate in a process of education and support while making these difficult decisions about his future. As discussed below, although he is unable to provide legally binding consent, his assent to treatment will be critically important. If he remains unpersuaded by the benefit-burden analysis and adamantly opposed to amputation, however, it may be necessary to proceed with surgery over his objections. Ultimately, the gravity of his condition and the potential for life-saving treatment, the clinical judgment of his caregivers, and the experience and devotion of his mother will assume greater weight than his choice in making decisions with profound and lasting consequences of this magnitude.

CONSENT FOR MINORS

How and by whom decisions are made has special significance in the health care setting. Because the law almost always considers minors to lack the judgment and experience necessary for responsible decision making, it generally denies them legal power and requires the consent of one or both parents or a legal guardian to authorize medical care. Sometimes, however, the law departs from this requirement when it appears that the young patient's best interests will be served by having others assume decision-making authority.

Newborns

The neonatal intensive care unit (NICU) is the scene of both high drama and devastating choices. The care of newborns has changed enormously over the last few decades. Because of technological advances, substantial medical progress has been made in the

care of very premature, seriously ill, and handicapped neonates. In addition, decision making about the treatment of such infants has become more collaborative, including clinicians, parents, and other family members, and occasionally lay persons who work outside the NICU. Careful scrutiny is increasingly important because, while new techniques enable health professionals to maintain the lives of infants who would otherwise not survive, this rescue is often at the cost of significantly diminished prospects for a meaningful life.

These issues began to attract public attention and governmental regulation in 1982, when a baby born with Down's syndrome and an opening between the esophagus and trachea was permitted to die without life-saving intervention. The parents' concern about the potential for some degree of mental retardation made them refuse the recommended surgical repair, a decision upheld by the state court. The case of Baby Doe generated considerable publicity, the outrage of right-to-life groups and advocates for the developmentally disabled, and a controversial response by the U.S. Department of Health and Human Services. This case and its regulatory results are discussed further in part VI.

The ethical principles that guide neonatal intensive care decisions include beneficence, nonmaleficence, and justice. Beneficence and nonmaleficence create the professional obligation to provide care for the newborn that maximizes benefit and minimizes harm. Moreover, because the infant is the patient, his interests must be assessed independently of the interests of the family. Beneficence is also invoked as a guiding principle for parents, obligating them to make decisions that will promote the welfare of their baby. Conceptions of benefit and harm may be defined differently by health professionals and parents, however, creating conflicts in the NICU over how or even whether to treat. Justice requires that treatment decisions be based on the infant's best interests, without considerations of race, ethnicity, or ability to pay.

Taken together, these ethical principles create the obligation that newborns, who are especially vulnerable, receive heightened protection. Decision making for critically ill and handicapped infants is complicated by two factors. First, prognostication can be very uncertain in the early neonatal period and may not be clarified until numerous aggressive measures have been instituted. Second, decisions to provide, withhold, or withdraw aggressive life-sustaining measures frequently involve quality-of-life judgments. Because parents and clinicians may have very different notions of what constitutes an acceptable or unacceptable quality of life for the child, consensus on these deeply personal issues is often difficult to achieve. The resulting collision of principled obligations can create painful conflict for those who care for and about the infant.

Our society's deference to parental decisions rests on respect for family integrity, the presumption that parents act in their child's best interests, and the need to have a designated authority to make such decisions. Accordingly, parental decisions about the care of newborns are routinely honored unless they contradict the clinical judgments of the care team. Typically, when physicians recommend a course of treatment that is

clearly in the newborn's best interests, parents agree. In rare cases, parents make decisions that are likely to harm their child and not provide compensating benefit. Decisions that put children at unjustified risk are considered abuse of parental authority and usually trigger outside intervention.

