Health Care Ethics USA

2002 - Vol. 10 No. 2

A publication of the Catholic Health Ethics Partnership at the Center for Health Care Ethics®, Saint Louis University Health Sciences Center

- From the Director...
- Medical Error and Patient Safety
- Is Living Organ Donation Ethically Acceptable?
- Is It Ethical to Legislate an Age of Consent for Health Care Decision Making?

More information on how to subscribe to Health Care Ethics USA.

Review the Health Care Ethics USA Index of Past Publications.
We have now begun the academic year at the Center for Health Care Ethics. I am delighted to inform you that we have another two faculty personnel at the Center. In addition to our regular faculty (Jim DuBois, Griffin Trotter, Jill Burkemper, and myself) the following faculty are joining the Center as permanent faculty: Sandra Johnson, who is our Tenet Endowed Chair in Health Law and Ethics, stood down as the University Provost last Spring and "activated" her appointment at the Center in July; and Ana Iltis will join the Center in January to initiate a tenure-track appointment as an assistant professor, specializing in organizational ethics and Institutional Review Board issues. We are immensely blessed to have Sandra and Ana at the Center – we extend the warmest welcome to both. And, of course, we offer a warm welcome our new students and a welcome back to all our other students as we begin the new academic year together.

Last Spring the Center developed its strategic plan which was approved by the University administration over summer. Let me quote the all important description of our mission: "The mission of the Center is academic research integrated with teaching, learning and service in health care ethics. Our mission brings the Catholic, Jesuit tradition into interdisciplinary discourse with our pluralistic society." This mission statement will inspire and shape our Center's contribution to the University's Capital Campaign that was initiated in July 2002 ("The Campaign for Saint Louis University: Where Knowledge Touches Lives"). I look forward to working with our many partners in Catholic health care as the Center pursues this campaign to realize its main strategic goals: to expand the Center's academic research; to enhance the scholarly reputation of the Center's interdisciplinary PhD program in health care ethics; to develop innovative and cross-cultural partnerships in the academy and in health care.

As usual, this issue of Health Care Ethics USA has three essays addressing organizational ethics, medical ethics, and ethics foundations. The first essay, "Medical Error and Patient Safety" by myself addresses an increasingly worrisome issue in organizational ethics in health care. The essay advocates for a major shift from blaming professionals to fixing systems and processes as the best way of enhancing patient safety. The second essay, "Is Living Organ Donation Ethically Acceptable" is by James DuBois, PhD, DSc, who is a member of the tenured faculty at the Center. Jim discusses this much disputed issue in medical ethics by arguing not only for policies and practices that minimize risks but also for consent that is both free and informed. The third essay, "Is It Ethical to Legislative an Age of Consent for Health Care Decision Making?" is by Ann Suziedelis, MA, who is a senior student in our PhD program. Ann considers the tension between autonomy and beneficence based approaches as contributing significant insight from discourse on ethics foundations to this policy dilemma. I hope you enjoy the essays and I look forward to receiving suggestions for topics that we might address in future essays.

Professor Gerard Magill, PhD
Executive Director & Department Chair
Center for Health Care Ethics
Medical Error and Patient Safety

In a recent study in the *Archives of Internal Medicine*, it was reported that drug errors occurred daily in one out of five doses in a typical 300-bed hospital. This 1999 study of 36 hospitals in Colorado and Georgia confirms the increasing awareness of the problem of medical error in our hospitals. The study focused upon the problems arising from administering errors after a physician had properly prescribed for the patient – it did not look for the errors, discussed in other reports, that deal with the wrong prescription of a drug by a physician or the wrong filling of a prescription in the pharmacy. No wonder the Institute of Medicine’s report, *To Err is Human*, (1999) estimated there were 44,000-98,000 medical errors that lead to mortality each year in US hospitals. For the sake of caution, even the lower range of the estimate is astounding. In light of such shocking information, perhaps our hospital beds should have a warning board reading, "hospital care can seriously damage your health"! In a follow-up report, *Crossing the Quality Chasm* (2001), the Institute of Medicine focused upon both systems and the environment to remedy the problem: to critique weak systems in the delivery of care that increase the probability of error; and to reconfigure the environment of health care delivery in a manner that enhances patient safety. This essay offers an analysis of medical error as a problem in organizational ethics in health care.

