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Minor Rights and Wrongs

Michelle Oberman

Inconsistency may well be the hallmark of the teenage years. Frequently, teenagers are serious and adult-like, yet just as often, they are callow and unpredictable. Generally, they are all of these things, in no particular order. They studiously observe the adults in their lives, adopting certain values and behaviors, while wholly rejecting others. Their moods shift without warning, leaving entire households with the sensation that they are living on a roller-coaster. As a result, it is not entirely surprising that the legal system has had difficulty deciding how to respond to them. The laws devised to govern teenagers are layered, reflecting society’s alternating perceptions of teenagers as adult-like and child-like, and our accompanying impulses to respect as well as to protect this population. Read together, these laws defy any consistent description of adolescent capacity. We have lived with these inconsistencies for so long, though, that they have grown rather familiar to us, and that we hardly recognize the puzzle in the fact that we trust eighteen year olds enough to let them fight and die in the military, but not enough to let them drink alcoholic beverages.

These inconsistencies extend into health care, where the laws governing adolescent capacity form a patchwork quilt of rights and limitations. A teenage mother must give consent before her baby may be treated, but, by and large, is not permitted to consent to her own health care. An adolescent boy can be tested and treated for HIV without parental involvement, but his parents must consent to setting his broken leg.

The laws governing minors in the health care setting do not reflect a comprehensive theory of adolescent capacity; rather, they have evolved more or less in accordance with societal perceptions of adolescents’ health care needs. In large part, modifications to the traditional rule that adolescents must obtain parental consent prior to treatment have been accomplished by way of the mature minor doctrine. Many health care providers and social liberals view this doctrine as the progressive solution to an archaic rule.

Ironically, when one observes the mature minor doctrine in practice, it becomes apparent that, despite the fact that the exception is premised on adolescent maturity, no consensus exists, nor even a coherent description to guide those who assess maturity. Instead, the laws governing minors reflect society’s evolving intuitive sense of the extent to which adolescents require protection. Maturity operates as a code word, invoked to permit minors access to treatments that society deems desirable, and to limit their access to treatments that carry the possibility of long-term negative consequences. The present system works not because minors are mature, but because of the tacit utilitarian calculus that governs minors’ access to care.

Until recently, the nascent state of scientific inquiry and knowledge about adolescence yielded little alternative to this euphemistic invocation of maturity. However, the last several decades have brought forth two developments that magnify the problems inherent in the current formulation of the maturity standard, and render reconsideration of the mature minor doctrine both necessary and inevitable. First, the study of adolescence has blossomed, and we now have access to a considerable amount of information about the nature and the limitations of adolescent maturity. At the same time, adolescents and their advocates have petitioned courts, seeking to invoke ever expanding legal rights under the mature minor doctrine.

Because of this confluence of events, the law is at a critical juncture. For the first time, those asked to evaluate minors’ requests for treatment may do so by reference to...
their abilities and needs. At the same time, the nature of the treatments requested by minors are increasingly controversial in nature, and health providers have no easy utilitarian calculus by which to determine the permissibility of access.

This article takes a critical position on the hasty, unexamined expansion of the mature minor doctrine, and ultimately calls for a systematic reevaluation of the justifications underlying adolescents' access to care. The emerging right-to-die cases involving "mature minors" provide ample evidence of the problems in the law as presently configured, and of the importance and timeliness of this reevaluation. These cases therefore provide the point of departure for this inquiry. The following section struggles to make sense of modern law by exploring the evolution of the law governing minors' capacity in the health care setting. Finally, having illustrated the law's failure to address the abilities and vulnerabilities of the adolescent patient, and the dangers inherent in an uninformed expansion of the mature minor doctrine, I return to the problem of regulating access to care for minors. The final section explores three alternative models for responding to the challenges posed by adolescents in the health care setting. Ultimately, I suggest that the difficult new cases, on which no societal consensus exists, be resolved on a case-by-case basis that is similar to the present approach, with one critical exception: the notion of maturity and capacity for decision making must be informed by contemporary research on adolescents.

Mature minors and the right to die

In 1989, the Illinois Supreme Court became the first court in the United States to rule that a minor patient should be permitted to refuse medical treatment necessary to save her life. In re E.G. involved a seventeen-and-one-half-year-old leukemia patient whose doctors recommended a course of treatment that included a series of blood transfusions. She objected to these on the basis of her religious convictions, and the court upheld her right to refuse the transfusions, reasoning that:

Although the age of majority in Illinois is eighteen, that age is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood.... If the evidence is clear and convincing that the minor is mature enough to appreciate the consequences of her actions... then the mature minor doctrine affords her the common law right to consent to or refuse medical treatment.

The court was cautious in articulating the minor's right to refuse treatment, and it limited its decision to these facts: a seventeen-and-one-half-year-old patient, with an emotional maturity far beyond her years, who refuses treatment on the basis of deeply held, family-shared religious convictions. At a surface level, it is hard to disagree with this outcome. E.G. was a mere six months shy of her eighteenth birthday, and her psychologist testified that she had the maturity of a twenty-two-year-old. Moreover, because of the slow pace of the Illinois judicial process, E.G. was transfused in order to preserve her life pending the outcome of her case. Thus, as her own attorney confessed to me, with a touch of irony, "her victory gave us the best of both worlds... she's now a healthy twenty-year-old, whose right to die was vindicated."

At a more profound level, however, the decision is problematic. In effect, it marked the first time a court indicated that minors should be permitted to make the most controversial of health care decisions—those with fatal consequences. Although E.G. enjoys the unique satisfaction of obtaining legal recognition of her right to die, even as she survives into adulthood, this only occurred because of the slow moving judicial process. The impact of the decision necessarily was to raise the possibility of a less felicitous outcome for other minors.