Between these two extremes, many decisions made by parents fall into a gray area, where it is not at all clear whether the choice will benefit their newborn. In these cases of uncertainty, parental decisions tend to be respected. The difficult issues that arise in the NICU place significant ethical responsibilities on caregivers, including

- putting the child's interests at the center of decision making
- involving parents in the decision-making process
- providing parents with full and accurate information about their child's condition, prognosis, and treatment options
- providing parents with guidance, support, and time to decide on care goals and plans
- being willing to make care recommendations
- letting parents know that it is appropriate to forgo treatment when the burdens clearly outweigh the benefits

When conflicting values and interests complicate decisions about neonatal care, hospitals are increasingly referring these cases to infant bioethics review committees for special attention.

Children

III Melissa is a one-month-old infant admitted with a severe infection that has resulted in significant and irreversible brain damage. She is currently on a ventilator and cannot suck, so a tracheostomy and a gastrostomy will be necessary to support her respiration and nutrition. She responds only to painful stimuli, such as the frequent blood draws necessary to monitor her infection. According to the treating team, her condition will not improve because, as the attending explained to her mother, "the infection has destroyed Melissa's brain."

Melissa's mother, Ms. Green, is a 45-year-old deaf woman who has eleven children, most of whom are in foster care and several of whom are in the process of being adopted. It is not clear why the children have been taken from her, but she maintains contact with some of them. Melissa's father is reportedly a violent man with a drug problem and Ms. Green apparently left him because he abused her.

Ms. Green has told the sign language interpreter that this is her last chance to be a mother because she rarely has a chance to see her other children. She enjoys coming to visit Melissa anytime she pleases, "touching her, holding her, and feeling like a real mom." She does not want to let her baby go and she will not consent to anything, such as a recommended do-not-resuscitate (DNR) order, that would prevent the doctors from keeping Melissa alive. Even when the pain and lack of benefit to Melissa are explained, Ms. Green remains adamant that aggressive treatment be continued.

How should Ms. Green's capacity to make decisions about Melissa's care be assessed? What factors might impair her ability to make decisions in Melissa's best interest?

As in other instances of surrogate choice, care issues related to young children concern who makes decisions, according to what standards, and with what review. Legally, the first question is almost always resolved in favor of the parents, who are responsible for upbringing and welfare because they are presumed by tradition and law to act in their child's best interests.

Note that this presumption of parental authority distinguishes health care decision making for a minor from decision making on behalf of an incapacitated adult. In the latter case, the power to make treatment choices may be accorded to the patient's family or assumed by the court only when the adult patient has been *shown* to be incapable of choosing. In contrast, recognition that children lack the capacity to make their own health care decisions *presumptively* confers this authority on parents or guardians unless they are specifically disqualified by a determination of unfitness.

Ms. Green's capacity to make decisions for her daughter requires careful scrutiny because of her apparent inability to understand Melissa's medical condition, prognosis, and limited treatment options. While her impaired hearing may hinder her understanding of the clinical situation, her deafness should not be the deciding factor. Her diminished capacity may be the result of several factors, including her deafness, possibly limited intelligence, and/or the stress of caring for a critically ill child.

These problems may be complicated by Ms. Green's apparent inability to appreciate her child's best interests or that they may be in conflict with her own interests. If her focus is on extending her opportunity to function as a mother rather than on what benefits her child, she may not be the best person to be making care decisions for Melissa.

III Larry is a 12-year-old who was struck by a car and has been brought to the trauma ER. There, it was discovered that he has a severe renal injury with significant internal bleeding. When his parents arrive, they tell the physicians that, because they and Larry are Jehovah's Witnesses, transfusion of blood or blood products is out of the question.

How should the religious convictions of Larry's parents influence the decision about his receiving potentially life-saving blood transfusion? What weight should be given to Larry's religious beliefs?

Just when you thought parental authority was secure from interference, the issues become more complicated. The rights granted parents or guardians, as well as the restrictions placed on those rights, are rooted in an ethical perspective that assigns top priority to the interests of the child. In this view, widely shared in our culture, parents are entrusted with the well-being of their children and charged with specific duties, including the provision of food, clothing, shelter, basic education, and health care.

Within the parameters set by these duties, parents may make choices based on their own values and beliefs about what is best for their children. So far, so good. Note, however, that parental authority is not unlimited because it is constrained by parental responsibility. When parents abuse their authority—for example, by refusing consent for clearly beneficial medical treatment—the child's interests trump even the well-established presumption of parental rights.