Principles

From the perspective of organizational ethics it is important to grasp that the problem of medical error is not recent in US health care. What is recent is the debate about shifting the burden of responsibility from individuals to systems. Ethics discourse on medical error and patient safety seeks to shed light on an ugly landscape that has been avoided or camouflaged for too long. To understand the discussion on the principle of responsibility it is helpful to be aware of both the extent of medical errors (the many forms it can take) and the developing scholarship on medical error.

There are many forms of medical error that include the following categories. Diagnostic errors can occur (either through omission or commission) when there is error or delay in diagnosis, failure to provide relevant tests or to act on the results of tests, or use of outmoded tests. There can be treatment-oriented error in the administration of a procedure or in surgical intervention, in the dose or method of using a drug or in inappropriate care for a disease. Preventative errors can occur via inadequate monitoring or follow-up or not providing prophylactic treatment. And there can be more general forms of medical error such as can be caused by communication failure or equipment malfunction.

The reality of medical errors has been recognized for a long time and serious scholarship on recent data has been available since the early 1990s. In a landmark study (1991) T.A. Brennan reported data on medical error from 1984 based on over 30,000 patients in 51 acute care hospitals in New York state – that work was followed by other landmark studies, such as by L.L. Leape and others on the prevention of medical errors and the need for systems analysis and by Noble and Brennan on organizational liability for patient safety. This developing scholarship on the entire range of medical errors has identified the crucial question as one of responsibility – whose responsibility is it to avoid medical errors and whom should we hold accountable for patient safety? In recent years the onus of responsibility has been shifting away from focusing upon individual professionals to highlighting organizational systems and processes that the professional relies on for the clinical care of patients.

Discussion

George Lundberg, the controversial former editor of *JAMA*, has argued for the need to focus on quality improvements and systems thinking in the delivery of health care if we are to remedy the problem of medical error. This approach has led to a tectonic shift in assigning primary responsibility for medical error – a shift from the so-called *professional sanctions model* to what is increasingly
The professional sanctions model seeks to punish individuals for their medical errors as a means to prevent future errors among fellow professionals. Prima facie, the model had plausibility. But its failure is widely recognized. This model contributed substantively to the seemingly endless pursuit of lawsuits for medical malpractice – and despite the increasing penalties and incumbent shame of many clinicians the dreadful record of medical errors continues to escalate. This model sought to blame the individual professional for carelessness or incompetence, and thereby focused upon who was responsible rather than ascertaining what caused the problem. The current malpractice system in health care amply demonstrates the failure of this model insofar as the main goal of deterring future medical mistakes is evidently unsuccessful. Moreover, a malpractice environment deters open reporting of honest professionals because of the climate of fear and shame that accompanies the malpractice system. Of course, tort law through compensation of victims can shed light on the need for improvements in patient safety. Yet, the malpractice system de facto does not tend to promote root cause analysis in order to discover what caused the problem insofar as its focus remains upon who was responsible to determine who can be blamed. The obvious inference is that the professional sanctions model, best exemplified in malpractice claims, does not adequately reduce medical errors.