In the years following the E.G. decision, at least four other courts have visited the issue of a minor's right to refuse treatment. Together, these cases demonstrate that the problems posed by such requests are complex and that their resolution requires a more explicitly articulated analysis than that provided by E.G. Each of these subsequent decisions involves minors who either were less mature or were younger than E.G. was when her case came to court. Thus, they fail to meet the Illinois court's standard of a "seventeen-and-one-half-year-old" patient who is mature beyond her years. Nevertheless, the courts do not simply revert to a bright-line age-based standard. Instead, they assume that some minors have a right to refuse treatment, and that the courts' task is to determine whether the minor before them is one of these. Ultimately, this determination rests on subjective judicial assessments of the patients' maturity. Unfortunately, these cases reveal that the courts are remarkably ill equipped to make such determinations.

In the Matter of Long Island Jewish Medical Center illustrates this point. The case involved Phillip Malcolm, a cancer patient who was only seven weeks shy of his eighteenth birthday at the time of his refusal of treatment. Both Phillip and his parents refused to consent to the recommended course of blood transfusions on religious grounds. At first glance, the facts of this case, especially the minor's proximity to the age of majority and his family's support for his refusal of treatment, lend strong support to the minor's request. However, the judge noted that the family had "joined the Jehovah's Witnesses in 1987," only three years prior to this decision, and that, although Phillip "did appear to understand the basic tenet of the religion's pro-
hospitality regarding blood transfusions," he was not sufficiently mature to make this decision on his own.7 In rejecting Phillip's request, the judge noted that:

He has never been away from home and has never dated a girl. He consults his parents before making decisions and when asked whether he considered himself an adult or a child, he responded "child." There was no evidence that Phillip had been urged by his parents to make his own decision regarding blood transfusion.8

The Long Island decision demonstrates the inherent flexibility of the maturity standard in practice. When faced with evidence indicating that the minor's decision merely reflects parents' wishes, the court deemed this nearly eighteen-year-old minor immature, and refused to honor his treatment preference. At the same time, the subjectivity inherent in this approach signals an ominous potential for inconsistent, even arbitrary and prejudicial, decision making. After all, this judge's determination was based in part on a belief that maturity is demonstrated by a minor's having gone on dates with members of the opposite sex!

The dangers inherent in the present formulation of the "mature minor" doctrine arise precisely from its subjective, inarticulated nature. As presently configured, the doctrine involves a maturity assessment that is only as sophisticated as the decision makers choose to make it. Maturity is not a discrete, easily measured vital statistic. Instead, it is a relative concept, influenced by many factors, including the circumstances that have led the minor to articulate a treatment preference. Thus, when a decision maker is faced with a minor's refusal of life-sustaining treatment, it is imperative to recognize that critical illness in any family member causes considerable tension and crisis for the entire family unit. If we acknowledge that adult's treatment preferences may be driven by factors such as guilt, financial worries, emotional manipulations, and other forms of family strife,9 then why believe that minors are immune from these factors. Instead, they serve to render the already complex task of ascertaining the minor's maturity all the more difficult. Two cases illustrate this problem.

To date, the most dramatic case involving an adolescent's refusal of treatment is that of Benny Agrelo, a fifteen year old who received a liver transplant during the summer of 1993.10 As is the case with all transplant recipients, Benny was prescribed heavy doses of anti-rejection medication. He found the side-effects of these medicines (nausea, migraines, stomach cramps, swollen joints, and edginess) too debilitating and painful to tolerate. He stopped taking the medicine in that fall. His mother and an older brother were aware that he was no longer taking his medications, and they believed, as did Benny, that he seemed better without the medicine than with it. It is unclear when his physicians learned of Benny's noncompliance, but no action was taken against him until June 1994, when state officials forced him to undergo treatment at a local hospital. A legal battle ensued, and a trial judge ruled that the state could not force the boy to take his medication. Benny died in August 1994.

Because the record is sealed, the basis of the judge's ruling must be inferred from context. It is reasonable to assume, however, that the judge applied the mature minor doctrine in reaching his decision. In a sense, it is hard to criticize the judge for his ruling. Benny was adamant that the pain of living with the medications was unbearable and that he felt far better without them. His family supported his decision and applauded his courage. Moreover, by the time the case came before the judge, the boy's condition was so weakened that it is doubtful that medications, or even a liver transplant, would have been viable life-saving options.

Several months after Benny Agrelo's death, sixteen-year-old Billy Best ran away from his home in Massachusetts to avoid undergoing chemotherapy for his Hodgkin's lymphoma. Like Agrelo, Billy claimed that the medicine was killing him, rather than curing him, and that he felt better without it. Best spent a month in Texas, where he lived with some friends he had met while skateboarding. He then returned home, explaining that his doctors had promised to modify his treatments, and that "his parents wanted him to, and he didn't want to get into an argument over it."11

For those who advocate extending rights to mature minors, the implications of these cases are troubling. Billy Best's family and physicians allowed him the right to refuse medical treatment in exchange for his return home. Although their concession was understandable, it is a bizarre standard that allocates adult rights to adolescents whose demand for autonomy takes the form of a grandiose temper-tantrum, as opposed to a reasoned demand for control.