Accordingly, the law deviates from the almost automatic deference to parents in the context of decisions about health care when the child's welfare or life is at stake. In such cases, the law requires physicians to act on behalf of the child and permits the state to intervene. For example, a standard exception to the requirement of parental consent for medical treatment is emergencies, when delaying treatment would threaten the child's life or health. Likewise, all states provide for removing children from abusive or harmful environments or situations in which they are deprived of necessary medical treatment. In addition, parents are prevented from interfering with needed medical care and can be criminally prosecuted for failing to provide that care.

Courts have agreed that parents may not withhold life-saving treatment from a child who is neither terminally ill nor permanently comatose. Treatment refusal has not been permitted even when the therapy is painful and only marginally effective if it is determined that the child will die without it. When the contested treatment is elective or carries substantial risks, however, courts are more likely to accede to parental refusal. Although decisions continue to vary, the trend appears to be limiting parents' authority when their decisions conflict with generally accepted medical judgment. Judicial intervention is less likely when parents are providing some kind of professionally accepted treatment. Several illustrative legal cases are summarized in part VI.

Court intervention usually involves authorization, at the request of health care providers, to perform a particular surgical procedure or course of medical treatment over parental objection. Because these cases focus on a specific, usually life-saving, therapeutic objective, courts are likely to override parents' refusal, which is usually based on religious or philosophical belief. In these singular instances, traditional deference to parental decision-making authority gives way to the determination by others of what is best for the child. For example, courts have ordered children inoculated over their parents' religious objections.

Similarly, parents who are Jehovah's Witnesses are not permitted to refuse life-saving blood transfusions for their children. Members of this faith believe that receiving blood or blood products places their souls in eternal jeopardy, making it worse to survive after transfusion than to die without having received the blood. This deeply held belief should be honored when it is expressed by capable adult patients who understand and accept the risks posed by their religious commitments. In contrast, a child who is too immature to have developed settled religious convictions or make autonomous decisions that place his life at risk cannot be permitted to assume this responsibility.

Given the extent of Larry's injuries and internal bleeding, he appears to be at risk of

serious harm and possibly death if he is not transfused. The likelihood and magnitude of the harm if he does not receive blood mean that his parents' decision to withhold transfusion is not in his medical interest. Under most circumstances, this would justify overriding their refusal to consent to transfusion. In this case, however, Larry is approaching the age when he might be considered to have settled religious beliefs and values. If he is able to express an informed conviction about being a Jehovah's Witness, it becomes more complicated to support paternalistic intervention to transfuse over his objections. One recommendation would be to interview him without his parents present to evaluate his maturity, understanding, and the strength of his religious convictions.

Finally, courts tend not to order treatment for children who are comatose, for whom death is imminent, or for whom the marginal benefits of treatment are outweighed by its burdens. In these situations, courts have held that the decision to forgo treatment was in the children's best interest.

Just as there are limits to parental rights to refuse treatment, there are also limits to parental rights to insist on treatment. When specific interventions are determined by the care team to be inappropriate or ineffective, when the burdens and risks clearly outweigh the benefits, physicians have an obligation to protect their young and vulnerable patients from measures that are not clinically indicated.

It is important, however, to recognize and address the motivation behind much of what may appear to be unreasonable parental demands. The job of parents is to stand between their children and danger, to protect them from injury and illness. When, despite their best efforts, their children are sick or hurt, parents may direct their efforts toward ensuring that everything possible is done to promote recovery. Whether the therapies they propose are standard of care or unconventional, they are likely to feel the obligation to advocate strongly for anything that holds out even the slimmest prospect of success. It is understandable, therefore, that they perceive refusal to provide the requested treatments as yet another barrier to fulfilling their nurturing responsibilities.