In contrast, the emerging patient safety model promises much greater success in the reduction of medical errors – if we can enable the model to get traction in our litigious culture. The model addresses medical error by seeking changes in the systems and processes of care that support the practices that engender medical mistakes by individuals. There is a shift from fixing blame upon individual professionals to fixing problems via root cause analysis of what happened in order to implement systemic safeguards that can prevent recurrence. Naturally, this model fosters continuous quality improvement and encourages open reporting to address system glitches that can lead to medical error. An obvious analogue occurs in road safety – when a specific site is associated with several car accidents, safety rails are built to prevent future crashes. Or, better still, the analogy of airline safety can help advocacy for the patient safety model. When airlines were freed from regulatory reprisals for reporting pilot error and near misses, pilot cooperation soared with the result of extensive, confidential reporting and consequent remedies throughout the airline industry to protect passengers. We need a similar system in health care that will encourage self reporting of medical error (and near misses) with confidential assurances that will encourage root cause analysis, system implementation of preventative measures, and appropriate compensation for victims. Just as occurs in workplace injuries to employees, health care might develop an approach of compensating families and patients for medical errors without excoriating the career of good and honest professionals who simply made a mistake – even a serious one. However we resolve the problem of fair compensation to victims, it is just as important to resolve the underlying problem that led to the original error, and that requires system-wide attention. Imagine a system (like airlines) in which one error in a hospital (e.g. wrong medication in surgery) kick starts a root cause analysis that reveals a systemic problem (e.g. possibility of mistaking dangerous drugs during surgery) that would be communicated immediately to all hospitals in the nation for immediate remedy. If the airlines can do it, why not health care!

To adopt another metaphor, we need to turn down the heat of malpractice litigation in order to turn up the light for root cause analysis and system remedies. In recent years health care has developed very sophisticated management audits to maximize margin and profitability. Perhaps we could invest similar energies and resources into safety audits that would develop appropriate safeguards and processes for patient safety.

Conclusion

There are serious flaws in our current system of addressing medical errors. Unfortunately, the relation between our legal and medical professions has led to an adversarial animosity that too readily trumps any hope for cooperative partnerships that could resolve this gaping hole in health care – between 44,000 and 98,000 medical errors that lead to mortality each year in US hospitals. The problem is immense; the "self-policing" approach of health care delivery and legal practice is evidently inadequate to fix the problem; and the increasing sophistication of research, technology, and therapy suggests the problem is destined to incremental increase unless we can find a moral high-road that can better protect our patients. Blaming good and honest professionals, hiding mistakes from families and patients, and focusing risk management on reducing pecuniary penalties rather than reducing risks of medical error are not the paving stones for this moral high-road!
The problem of medical error is so systemic in health care, with no obvious remedy in sight, that government intervention alone seems likely to succeed. Health systems and hospitals individually are in too much jeopardy to resolve the dreadful dilemma that the pervasiveness of medical errors presents to the nation. Some sort of national body, such as at the NIH, needs to be created and funded to combine the two crucial ingredients for future success: a guaranteed system for confidential, self-reporting by professionals of errors they encounter; and an efficient system of communicating and enforcing preventative measures to protect patients across health care in the US. And if the malpractice lobby needs consoling when faced with this new vision for patient safety, perhaps it will be satisfied with restricting tort law to injuries associated with intentional or reckless behavior. Keep malpractice for the rogues but establish a noble system for honorable professionals to communicate the medical errors they encounter in an environment that is committed to patient safety.

Professor Gerard Magill, PhD,
Executive Director & Department Chair,
Center for Health Care Ethics


Questions For Discussion

1. Can you recall an experience of medical error that was discussed widely in your health care environment? If so, what was the cause and remedy of the problem?

2. What is the difference between the professional sanctions model and the patient safety model as a means of resolving the problem of medical errors?

3. Given the pervasive nature of medical errors in US health care, can you suggest ways to remedy this problem?

Suggested Readings


Is Living Organ Donation Ethically Acceptable?1

The first known living organ donation was conducted in 1954 by Dr. Joseph Murray, who transplanted a kidney from one twin brother to another.2 Over the past decade, living organ has grown tremendously worldwide. In fact, in 2001, for the first time, living donors outnumbered cadaveric donors in the United States.3 At present it is possible to donate a variety of organs in this fashion, but the most common are a kidney, one lobe of the liver, and a portion of a lung.

Not only does living donation provide one important way to decrease the shortage of organs for transplantation, but living donation presents several advantages over cadaver donation. In general, living organ donation reduces the wait time for the recipient (reducing the risks of further deterioration), permits the surgery to be scheduled ahead of time, and reduces cold-ischemia time (the time the organ is stored without oxygenated blood).4 Moreover, living kidney donation is the most cost effective kidney replacement therapy we have.5 For all these reasons, living donation is likely to continue to grow more common.