Likewise, it is noteworthy that Benny Agrelo stopped taking his medication ten months prior to the state's intervention. Even if one believes that, at age fourteen, Benny might have been sufficiently informed and mature to exercise a right to die, no one made such a determination in his case until his health had deteriorated so as to make the determination virtually moot. Moreover, it seems possible that Benny viewed his illness as burdensome and costly for his mother and siblings, as well as for himself, and that his refusal of treatment was based in part on a sense of obligation to them.

The stakes are extraordinarily high in these cases, and the time is surely ripe for a critical assessment to determine how much judicial deference is owed to minors who claim to be sufficiently mature to exercise adult rights. To undertake that assessment, we must understand the evolu-
tion of adolescent rights over the course of the twentieth century.

A brief history of adolescent rights

Perhaps the most surprising fact about adolescence is that it is a relatively novel concept. It was not until 1904 that sociologist G. Stanley Hall gave the name adolescence to the second decade of life.12 His description of the Sturm und Drang (storm and stress) which characterized this phase of human development triggered considerable debate among social scientists.13 In fact, Margaret Mead’s well known early work in Samoa grew out of her determination to prove that “adolescence” was a cultural creation, rather than a biological phenomenon.14

Law and policy makers of the early twentieth century left the debate to the academics, and focused on crafting laws to accommodate this population. For example, this era witnessed the passage of laws mandating public schooling and regulating child labor.15 The juvenile justice system was developed in order to avoid housing minor criminals with adult criminals. Its goal was to shelter and redirect the behavior of wayward minors.16 All of these changes were driven by a moral conviction that adolescents, despite their adult-like appearances, were somehow different and in need of adult guidance and legal protection.

During the ensuing decades, the impulse to protect minors has remained in tact. For example, to this day, contract law protects minors from commercial exploitation by permitting them to void their contracts. In essence, this means that any contract formed with a minor will be valid and binding only insofar as, and for as long as, the minor agrees to be bound by it. Newer laws prohibit “minors” from purchasing or consuming alcoholic beverages, even after they have attained the age of majority.

More recently, however, a distinct set of laws has developed alongside these protective laws, and this set seems to indicate an expanded notion of adolescent competence and capacity. These laws include the Twenty-Sixth Amendment, which lowered the voting age from twenty-one to eighteen, the criminal justice system’s increasing willingness to charge juvenile offenders as adults, and the various provisions permitting minors to obtain certain forms of medical treatment without parental consent. At first glance, these recent changes may suggest that the legal system is moving toward recognizing adolescents as fully competent adults. This seems particularly true of the medical treatment laws, which are referred to as “mature minor” provisions. It is thus surprising to find that the purposes underlying laws that treat minors like adults have almost nothing to do with the perceived maturity of the adolescent population. A critical evaluation of the mature minor doctrine reveals that these laws, like those before them, grow out of the traditional impulse to protect this population.

Historically, minors have been precluded from consenting to their own medical treatment until they reach the age of majority.17 Any health care provider who treated a minor absent parental consent was therefore at risk of a lawsuit by the parents for assault and battery. The policy underlying this rule is reflected Chief Justice Burger’s opinion in Parham v. J.R.:18

Our jurisprudence historically has reflected Western Civilization concepts of the family as a unit with broad parental authority over minor children.... The law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience and judgment required for making life’s difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.19

From the earliest mention of this rule, an exception has been made for emergencies, in the event of which a child of any age may be treated absent consent.20 It is important to note that this exception was not premised on a minor’s greater ability to comprehend and, thus, consent to such care. Rather, the guardian’s consent to emergency care was implied, on the theory that any delay incurred in attempting to secure consent would jeopardize the minor’s health.21 A second traditional exception to this rule permitted emancipated minors to consent to their own care. The definition of emancipation varies from state to state, but it is generally limited to minors who are not living at home, who are not economically dependent on their parents, and whose parents have surrendered parental duties.22 In the past, this category consisted primarily of married minors and minors in the military service.23

During the 1960s, the U.S. Supreme Court articulated a right to privacy that barred states from illegalizing contraception. Because the decisions only addressed the rights of consenting adults, teenagers were excluded from their reach. During this decade, growing evidence suggested that sexual activity among teenagers was relatively commonplace, and that, because they could not consent to care on their own, teenagers’ health status was in jeopardy. Specifically, it became increasingly evident that an epidemic of sexually transmitted diseases was spreading among unemancipated teenagers. This public health concern, coupled with a fear that teens would not seek treatment for these communicable conditions if their parents had to be notified of—let alone give consent for—such treatment, led states to pass “minor treatment statutes.”24 Today, every state has a statute that permits unemancipated minors, ranging in age from fourteen to seventeen, to consent to care for sexually transmitted diseases.25 Along the same lines, many states also permit minors to consent to alcohol- and substance-abuse treatment,26 and to psychiatric care.27
Minor treatment statutes reflect a public consensus that ensuring minors' access to the given treatment outweighs parental interests in controlling the care a child receives. The focus of such exceptions rests not on an assessment of maturity, but on a calculus that grants minors autonomy only when the treatment is relatively low risk, and when denying access may cause the minor (or the public at large) to suffer permanent harm.

Even as state legislatures passed minor treatment statutes, a more contentious debate was brewing among law makers and physicians over the issue of minors' access to contraceptives and reproductive health care, generally. In 1977, the U.S. Supreme Court resolved this debate by invoking the common law mature minor doctrine to permit health care providers to dispense contraceptives to minors without parental consent. The mature minor doctrine grew out of a series of cases in which physicians treated minors without parental consent, and were subsequently sued for battery. The physicians defended themselves by arguing that the minors were sufficiently mature to consent to their own care. These defenses were by and large successful, provided that the treatment given was beneficial and low risk.