As discussed further in chapter 6, demands for treatment should trigger a discussion with parents that begins by exploring what "do everything" means, clarifying their expectations of the proposed therapies, and explaining the likely course with and without the treatment. The focus should be on the care that *will* be provided rather than what will not, emphasizing that the shared goal is to provide only care that will benefit the child and maximize comfort and quality of life. Whenever possible, parents should be involved as collaborators in care planning as a way of helping them retain their role as guardians of their children's well-being.

Adolescents

III Nora is a 17-year-old young woman initially seen in adolescent health clinic, referred by a pediatric nephrologist for primary care and contraceptive counseling. She has a history of urinary tract problems diagnosed two years ago after proteinuria was discovered on routine urinalysis. She has been taking Cozaar for the proteinuria.

Nora told the clinic physician, Dr. Gonzalez, that she became sexually active six months ago and has been intimate with the same male partner, Joe, who is 21 years old. She says they have always used condoms except once, which is when she became pregnant last year. At her mother's insistence, she terminated the pregnancy immediately.

During her clinic visit, Nora requested Depo Provera for contraception. Her last menstrual period had been six weeks earlier and she was awaiting her next menses. Routine blood work was ordered, including a test to rule out pregnancy before giving her the first Depo injection at her next period. Test results indicated an early pregnancy.

The clinic social worker made several unsuccessful attempts to schedule an appointment to discuss options, but Nora missed each appointment. Finally she came to the clinic twelve weeks after her last period. Dr. Gonzalez had a lengthy discussion with Nora about the potential risk to the fetus because, throughout the pregnancy, she has been taking Cozaar, a medication contraindicated in pregnancy. Nora insisted that she understood the possibility of prematurity and/or birth defects, but said that she wanted to keep this pregnancy. She promised to discuss the situation with Joe over the weekend. She was explicit about not wanting her mother to know, because "she made me have an abortion the last time." She was told to discontinue the Cozaar and return to the clinic on Monday.

When Nora and Joe met with the social worker, they communicated their decision to keep the pregnancy. Their plan is not to tell her mother until after Nora has moved in with Joe. It is also apparent that Nora has not told Joe about the risk of birth complications.

How should Nora's capacity to make decisions about this pregnancy be assessed? What factors should be considered? Is her mother required to be involved in these decisions?

Adolescents, who are neither children nor adults, stand with a foot in each world. Their intellectual and emotional development is greater than that of young children, yet most are not fully mature. While their cognitive skills are growing and they are likely to have a well-developed set of preferences and moral values, they still lack the experience and judgment of adults.

Because the legal age of majority in almost all states is 18, adolescents are technically minors for most purposes. The few exceptions, provided for in state law, are the ability of the emancipated minor and the mature minor to make legally binding decisions. For example, a minor who has given birth may relinquish the child for adoption.

The age of and criteria for consent to health care vary by state, and the law has relaxed the customary requirement for parental consent by carving out specific situations in which adolescents may make decisions about their treatment. The trend began in 1976 with a line of cases in which the U.S. Supreme Court held that minors who are sufficiently mature should be able to authorize abortions without parental consent or notification. Subsequent cases permitted teens access to contraception and statutes provided access without parental consent to treatment for substance abuse and sexually transmitted diseases.

These pragmatic exceptions to the parental consent requirement apply in situations

in which it is imperative that teens are treated for their own good and as a matter of public health. The underlying concept recognizes that some highly sensitive health care circumstances have serious implications for young patients and others. In these situations, adolescents are more likely to seek and, therefore, receive health care if they can consent to it without involving or notifying their parents. This utilitarian reasoning is similar to the justification for confidentiality, discussed in chapter 4.

The mature minor doctrine is based on the notion that some minors have the cognitive ability and maturity to make informed decisions about their care. This doctrine, given force in many states' case or statutory law, provides for minors to consent to care in the following circumstances:

- The minor is an older adolescent (e.g., older than fourteen or fifteen years)
- The minor is capable of giving an informed consent
- The care is for the benefit of the minor
- The care does not present a high level of risk
- The care is within the range of established medical opinion (English, 1999, p. 86)

Minor treatment statutes address the societal obligation to protect adolescents and provide access to care, rather than a societal recognition of adolescent maturity and decisional capability. The reasoning behind them is similar to a sliding scale, making it more likely that adolescents will be permitted to make care decisions that do not carry great risks. In this way, these laws reflect the dual goals of protecting society and promoting minors' best interest.