Nevertheless, living organ donation raises several ethical concerns. First, living organ donation involves mutilation of a healthy body. Second, living donation brings with it a threat to the health and even the life of the organ donor. Mortality from donating a kidney is estimated at .03 percent and mortality from donating a lobe of the liver is estimated at 1 percent (though some speculate it may be higher).9 Third, living organ donation presents special challenges to obtaining informed consent. Many people maintain that only relatives should be allowed to take on the risks that come with living organ donation. Yet family members may so strongly desire to help a loved one that they do not truly absorb information about risks. Others may want to help, yet be reluctant to undergo surgery. Such individuals may find saying "no" awkward or possibly harmful to relationships. Finally, some have proposed offering financial incentives to increase live organ donation.7 This raises a number of concerns related to coercion, the commodification of the body, and the provision of incentives to withhold important aspects of one's medical history.

Throughout the discussion of this issue, we will not only consider the ethical principles that are relevant to Catholic health care, but will consider the recommendations of an interdisciplinary expert panel, the Live Organ Donor Consensus Group.8

Principles

Several ethical principles exist that can offer guidance in evaluating and implementing living organ donation programs. Regarding the matter of mutilation, Catholic moral theologians have long recognized the principle of totality. The principle of totality presents a general duty to maintain the human body in its wholeness. However, it is typically applied with two qualifications. First, foreseen but unintended mutilation may be permissible when the principle of double effect is properly applied, e.g., a gangrenous limb may be amputated. Second, and more relevant to our purposes, for proportionately grave reasons mutilations may be allowed that do not disable any significant functions. Thus, the Catechism of the Catholic Church specifically states that it is "morally inadmissible directly to bring about the disabling mutilation or death of a human being, even in order to delay the death of other persons" (emphasis added).9 Referring specifically to living organ donation, paragraph 30 of the Ethical and Religious Directives embodies these same principles, only it articulates them within a conditional statement of permission:

The transplantation of organs from living donors is morally permissible when such a donation will not sacrifice or seriously impair any essential bodily function and the anticipated benefit to the recipient is proportionate to the harm done to the donor. (emphasis added)
The key task in prudential deliberation is determining whether donating an organ or a piece of an organ always constitutes "disabling" mutilation.

In general, living donation of the most common organs – a kidney, a lobe of the liver or a portion of a lung – meets the criteria laid out in these statements. Because kidneys are paired and the body can function with one healthy kidney, the removal of a kidney does not seriously impair an essential function. Likewise, removal of a lobe of the liver typically does not impair function, largely because the surgically reduced liver amazingly regenerates to nearly its full size, doubling its mass in only seven days.

Nevertheless, while living donation does not typically involve injury to the detriment of the whole human being, it does carry with it the risk of impairment and even death. This risk requires us to invoke two other ethical principles that are widely recognized in the practice of medicine.

The principle of non-maleficence – i.e., the principle of not harming patients – does not merely refer to the avoidance of intentionally inflicted harms, but requires us to do what we can to minimize risks. Nevertheless, because the practice of medicine cannot wholly eliminate risks of harm (e.g., when undergoing surgery) and frequently foresees unavoidable harms (e.g., the harmful side effects of certain medications), the principle of informed consent is a necessary complement to the principle of non-maleficence.

The first element to informed consent with a competent patient is the provision of information that a reasonable person would want to know in making a decision. In living organ donation this involves not only standard items such as a description of the procedure, risks, follow-up care, and medical alternatives, but also some items peculiar to the transplant setting, the most unusual of which involves sharing information about another patient – the prospective organ recipient. For example, the 2000 Live Organ Donors Consensus Group urged medical personnel to inform potential donors of options to the transplant recipient, of the recipient's prognosis, and of the transplant center's outcome statistics. They should also be informed that donation could affect their ability to obtain life and health insurance, especially without paying higher premiums. Donors should be informed of any special treatment they can expect should they go into organ failure and require a transplantation themselves.