In applying the mature minor doctrine to reproductive health care, the Supreme Court relied on the same underlying justifications presented in the earlier decisions. The Court reasoned that sexually active minors need protection from unwanted pregnancy, and that, to the extent that the law mandates parental consent, minors who fear parental disapproval will risk pregnancy rather than obtain contraceptives. The determination to expand minors' rights does not reflect a sense that minors are mature; rather, it reflects a belief that unwanted teenage pregnancy was both a predictable and an undesirable consequence of the common law rule. Thus, the decision makes no mention of the definition or level of maturity that the minor must possess in order to avail herself of this provision. As a result, the law has been interpreted as meaning that any minor who seeks contraceptives is, by definition, sufficiently mature to consent.

The lack of definition of maturity returns to haunt the court in the abortion cases, where the consensus regarding the benefits of the treatment falters. Among the very first challenges brought before the Supreme Court in the wake of its decision to legalize abortion were cases involving state laws that restricted minors' ability to consent to the procedure without parental involvement. Between 1976 and 1990, the Supreme Court issued six opinions regarding parental involvement in minors' abortion decisions. Ultimately, the Court resolved the issue by permitting states to require minors who seek abortions to obtain either the consent of their parents or the approval of a judge. The latter entails a judicial bypass hearing, in which the minor must demonstrate that she is sufficiently mature to make her own decision regarding abortion.

Despite explicit reference to maturity, the definition of maturity that emerges from these cases remains elusive. The cases indicate that a minor is entitled to a court-order permitting an abortion if she understands her situation, understands the abortion procedure and its risks, and articulates a desire to have an abortion. In the event that a judge finds the minor immature, the law requires that the judge must grant consent for the abortion if it is "found to be in the minor's best interests."

The abortion decisions never explain how a minor is to demonstrate her maturity, nor do they guide the judge in making this assessment. Because the abortion cases offer no substantive analysis of adolescent maturity, it is unsurprising that the practical consequence of the abortion rulings is that virtually all minors who seek judicial permission to obtain an abortion without parental involvement are deemed sufficiently mature to consent.

The cumbersome route to permitting adolescents to consent to abortion reflects the politically divisive nature of the abortion debate, and the fact that, unlike contraception, there is less public consensus about whether it is in a minor's best interest to procure an abortion. This debate is not about adolescent capacity—it is about parental rights to control their children. As one court noted in an early decision on the matter, the parental notification abortion cases are ultimately cast "not in terms of protecting [minors], but in recognizing independent rights of parents."

This analysis suggests that the cases that purport to turn on the maturity of minors actually rest on factors that have little to do with maturity, but far more to do with politics. The mature minor decisions reflect the dual goals of protecting society and promoting minors' best interests, and when no consensus exists on whether permitting access to a given treatment furthers either of these two goals, minors will be denied access.

Nowhere is this more evident than in the law regulating access to government funding for sterilization. In contrast to the laws guaranteeing minors' access to contraceptives without parental involvement, and permitting states to fund that contraception, when the same minors seek access to a permanent form of contraception—sterilization—federal law precludes the funding of such procedures until age twenty-one. These regulations have withstood constitutional challenges brought by young mothers, who argue that, by age eighteen, they have reached the age of majority; and the law deems them sufficiently mature to consent not only to all other forms of contraception, but also to all other medical care generally. The refusal to permit these women to exercise their autonomy in choosing sterilization reflects more than societal ambivalence about sterility. It also indicates a consensus that the decision to be sterilized is one that should only be made by those whose capacity is unquestionable, and implicitly reveals our sense that even those who have reached age eight-
teen may not possess sufficient maturity to make an irreversible medical decision.

Toward a working definition of maturity

For more than twenty years, we have witnessed the development of laws and policies predicated on minors’ maturity, and yet we have scarcely begun to consider what we mean by this standard. To some extent, this lack of discussion may result from the controversial nature of the medical treatments at issue in most of these cases. Our society’s general unwillingness to engage in open discussions regarding sexuality may account for our reluctance to articulate the factors that we consider preconditions to an individual’s readiness to explore and enjoy his/her sexuality. Furthermore, those who favor teenagers’ access to reproductive health care may be reluctant to focus directly on the meaning of maturity for quite another reason. If access to contraceptives is predicated solely on maturity, we may not really want to know whether a sexually active twelve-year-old girl is sufficiently mature to consent to receiving a prescription for the birth control pill.

The inevitable result is that, when confronted with minors who request medical treatment that is contrary to what we consider to be in their best interests, we find ourselves at an impasse. We generally resolve this by determining that they are simply too immature to make this medical decision on their own. This is most certainly disingenuous, of course, because the same minors might easily have been found mature had they sought a more acceptable course of treatment—one that parents, doctors, and lawyers could deem to be in their “best interest.”

This point is illustrated by exploring the following hypothetical case. Recall fifteen-year-old Benny Agrelo, who received a kidney transplant, but decided to discontinue his anti-rejection medication because the side-effects were too debilitating. Now imagine that his family, including his mother and his adult brother, did not support his decision, but instead brought him to his doctors and insisted that he be treated. It seems extraordinarily unlikely that, in the face of a guardian’s request to render life-saving treatment to a minor, the health care providers would insist that the minor was sufficiently mature to refuse treatment and die. If the treatment team was highly sensitive to ethical and legal conflicts, the matter might have found its way to an ethics committee, or perhaps into court. Most likely, though, the treatment would have been rendered without further ado.