Statutes in every state, known as minor consent statutes or medical emancipation statutes, authorize minors to consent to care based either on their *status* or on the specific *service* they are seeking. The categories of minors authorized by one or more states to consent to medical care based on their *status* are:

- Emancipated minors [often defined using one or more of the following criteria]
- Married minors
- Minors in the armed forces
- Mature minors
- Minors living apart from their parents
- Minors over a certain age
- High school graduates
- Pregnant minors
- Minor parents (English, 1999, p. 85)

Central to this legal framework is the notion that, because these minors are no longer under effective parental supervision, parental consent is not a sensible precondition to accessing care.

The categories of *services* for which one or more states authorize minors to give consent are:

- Emergency care
- Pregnancy related care
- Contraceptive services
- Abortion
- Diagnosis or treatment of venereal or sexually transmitted diseases
- Diagnosis or treatment of reportable, infectious, contagious, or communicable diseases
- HIV/AIDS testing or treatment
- Treatment or counseling for drug or alcohol problems
- Collection of medical evidence or treatment for sexual assault
- Inpatient mental health services
- Outpatient mental health services (English, 1999, p. 85)

Because these statutes are state-specific and their provisions differ, clinicians treating adolescents should be very familiar with the laws of the jurisdiction in which they provide care. Likewise, if your ethics committee addresses issues of adolescent health care, knowledge of the relevant laws and regulations in your state would be important. The take-away message is that the range of adolescent decisional capacity and the range of health care issues requiring decisions demand a heightened level of scrutiny and a constant balancing of rights and interests.

CONFIDENTIALITY AND DISCLOSURE

III Donna is a 15-year-old who has come to the clinic for her annual physical prior to the beginning of school. Her mother, who accompanied her, remains in the waiting room during the exam. Donna appears healthy and active. In addition to a demanding scholastic schedule, she is on the track team and participates in several extracurricular and community activities. Although she appears bright and pleasant, she is clearly uneasy about something. Finally, at the end of the examination, she tells Dr. Jin that she and her boyfriend have recently begun having sex and she feels it would be responsible for her to be on birth control pills. She asks for a prescription, but insists that the doctor not tell her mother about her sexual activity or her request for contraception. Dr. Jin's discussion with her about sexual relations and contraception indicates that her decision is not coerced and that she understands its implications.

When Dr. Jin leaves the exam room, Donna's mother approaches her in the hall and says, "Doctor, I suspect that Donna's boyfriend is pressuring her to have sex. She's just not ready for that and I need to know what is going on. Please tell me if she has discussed this with you."

What are Dr. Jin's obligations to Donna? What are Dr. Jin's obligations to her mother?

Remember when you were 15 and did not want your parents to know about something in your life? Remember when you were afraid that your teenager was growing up too fast? Sorting out the boundaries of adolescent privacy and confidentiality is difficult

under any circumstance; it can be especially challenging in the health care setting when so much more is at stake.

Maintaining the confidentiality of adolescents' health information serves many of the same important functions that it does for adults and some that are especially important to the adult-in-training. Patients are more likely to seek treatment, especially for conditions that are sensitive or socially stigmatizing, and, once in treatment, are likely to provide more complete and accurate histories if they know their confidences are secured. Protecting the privacy of adolescents also shields them from embarrassment, discrimination, and potential family disruption or even violence. Finally, honoring their privacy helps adolescents in their critical development of autonomy.

Adolescents' health care confidentiality is guarded by the protections built into federal and state constitutions, statutes and regulations, court decisions, and professional ethical standards. However, these safeguards are never absolute and the ambiguous status of adolescents adds to the difficulty of determining what information should be protected or disclosed, to whom, and under what circumstances. Some state statutes pair adolescents' right to consent to treatment with their right to decide about information disclosure. Others require disclosure of health care information over the adolescent's objection in certain situations, including specific disclosure to parents, mandatory reporting of physical or sexual abuse, or disclosure when the adolescent poses a severe and imminent danger to herself or others.