Informed consent also involves confirming that potential donors are not under coercion and are capable of giving free consent. This aspect of informed consent is deeply influenced by the motives of donors and will be discussed below in relation to a variety of scenarios.

Discussion

While many other ethical concerns arise in connection with living donation, the risk of death is by far the most serious and needs to receive close attention from the medical community. Those engaged in this debate have emphasized the importance of having surgical teams that are skilled and experienced, as well as providing high-quality post-surgical care. Some recommend that the best way to achieve these aims is to create a program that would certify and regulate centers. Such a national program might also collect outcome statistics that could be stored in a national database that would enable medical personnel to better estimate risks to donors.

Obtaining informed consent from potential donors is particularly tricky in living organ donation given that some of the relationships that donors have to recipients may present obstacles to a truly free decision. A recent article identifies six types of living donors based on their relationship to organ recipients and their motives: the genetically related (e.g., siblings or parents), the emotionally related (e.g., a spouse or in-law), "Good Samaritans" (e.g., an altruistic stranger), vendors (i.e., those who would sell organs, which is currently illegal), and organ exchangers (those who "exchange" organs with another donor, e.g., because their blood type is incompatible with the loved one to whom they would like to donate).10

For years, living donation was only permitted between those who were genetically or emotionally related to the recipient. It was believed that such relationships on the one hand helped to justify undertaking the risk involved, and on the other hand, prevented a slippery slope toward the sale or commodification of organs. Nevertheless, informed consent with related recipients also gives rise to unique challenges. There exists a very real danger that individuals will feel compelled to donate. Therefore, the psychosocial evaluation must attempt to rule out coercion, whether imposed by others...
or self-imposed. There is also the danger that the individual will so badly desire to help a loved one that the donor will be unable to appreciate properly the risks involved. Ethicists engaged in this debate ask us to consider two questions. First, can we consider consent that emanates from care and concern to be just as valid as consent that is fully informed and free of emotional influence? Second, in such cases can others – e.g., the transplant physician – assume some of the duty to weigh risks against benefits in an effort to protect potential donors?

While many centers have been reluctant to use altruistic donors, the Consensus Group suggested that the criteria for the ethical acceptability of altruistic donation are fundamentally the same as those for related or directed donation. Others have suggested that there may even be ethical advantages, in part, because it may be easier for altruistic donors to given genuinely free informed consent.

Some people have suggested that we might increase organ donation by offering financial incentives. However, this practice would go against both current US law and directive 30 of the Ethical and Religious Directives, which states that "the freedom of the prospective donor must be respected, and economic advantages should not accrue to the donor." This prohibition against the sale of organs can be ethically defended on at least three grounds: financial incentives could lead to the exploitation of the poor and interfere with their free informed consent, it could lead potential donors to withhold important information about their health history and risks, and most importantly, it would lead to significant changes in the way we view ourselves (e.g., as individuals who possess bodies as property rather than as embodied persons who have stewardship over their lives). Nevertheless, social justice would require that the health care system not penalize those who freely give a part of themselves for others. In keeping with this, the Consensus Group recommends that living donors "should not personally bear any costs associated with donation. In addition, guidelines should be established that are similar to those for short-term disability to defray lost wages."

As an alternative to financial incentives, some transplant organizations are experimenting with organ exchanges in which a person directs donation to a stranger and in exchange his or her loved one is either moved to the top of the waiting list or receives an organ from someone related to the recipient. Such practices do not appear to raise unique ethical issues regarding informed consent. But a number of logistical, legal and ethical problems remain (e.g., insofar as persons with the O blood type are disadvantaged, or given that some donated organs are not successfully transplanted). However, the participants in the Consensus Group did not find these concerns to be insurmountable and they recommended a pilot study using a nationwide list under the surveillance of a group like the United Network for Organ Sharing with prospective monitoring of beneficial and adverse consequences.