At least two plausible explanations account for this outcome. First, we may reason that a fifteen-year-old who wants to refuse treatment and die, even though his parents and doctors believe that he will survive if treated, is by definition, immature. Perhaps we assume that, because the adults in his life would consent to treatment, his refusal reflects his adolescent inability to endure short-term pain in order to reap long-term benefits. Some research indicates that younger adolescents are motivated by short-term hedonic needs, and that until they develop a higher cognitive maturity level, they will be disinclined to comply with an uncomfortable course of treatment.

On the other hand, why assume that this is true of all fifteen year olds who refuse treatment? Moreover, even an adolescent whose parents support his/her refusal of treatment may be motivated by hedonic, short-term goals. The problem with any of these explanations is that they assume a direct and skillful evaluation of the adolescent’s maturity. Yet, as we know from the earlier analysis, to date, medical and legal decision makers have been hesitant to define the factors that comprise legal maturity.

More likely, then, the fact that we are more inclined to permit an adolescent to refuse treatment when his parents support him/her than when they do not reflects our longstanding “concept[s] of the family as a unit with broad parental authority over minor children... [in which] natural bonds of affection lead parents to act in the best interests of their children.” The irony here is that the legal system defers to parents only insofar as parents are believed to be acting in their children’s best interests. In the medical setting, and elsewhere, the law intervenes to limit parental discretion when their choices threaten their children’s well-being. Health care providers routinely seek and obtain court-ordered medical treatment for minors over parental objections.

Therefore, it seems that when the law permits an adolescent to refuse medical treatment because he/she has parental support, we express our tacit agreement that treatment is not in the child’s best interests. Yet, if we consider whether it was truly in Benny Agrelo’s best interests to refuse treatment, the answer is far from self-evident.

As the foregoing analysis indicates, the unexamined manner in which we use maturity in evaluating adolescent assertions of autonomy in the health care setting results in random outcomes that only serve to disguise that we have little sense of the appropriate way to respond to this population. In an effort to move beyond the arbitrariness of the present approach, I now explore three alternative models for resolving the problems inherent in treatment of adolescent minors.

Lowering the age of medical competence

Perhaps the simplest way to resolve the problems posed by adolescents is to adopt a strict chronological standard, identifying an age at which minors will automatically be deemed competent to consent to (or refuse) all medical care. For example, research indicates that between ages twelve and fourteen, adolescents undergo a major shift in cognitive functioning that enables them to reason abstractly, as well as to consider cause and effect relationships. Thus, there
is reason to advocate a standard treating fourteen year olds as fully competent in health care decision making. This proposal has significant advantages beyond its simplicity. It does not require the health care provider (or the legal system) to engage in a difficult and often elusive search for maturity. As a result, it ensures consistent outcomes via a process that is most certainly more efficient and less costly than the present approach. Furthermore, depending on what age we select, this standard could maintain most minors’ access to reproductive health care, as well as to any other medical treatments this population requires.

Unfortunately, an age-based standard creates equally weighty problems. To begin with, it is no less arbitrary than the present approach, because it ignores the fact that teens have widely varying levels of competency that depend not only on their biological stage of development, but also on their life experience. The same research that establishes the adolescent onset of cognitive functioning also indicates that these abilities are acquired gradually, and that they reflect both a biological and an environmental component. Thus, it is over the course of years that an adolescent will acquire an adult capacity to "ponder ethical dilemmas about [them]selves, ... to weigh choices and to experience the anguish or satisfaction of choice." Moreover, it is inevitable that some minors who are younger than the minimum age will seek to consent to their own health care treatment without parental involvement. This standard leaves unresolved the problems posed by a sexually active eleven-year-old girl. If we eliminate a maturity analysis, we must articulate some other standard that permits this population access to necessary health care. Otherwise, by denying them access to substance abuse treatment, contraceptives, and the like, the law may exacerbate the health status of the very population it seeks to protect.

**Adopting a uniform best interests approach**

A second alternative is to reassert the common law principle denying adolescents autonomy until they reach the age of majority. Rather than attempting to discern an adolescent’s competence to consent to certain forms of treatment, parents or guardians would be granted presumptive authority over their child’s health care. Under this standard, providers would be required to obtain parental consent before treating a minor. If consent is denied and the provider believes that the treatment is in the minor’s best interests, the provider must request a court-order to provide treatment.

Such a rule would be as efficient as any other age-based standard, in that it would not require competency determinations. It has the further advantage of acknowledging the interdependent nature of individuals within families, and the way in which medical decisions may affect not only the adolescent patient, but also the entire family unit. The basic premise of this proposal is that most adolescents need assistance in making important medical decisions, and such assistance should come from people who care deeply for the adolescent, rather than from strangers.

Despite the potential benefits reaped by this model, significant dilemmas are inherent in this approach. The first is that adolescents may not want their parents involved in certain health care decisions, and, as a result, they will avoid seeking treatment if parental consent is required. It is precisely this fear that gave rise to the “mature minor” exception, and thus, a return to a strict age of majority standard must contend with the consequences of limiting minors’ access. This dilemma could be resolved, in the name of the patient’s best interests, by permitting minors access to low-risk preventive and reproductive health care. In practice, this approach would yield approximately the same results we achieve under the law as it now stands, in a manner that is far less disingenuous.

Although there are benefits to recommend it, the best interests test poses profound problems. Many families are not sufficiently in tact and supportive to be trusted to make decisions that are truly in their child’s best interests. Moreover, even functional families may be strained by a child’s illness, and thus factors such as dissension between spouses and family financial strains may contribute to treatment decisions. The blunt instrument of the law is ill suited for ascertaining the extent to which a refusal of treatment derives from a parent’s (or a child’s) emotional exhaustion, or even from their preoccupation with the impact on the family of the high costs of treatment. Although one commentator has suggested that one could justify a policy honoring all parental decisions, including a parent’s financially motivated refusal to consent to a child’s treatment, this position lacks legal and ethical support.