Dr. Jin's obligations to Donna's mother are the same as they would be to the concerned family of any patient—to provide her daughter with the most appropriate health care in light of her medical needs, her appreciation of her condition, her options and their implications, and her wishes. Here, the ethical analysis would balance the likely benefits of protecting Donna's confidences (strengthening the trust in the therapeutic relationship and promoting further beneficial patient-physician interaction, preventing unwanted pregnancy, and facilitating autonomous decision making) against the likely risks (erroneously presuming that Donna is making a voluntary and mature decision about sexual activity, and inhibiting mother-daughter discussion about a sensitive topic that might benefit from parental guidance).

If Dr. Jin's clinical assessment indicates that maintaining Donna's confidentiality would promote her best interest, her ethical obligations would not include disclosure of information about contraception that Donna wishes to remain between herself and her doctor. It would be appropriate, however, for her to explore with Donna the potential advantages of confiding in her mother and the possible ways to do it.

SPECIAL PROBLEMS OF THE ADOLESCENT ALONE

III Andy was 15 when he learned he had rhabdomyosarcoma of the spine. With his specific form of cancer, cure is highly unlikely. Andy's mother is an alcoholic who has been in and out of substance abuse treatment for years. Throughout his illness, she has not been available for

support or help in decision making. Andy's father also has not been present in his life. Andy did rely heavily on a close friend of his mother's who, unfortunately, is no longer available to him.

Before his illness, Andy was a bright, athletic young man who enjoyed many activities. He has tried to make the best of his situation. He underwent surgery to remove the tumor and also had radiation therapy and chemotherapy, but none of the treatments was totally effective. He has never achieved remission and his pain has increased. Because of his mother's absence, the health care providers have discussed Andy's treatment options with him, although they actually have made most of the day-to-day decisions.

A significant turning point in Andy's illness occurred when his mother refused to move from her walk-up apartment into an available ground floor apartment. His deterioration has made it impossible for him to negotiate the stairs, and his mother's resistance to relocating means that he can never return home. Since he is in the last stage of his illness, his doctors have asked Andy to consider whether he wants to continue chemotherapy. Against their recommendation, Andy has declined further treatment.

Should Andy's refusal to continue treatment be honored? Is he capable of making this decision? What responsibilities do Andy's care providers have to him as his disease worsens?

The journey from childhood to adulthood is filled with the potential for growth, achievement, and self-fulfillment. It is also fraught with confusion, uncertainty, and risk. Fortunately, most young people have the security of at least one caring and responsible adult to help them navigate the distance. Some are not so lucky.

A special category of minors is the adolescent alone. These young people are actually or functionally alone because they do not have a supportive relationship with an adult in a birth, foster, adoptive, or chosen family. No trusted adult is consistently available to guide and monitor their passage to adulthood or help them evaluate and make appropriate decisions about medical options.

The number of adolescents alone has increased in the past several years, causing clinicians, researchers, other service providers, and policy analysts to focus on the special problems they present. Some of these young people have been orphaned because their caregiving parent died of AIDS or other diseases, substance abuse, or violence. Some are functionally alone because their parent, grandparent, or other nominal caregiver is mentally ill, addicted to drugs or alcohol, or simply overwhelmed by poverty or other pressures. Some gay and lesbian youth have been ostracized by their families. Some adolescents have run away from homes where adults physically or sexually abused them. Some in foster care may feel that, although they have both biological and foster parents, they have no one to trust with private information and concerns. Some have parents or other adults who drift in and out of their lives, leaving them without the security of a stable relationship.