Conclusion

Over the past few decades organ transplantation has moved from an experimental procedure to a relatively common therapeutic treatment. In the year 2000, nearly 23,000 organ transplantations were performed. In 2001, more than 6,400 living people donated an organ or a part of an organ. In such an environment it is all too easy to think of organ transplantation as "routine." But there is nothing routine about walking around with someone else's organ inside you, and there is nothing routine about undergoing surgery and having an organ removed – not to cure your own disease – but to benefit another person. Those who choose to become living donors truly perform a heroic act of charity. We owe it to them to ensure that our policies and our practices minimize the risks that they undertake and ensure that their consent is both free and informed.

James M. DuBois, Ph.D., D.Sc.

1. Much of this article is excerpted from James M. DuBois, "Organ Transplantation: An Ethical Road Map," National Catholic Bioethics Quarterly, 2, no. 3 (2002): 413-453. This larger article provides further references and addresses other ethical issues in organ transplantation.
Nevertheless, more organs were procured from cadaveric donors, because they are capable of donating both kidneys and other vital organs like the heart and lungs.


---

**Suggested Readings**


**Questions For Discussion**

1. Could any motive other than charity ethically justify living organ donation?
2. How might we offer guidance to those who are considering living organ donation?
3. Should ethics committees play a significant role in shaping local living organ donation policies, or should we rather strive to establish a uniform, national standard of practice?
Is It Ethical to Legislate an Age of Consent for Health Care Decision Making?

U.S. Supreme Court Justice William O. Douglas remarked in 1972, that "the moral and intellectual maturity of a fourteen-year-old approaches that of an adult." Seven years later, Chief Justice Warren Burger countered with the comment that "most children, even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment." These disparate statements reflect the conflict that law makers in our society face in regard to granting minors the legal authority to make their own health care decisions. We have chosen to legislate an age for such decision making, until which time parents generally decide for their children. That has hardly laid the question to rest, though, and we do make exceptions. For example, in regard to contraception, sexually transmitted infections, mental illness, and alcohol and other drug abuse, most states have laws that allow minors to consent to treatment without their parents' knowledge or consent. Society even goes so far as to fund these services in order to eliminate any financial need for parental notification. Such exceptions, however, do not reflect a belief that these young people are particularly well-suited to make such decisions. (Indeed, the opposite would generally appear to be so.) Instead, they result from concern that access to such treatment must be unimpaired, not only for the sake of the minors involved, but for the sake of the common good – the welfare of society as a whole. Justification for this concern is illustrated in a recent issue of the Journal of the American Medical Association, which reports on a study in which fifty-nine percent of teenage girls surveyed indicated that if parental notification were required, they would not only not seek testing or treatment for HIV and other sexually transmitted infections, but would also not stop being sexually active. In essence, if they could not give consent for confidential treatment, they would become public health hazards.

States also acknowledge that minors who are married, are parents, or are on active military duty, may give consent for their own health care, and often for that of their spouse and children. Again, though, these exceptions are based on specific circumstances, and not on any evaluation of the decision-making capacity of the minor involved, nor even of what is in his or her best interest. This essay will not further consider any of these exceptions. Nor will it explore the issue of mature minors and the related questions of whether, and to what extent, minors should be allowed to at least participate in decisions regarding their health care. It focuses instead on the majority of minors in the majority of circumstances, asking if it is ethical and reasonable to legislate health care decision-making rights solely on the basis of age, and if so, if eighteen is a sound age at which to lift such restrictions.

Principles

These questions are rooted in the bioethical principles of autonomy and beneficence. 'Autonomy', as used here, refers to what Beauchamp and Childress describe as "the personal rule of self that is free from controlling interferences by others, and from personal limitations that prevent meaningful choice, such as inadequate understanding." Ronald Dworkin offers an expansion of this that is critically important for our discussion of minors, when he argues that the value of autonomy is derived "from the capacity it protects: the capacity to express one's own character – values, commitments, convictions, and critical as well as experiential interest," in his or her own life. The second principle, beneficence, requires that we act in the interest of the well-being of others. While there is much discussion about questions of to whom and to what extent we are required to be beneficent, we can limit our discussion here to looking at beneficence in the specific relationships of parent and child, and physician and patient.