Finally, even if we determined that the law should permit parents the latitude to impose treatment on resistant teenagers, the image of strapping a resistant sixteen year old to a gurney in order to force treatment is difficult to support. Whatever our legal standards may be, it is certainly a violation of ethical norms of autonomy to eclipse wholly the minor from the decision-making process.

**Seeking and finding maturity**

Ironically, the flaw with any bright-line standard is its imprecision. In health care, the stakes are so high that the efficiency-related benefits of chronological markers are far outweighed by their arbitrary and potentially cruel results. As a result of the shortcomings inherent in any bright-line standard, it seems logical to pursue a direct inquiry into maturity. The law has already given credence to the intrinsic value of maturity as a factor that should compel respect for autonomy in an adolescent patient. Yet, as presently
defined and applied, the “maturity” standard poses two major risks. First, maturity is so ill defined that its very vagueness invites enormous discretion on the part of the party charged with evaluating the minor’s maturity. Hence, as discussed, even if the law permits “mature” adolescents to elect treatment without parental involvement, it is highly likely that a health care provider or judge will simply substitute personal bias, finding the minor to be mature if the adult approves of the minor’s treatment choice, and immature if he/she disapproves.

A more important problem relates to our inability to define maturity with any real precision because of our limited substantive understanding of the subject population. If we expand the mature minor doctrine to permit minors to make treatment choices that lack strong societal consensus, we are, by definition, limiting, if not abandoning, the tacit utilitarian calculus that has driven minors’ access to care to date. Such a move can be tolerated only if those regulating minors’ decisional autonomy understand the nature of adolescent capacity.

It is only in the past three decades that adolescence has become an active and respected area of scientific inquiry. To develop a standard for evaluating the capacity of adolescents to make independent decisions regarding their health care treatment, the law must be informed by substantial information regarding three subsets of adolescent patients: (1) healthy adolescents who seek preventive and wellness care, (2) chronic and/or critically ill adolescents, and (3) adolescents who seek to participate in medical research.

1. Maturity in healthy adolescents

Adolescence essentially is a transitional phase during which a child grows into adulthood. A number of developmental tasks must be accomplished in order to complete this transition: development of a sense of identity, adjustment to a changing body, development of abstract thought and an independent value system, development of interpersonal skills and a new relationship with one’s family, and the establishment of goals for the future. These skills are interrelated and cumulative, and they are acquired gradually during adolescence.

Because many factors contribute to the capacity to make sound health care decisions, at no one age do adolescents suddenly become “mature” or competent. As noted above, the early adolescent develops the “ability to reason abstractly and to consider cause and effect relationships, ... [yet] has had little experience in applying these skills to decisions in a more autonomous manner.” As a result, adolescents experience a chronic disjuncture caused by varying levels of biological development, cognitive ability, and experiential knowledge.

Rather than mistaking one of these markers, such as cognitive ability, as indicative of adult-like capacity, the health care system’s response to adolescents should reflect our awareness of this disjuncture. In a sense, the law already manifests this by recognizing adolescents’ need for access to certain forms of medical treatment based on biological maturity, in spite of our uncertainty about whether an adolescent at any given age in fact understands the implications of a particular health care decision. As noted earlier, we justify providing this population access to preventive care or low-risk treatments on the basis of a utilitarian calculus.

This approach may be sufficient when the patient is a healthy adolescent and the low-risk treatment is in his/her best interests. However, it is crucial to recognize that we are motivated here strictly by our agreement on the patient’s best interests. As soon as the adolescent patient requests care that carries with it serious medical risks, or is not plainly in his/her best interests, the law must confront the disjuncture between his/her varying levels of biological, cognitive, and social maturity, and attempt to discern an appropriate course of action. This cannot be accomplished without the assistance of experts who understand the nature of adolescent development and who can conduct an individualized assessment of the minor’s capacity to understand the implications of the decision he/she wants to make. Of course, those who are experts on adolescence are few, and the standards by which they may ascertain competency are vague at best. Research into this population is barely two decades old, and as yet no formula has been developed by which maturity might be measured.

Therefore, we may reject this approach because it is costly, or because mistakes will inevitably be made in determining competency, or finally because the benefit of permitting minors to refuse or accept relatively “high stakes” medical treatment without parental consent is outweighed by the risks of harm to both the minors and their families. But if we truly advocate an approach premised on maturity, at present, when the treatment at issue is high risk, and the utilitarian result is unclear, a case-by-case evaluation remains the only means to this end.

2. Maturity in chronically and/or critically ill adolescents

The result of the disjuncture among biological maturity, cognitive ability, and experiential knowledge is that the adolescent character is generally self-conscious and insecure, and demonstrates a heightened susceptibility to peer-influenced, impulsive, risk-taking behavior. The nascent and relatively sparse medical literature on sick adolescents demonstrates the ways in which these qualities generate pernicious effects when coupled with chronic or critical illness.

Research on the psychosocial experience of sick adolescents reveals exceptionally high rates of illness-related
emotional distress. Adolescents generally strive to be autonomous and to develop identities distinct from their families. These goals are necessarily more difficult to achieve for the chronically and/or critically ill teen. At a fundamental level, illness may impede an adolescent's progress toward accomplishing the principle tasks of normal adolescent development, such as developing independence and a new relationship with one's family. Because the sick adolescent may spend considerable time in hospital or simply isolated from peers, the developmental experience is interrupted and the adolescent may in fact regress to an earlier developmental stage.