The adolescent alone occupies an ambiguous legal status, which can present particularly difficult problems regarding consent and confidentiality in health care. A vari-

ety of legal mechanisms may justify the provision of care to the adolescent alone based on his own consent in specific circumstances. These include the emancipated minor and mature minor doctrines, as well as state-specific medical consent laws, discussed above. These doctrines are not accepted in all jurisdictions, however, and consent provisions vary from state to state. For this reason, health care professionals are advised to familiarize themselves with the relevant laws in the states where they practice, particularly those that might provide the basis for the adolescent's legally valid consent. In addition, because clinicians and administrators may interpret the doctrines inconsistently, care may be provided differently to these adolescents within the same state or even within the same institution. Finally, even when the laws are consistently understood and interpreted, they do not adequately address the range of ethical issues presented by the care of the adolescent alone.

Many of the ethical principles that apply to adolescents with adult supports also apply to adolescents alone, including principles that govern capacity and informed consent and those related to the right to refuse and demand care. Thus, health care providers should assess any adolescent's capacity to consent in light of the specific decision at issue and its implications, as well as the young person's developmental characteristics, life situation, and medical history. Heightened concern about the adolescent's capacity is appropriate whenever the decision involves long-term negative health or life consequences. When recommended treatment is refused, health care providers should initiate an extensive discussion with the teen and explore mutually acceptable alternatives. As is true in the adult setting, refusal of treatment is not the end, but only the beginning of the discussion with the adolescent patient. Likewise, the same assessment and serious discussion should be initiated by health care providers when the adolescent requests treatment that providers judge to be inappropriate or dangerous.

The obligation to protect patient privacy and confidentiality is as important for the adolescent alone as it is for other adolescents. Breaches of confidentiality may carry particular risks and be especially counterproductive for these vulnerable minors. The result can be their return to the abusive homes from which they fled and the exacerbation of problems that led them to their current difficult situations. At the outset of the clinical relationship, therefore, health care professionals should assure adolescents that confidentiality will be protected except in specific limited circumstances, which should be clearly defined.

Finally, when treating an adolescent alone, the natural inclination of many caregivers is to expand their role to meet many of the youth's unmet needs. Although clinicians may feel as if they are acting like family, it should be clear to them and to the adolescent that they are professionals with the skills and the limits of professionals. Far from rejecting the adolescent alone, establishing and reinforcing the boundaries of the therapeutic relationship creates a stable atmosphere of dependability and trust that is so badly needed in their lives.

The special needs and vulnerability of this population make it likely that, if an adolescent alone is receiving care in your institution, the case will come to the attention of your ethics committee. Your familiarity with the ethical and legal issues will enhance the quality of your deliberations and the usefulness of your recommendations to the team caring for the patient.

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End-of-life Issues

Decision making at the end of life

Defining death

Advance health care planning

Advance directives

Do-not-resuscitate orders

Goals of care at the end of life

Forgoing life-sustaining treatment

Protecting patients from treatment

Rejection of recommended treatment and requests to "do everything"

Medical futility

III Mr. Tofer is a 77-year-old man admitted for resection of a squamous cell carcinoma of the tongue. The surgery was successful but, on the following day, he experienced respiratory distress that required intubation. Because he was not able to be weaned from the ventilator after three weeks, a tracheostomy was performed to place the ventilator tube directly into his trachea, which would be safer and more comfortable than continuing to pass the endotracheal tube down his throat. He has had two subsequent episodes of low blood pressure and is experiencing progressive renal failure. His mental status has deteriorated during the four weeks he has been in the ICU and he is responsive only to painful stimuli, such as suctioning of his tracheostomy.

Mr. Tofer's only family is his nephew, Lawrence. Although they have not had a close relationship, they have maintained contact over the years and Lawrence appears concerned about his uncle. Lawrence is not Mr. Tofer's appointed health care proxy agent and they have never had discussions about care at the end of life.

The renal team met with Lawrence to discuss the plan of care. Dr. Cooper, the renal attending, said that, although dialysis might improve Mr. Tofer's mental status, it would not change his overall grave prognosis. The consensus of the renal team is that the patient is a poor candidate for dialysis and has less than a one percent chance of surviving this hospitalization. Given the considerable risk and the slight benefit, the team would consider dialysis only if the family insisted. Dr. Cooper also recommended a do-not-resuscitate (DNR)