It is the responsibility of health care professionals to balance autonomy and beneficence in caring for all patients – that is, to balance the patient's right to self-determination versus what could objectively be considered to be in his or her best interest. There is broad acknowledgment, in both medicine and law, that autonomous decisions of competent adults will hold sway, regardless of what others might
feel would be more in their best interest. Unless and until proven otherwise, a competent adult is presumed under law to hold sufficient decision-making capacity to decide autonomously to accept treatment, or to refuse or withdraw it, even if it leads to his or her death.

Some adults, of course, are found not to be legally competent. That is, they are judged not to have the actual capacity to make reasoned decisions. Some of these persons, those with serious mental limitations, for example, may never have been competent, and when their thoughts have never been expressed, beneficence will come into play. Surrogates will make decisions for them by asking, "What is in the best interest of this person? What would the reasonable person want in these circumstances?" Other incompetent adults were once competent, but have become unable to make reasoned decisions through injury or illness. When this occurs, surrogates often base their decisions on the autonomy-based standard of substituted judgment. According to this approach, the surrogate considers expressions of preference that the person made in the past, and uses them to determine what he or she would now choose. In other words, "What would this person want in these circumstances, if still able to decide for him or herself?" Surrogate decision makers might also employ aspects of both these standards, focusing on what is ultimately in the best interest of the patient, but also taking into account the thoughts and values that the person may have expressed while competent.

But what of minors? As noted above, persons are generally considered 'incompetent' under law to make health care decisions until they are eighteen years of age. Yet we all know that there is nothing magical about a birthday. We don't awaken on that day, suddenly more capable of sound decision making than we were the evening before. In reality, we each grow toward decision-making capacity at our own pace; often two steps forward one step back, as we make our way through childhood and adolescence. Minors should thus be classified not as 'incompetent', but as 'not-yet-competent', and this brings us back to the thesis questions of this essay: Is it ethical to legally restrict health care decision-making rights on the basis of age alone, and if so, is it reasonable to maintain eighteen as the age at which such restrictions are lifted?

Discussion

The first challenge in answering these queries is to determine whether most young people under the age of eighteen even possess sufficient cognitive ability to make rational decisions, for a lack of such capacity would render further inquiry moot. A survey of empirical studies, however, shows consistent conclusions that there are few demonstrated cognitive decision-making differences between minors over the age of thirteen and adults, and that even nine-year-olds can make some reasonable choices regarding health care treatment. These studies do not support the denial of the right of health care self-determination solely on the basis of an age-based presumption of cognitive incapacity.

The next consideration is whether it can be shown that minors generally have enough of a grasp of illness to make important treatment decisions. On this, the literature indicates that there is reasonable evidence that even young children can understand not only the symptoms of their own specific disease, which would be expected, but that they also can show maturity and sophistication in their thinking about them. As a matter of fact, the data show that children who suffer from an illness (and are thus 'experts') actually outscore healthy adults who do not suffer from that disease ('novices'). These data also offer support for the autonomy-based contention that minors should be allowed to make their own health care decisions.

In many cases, a thorough comprehension of the meaning of death and its relationship to illness is also critical. Various studies indicate that by age seven, children understand the concept of death; that at around age nine it is often understood as a biological process that is inevitable and final; and that children develop a sophisticated understanding of the relationship between illness and death somewhere between ages eleven and fifteen. Another group of researchers would disengage this understanding almost entirely from age, placing emphasis on experience, instead, as we saw in the expert/novice dichotomy above. Again, both approaches seem to support arguments for decision-making autonomy for minors.