Not surprisingly, chronically and/or critically ill teens report suffering from depression, family system problems, anxiety, and other major emotional disorders at rates far exceeding not only their peers, but also those reported in adults and children with similar illnesses. For example, in one study of early adolescents being treated at a pediatric renal clinic, 49 percent were found to suffer from a major emotional disorder related to their illness.

The negative psychological impact of illness on the adolescent necessarily influences their decision-making capacity. The law recognizes that depression and other emotional disorders may render an otherwise competent adult incapable of rational decision making. The same is all the more true for the adolescent, whose baseline ability to make such decisions is, in and of itself, questionable. One example of this is seen in a study of adolescent girls who refused to comply with chemotherapy regimens. When interviewed, several of the critically ill patients reported that they had ceased taking immunosuppressant steroid medication because "their appearance was so repugnant to them and caused such problems in their social relationships that, 'it was not worth it.'"

Because of these factors, the health care system should be particularly concerned about noncompliance and refusal of treatment by chronically or critically ill teens. Generally speaking, the treatment of illnesses like cancer and diabetes demand a high degree of patient cooperation, which in turn requires that patients understand the long-term significance of their illness as well as the likelihood that complications will result from a failure to comply with the proposed course of treatment. Although patient compliance is notoriously poor across all ages, adolescent noncompliance in part reflects the inevitable and necessary struggle toward adulthood. As a result, "[p]artly as a statement of independence, most adolescents refuse, at some point, to comply with medical treatments, but they do so without a good sense of the consequences of noncompliance." This analysis may cast a different light on some of the cases discussed earlier. For example, Benny Agrelo's refusal to take his post-transplant medication may have reflected his striving for normalcy, coupled with a desperate desire to feel healthier in the short-run, regardless of long-term consequences. Additionally, abandoning the "sick role," Benny was able to experience, however briefly, the beginnings of independence from his family.

What insight we gain from the research on adolescent patients, though, fails to resolve the legal dilemma raised by adolescents' refusals of treatment. A host of reasons may lead a teen to articulate a desire to reject treatment that seems to be quite "mature": pain, fatigue, futility, social isolation and the failure to develop meaningful relationships, low self-esteem, frustration with dependency on parents, or a distorted sense of future options. Many of these justifications are integrally related to the developmental process of adolescence. In some cases, we may also find them to be compelling. However, even in those cases when adults might concur in the adolescent's decision to refuse treatment, we generally do so not out of deference to maturity, but out of compassion for human suffering. Here, even more so than in the context of a healthy adolescent, an expert's independent evaluation of each patient's capacity to make health care decisions seems imperative. Yet, precisely because of the high stakes involved in these cases, we must remain cognizant of the inherently elusive nature of maturity, and we should be even more skeptical of adolescents' requests to refuse life-sustaining treatment than we are of treatment preferences that are less risky and less permanent in nature.

3. Adolescents and medical research

The issues of competency and autonomy that complicate the care of sick adolescents also emerge when one considers whether adolescents should be permitted to participate in medical research. Medical research has traditionally been viewed as nontherapeutic. Thus, when the federal government undertook the regulation of medical experimentation, it sought to protect minors and other vulnerable populations by erecting barriers to their participation in clinical trials. The result was that, even with parental support, minors were limited in their ability to participate in clinical trials. Over the past decade, however, the restrictive policies have been relaxed, largely in response to challenges brought by excluded groups. These groups persuasively argued that research trials often constitute the only "treatment" option for sick patients, and that the exclusion of entire subpopulations from research is unjust and produces results that are scientifically compromised and incomplete. As a result, the few clinical papers that analyze ethical and legal issues in adolescents as research subjects all advocate their inclusion.

Analysis of the permissibility of adolescent participation in clinical research must take into account the various circumstances in which such participation might occur. First, some adolescents may wish to participate in medical...
research and have full parental support. Particularly if the research protocol is therapeutic, this is a relatively easy case. The minor is, in effect, seeking help for an acute or chronic disease, and, provided that the parents and the minor understand that the treatment still is under investigation, it is difficult to justify excluding the minor. We have reason to be somewhat more hesitant when the research is nontherapeutic. We may worry that the adolescent is being exploited, or that the intangible benefits which come from participation in nontherapeutic research can only be realized by an adult sensibility. These potential harms weigh against an adolescents' participation in nontherapeutic research, particularly if it entails any risks to the adolescents' well-being.

The far more complex issue, at least for our purposes, is whether an adolescent should be permitted to participate in medical research without parental consent. At least two commentators argue that the answer lies in the "mature minor doctrine," in that any minor sufficiently mature to "weigh risks and benefits" of other medical treatment can also do so in the research context. Although they acknowledge the utilitarian, public health roots of the minor treatment statutes, and note that adolescents demonstrate considerable variability in terms of understanding the process of informed consent in research, the authors nevertheless conclude that "[m]ature adolescents require only the same procedural, well-defined safeguards as adults." Here we have yet another example of the unexamined expansion of this ambiguous doctrine.

The rising prevalence of HIV among minors well may give rise to cases in which adolescents seek access to research without parental involvement (or in which the minors who seek access lack parents who might be involved). I would argue that health care providers should only accede to these requests on a case-by-case basis, and only when it is clear that the same circumstances that justify a minor's access to other forms of health care are present. This requires either that the proposed research be in the minor's best interests, or that an independent expert's evaluation demonstrate the minor's capacity to choose to participate.