But there are other important considerations. Cognitive decision-making capacity and an understanding of illness and death may not be sufficient to the task of making life-affecting—and sometimes life-saving or life-ending – health care decisions. Other factors enter into this equation. For example, consider the case of Gwen. She was a happy sixteen-year-old, looking forward with excitement to her senior year of high school, when her dreams were abruptly interrupted by a
diagnosis of non-Hodgkin's lymphoma. Gwen's physicians proposed that she immediately receive emergency inpatient radiation, followed by chemotherapy. They were honest with her and her parents that there were some rough months ahead. She would be hospitalized for an extended period, and the chemo might make her very sick; she would probably lose her hair temporarily. The very good news, they emphasized, was that she had an excellent chance of recovering completely. Gwen asked her parents for time to consider what she called "her options." After a short while, she was adamant: She wanted no treatment. Despite being told that her odds of even surviving without radiation and chemo were grim, Gwen had other priorities. She did not want treatment for her cancer that would interfere with the coveted role of captain of the cheerleading team, to which she had just been elected. "You don't understand," she cried, when her parents and the doctors tried to explain to her the importance of treatment. "I feel fine, and I don't want to miss my senior year . . . all the games, and maybe being Homecoming Queen." Most of all, she rejected the notion of treatment because, as she said, "I don't want to be bald. I don't want everyone looking at me." This certainly seems an objectively unreasonable decision. The questions for this essay are how did she reach it, and should she be allowed by law to have the final say?

In his discussion of autonomy, we saw Ronald Dworkin suggest that some people should not be allowed to make their own decisions, not because they don't know how to reason, but because they will not make decisions in a manner that protects their capacity to express their own character; the things they value, commit to, and take a critical interest in. This is particularly applicable to our questions regarding minors, since it is not clear at what age most persons have developed sufficient moral maturity to say with meaning, "I value this or that," so that a particular decision is an authentic expression of who he or she really is in a moral sense. In other words, when do most persons grasp that "this is the kind of person I am," or "this is what is really important to me"? Has Gwen? It appears that she is, instead, so sidetracked by the fleeting joys of high school that she has temporarily lost sight of her lifelong goals of college, family, and career—indeed, of life itself. She is, in effect, manifesting typical symptoms of adolescence that reflect a still-developing fundamental moral self, making a decision that is thus not only unreasonable, but inauthentic as well.

In a manner similar to the law's recognition of stages of incompetence (never-competent, once-competent, etc.), bioethicists often speak of 'moral self' in terms of those who once had a moral self and those who never had a moral self. But something is missing, for this distinction ignores minors such as Gwen, who are still in the ongoing process of developing their authentic and fundamental moral selves. If one believes that cognitive decision-making ability is not enough, that moral maturity or selfhood is necessary in health care decision making, and that that slowly develops over time, then the inclusion of this additional category of "those who are still developing a moral self" is critical. Its acceptance undermines the autonomy-based position that even young children should be allowed to make their own health care decisions. It supports, instead, laws and policies that seek to protect minors until the difficult adolescent years have passed, years which have been described as being, by definition, "a time of unpredictability, of shifting from black to white and from hot to cold." Beneficence-based reasoning argues that even older minors, such as Gwen, need this time to experiment and explore, to learn to cope with peer pressure (reflected in Gwen's concern about being bald), to unfold personal life goals, and to develop their own understanding of "the good life." They need this time to become who they are, before being allowed (or forced) to assume responsibility for medical decision making.

Conclusion

This brings us, then, to the following crucial question. If one accepts that the beneficence-based approach is ethically sound – that a legal age of consent can be ethically defended – the question of whether eighteen years is the right age, still remains. To the accusation that it is an arbitrary marker, one can only respond that that is absolutely correct. However, unless we choose to have no age restrictions at all – not for marriage, voting, driving, or drinking – the selection of any of these age limits will be similarly arbitrary. The fact of the matter is that eighteen is the age which our society has chosen to acknowledge as the transition point from adolescence to adulthood. Eighteen is the age at which persons are legally emancipated from parental care and responsibility, and it thus seems the most reasonable point at which to grant health care decision-making rights as well.
Ann K. Suziedelis, MA


**Suggested Readings**


**Questions for Discussion**

1. What would be some practical obstacles to allowing minors autonomous access to health care in the United States?
2. Why do some states that allow young teenagers to give consent for contraception, drug and alcohol treatment, and HIV testing, require parental notification for the same minors to have abortions, and parental consent to have their ears pierced?

[Return to Index]