Conclusion

Ideally, the struggle to understand and develop appropriate responses to adolescents in the health care setting would be part of comprehensive social and legal undertaking. The laws that govern minors are inconsistent and outmoded, the institutions designed to protect the most vulnerable minors are in shambles, and, increasingly, we are made aware that adolescents are capable of massively destructive and self-destructive behavior. Because we are only a few decades into our efforts to identify and describe the phase of life we have come to call adolescence, it is not surprising that the questions raised by this population are more readily discerned than are the sophisticated answers they require. However, we must guard against a tendency to simplify the questions in an effort to wish away the very fundamental challenges they pose to our medical, ethical, and legal constructs. The trend toward an unexamined expansion of an ill-defined "mature minor" doctrine threatens to harm the very population it aims to empower.

References

2. Id. at 327-28.
3. Id. at 324.
5. See Belcher v. Charleston Area Medical Center, 422 S.E.2d 827 (1992) (holding that failure to instruct jury as to mature minor exception to parental consent constituted reversible error); O.G. v. Baum, 790 S.W.2d (1990) (holding that appointment of conservator to consent to sixteen-year-old minor's blood transfusion was not an abuse of discretion); In the Matter of Long Island Jewish Medical Center, 557 N.Y.S.2d 239 (1990) (holding that patient who was a few weeks shy of his eighteenth birthday was not a "mature" minor and thus court had authority to order life-saving treatment); and Caldwell v. Betcholt, 724 S.W.2d 739 (Tenn. 1987) (holding that consent to spinal manipulation by a person of seventeen years and seven months could constitute a defense to a claim of battery if the minor had the ability to appreciate the nature, risks, and consequences of the medical treatment).
7. Id. at 727.
8. Id.
16. Id.
21 or Older, 42 C.F.R.
cially conservative districts, tend to deny minors' requests with
American Constitutional Law

19. Id. at 602-03.
22. Id. at 139.
25. See Ewald, supra note 24.
30. Walter Wadlington identified the following factors that are common to case law permitting a minor to consent to treatment:
1. The treatment was undertaken for the benefit of the minor rather than a third party.
2. The particular minor was near majority (or at least in the range of 13 years of age upwards) and was considered to have sufficient mental capacity to understand fully the nature and importance of the medical steps proposed.
3. The medical procedures could be characterized by the court as less than "major" or "serious."
34. Id. at 630.
39. The outcome-determinative nature of competency findings is not unique to adolescents. Indeed, it has been identified and discussed in the context of refusals of medical treatment, generally. See Cruzan v. Director, Missouri Dept of Health, 497 U.S. 261 (1990) (holding that clear and convincing evidence of an incompetent's wishes to refuse life-sustaining treatment was necessary to honor such a wish); Washington v. Harper, 494 U.S. 210 (1990) (holding that the state may forcibly medicate a mentally ill prison inmate if he is a danger to himself or others and it is in his medical interest to do so); and R. Michels, "The Right to Refuse Treatment: Ethical Issues," Hospital Community Psychiatry, 32, no. 4 (1981): 251-55.
42. See Prince v. Massachusetts, 321 U.S. 158 (1979) (distinguishing a parental decision which is made for herself and a parental decision which is made for her child); and State v. Perricone, 181 A.2d 751 (NJ. 1962) (granting hospital permission to administer a blood transfusion to a critically ill infant despite parental objections).
45. Battle et al., supra note 44, at 480.
46. Bluestein, supra note 9, at 6.
49. Id. at 9.
52. Miller, supra note 13, at 15.
53. Irwin and Millstein, supra note 44, at 91.
55. Irwin and Millstein, supra note 44, at 91.
57. Battle et al., supra note 44, at 481.
58. Id. "In addition to experiencing the usual stresses related to illness and disability, the adolescent patient is also experiencing the transition through the developmental turmoil of this stage of life." This is compounded because the disease itself hinders the usual pattern of development for the adolescent.
60. Id.
61. W. Kruse et al., "Patterns of Drug Compliance with Medications to be Taken Once and Twice Daily Assessed by Continuous Electronic Monitoring of Primary Care," *International Journal of Clinical Pharmacology Ther.*, 32 (1994): 452-57; and L. Evans and M. Spelman, "The Problem of Non-Compliance with Drug Therapy," *Drugs*, 25, no. 1 (1983): 63-76. These studies indicate that about half of all patients who receive medication from their doctor do not take the drug or fail to take it as prescribed; even more will stop treatment as soon as they feel better.
62. N. Hobbs et al., *Chronically Ill Children and Their Families* (San Francisco: Jossey-Bass, 1985): at 72. See also Korsch et al., supra note 59, at 872-75. This study of fifty adolescents with cancer who had undergone a renal transplant showed that fourteen adolescents interrupted their medication schedule at some point during treatment. Twelve of the fourteen were girls. They did so despite being advised about and understanding the importance of the medication. The reasons the adolescents gave for their refusal to comply with their medicinal regimen ranged from cosmetic concerns and guilt to a resentment of dependence on treatment and the medical establishment and a desire to "fool" the doctors, the system, and their parents.
64. G. Sigman and E.F. Gordon, "Ethical Issues in Research on Adolescents," *Adolescent Medicine: State of the Art Reviews*, 5 (1994): at 503. "Evidence indicates that adolescents have been excluded from necessary research." AIDS research is one area of research where adolescents were expressly excluded although they are at special risk for contracting HIV.
66. Sigman and Gordon, supra note 64, at 501.
67. Id.