Patients Doubtfully Capable or Incapable of Consent

CARL ELLIOTT

If the concept of autonomy has played the starring role in the development of bioethics, then the problems of non-autonomous patients have been its supporting cast. For better or worse, the way bioethics has come to see the problems of incompetent and marginally competent patients has been colored by the way it has seen the problems of competent, autonomous adults. The rights of competent adults were the focus of a considerable amount of the earliest work in bioethics – issues surrounding informed consent, for example, or the patient’s right to refuse life-sustaining medical treatment. Moreover, quite a lot of this work got its start in the individualistic, rights-conscious United States. Given this background, it should be no surprise that incompetent patients have presented bioethics with some of its most troubling ethical problems, and that the field is still struggling to find a conceptual framework in which to consider them.

Indeed, the very fact that all incompetent and marginally competent patients are often lumped together in the same category says something about the way the field has evolved. It is only in contrast to more commonly agreed-upon attitudes toward competent patients that incompetence comes to be identified as a morally distinctive feature. Yet identifying it as the most morally relevant feature about a patient downplays the fact that incompetent and marginally competent patients comprise a vastly diverse range of human beings who present very different ethical problems. From an ethical point of view, an anencephalic infant, a 65-year-old woman with Alzheimer’s disease, a violent man with schizophrenia, and a 6-year-old with incurable lymphoma are probably divided by more than they share. Not only do different incompetent patients present different ethical problems, they also occupy radically different places in our moral and emotional lives. We generally think of children, for example, in ways very different from the ways we think of incompetent adults. While our attitudes toward adults are often centered on respect for the patient’s previous values and the narrative of her past life, our moral attitudes toward children are commonly located within notions of dependence, protection, growth, and the child’s relationship to her parents.

Many of the ethical problems associated with pediatrics have developed in situations where there is a divergence between the attitudes of parents and health-care workers toward the care of a child. For example, parents of religious faiths such as the Jehovah’s Witnesses or Christian Scientists often have moral and religious objections
to certain medical treatments for their children in situations where health-care workers (in agreement with broader Western society) generally regard the treatments as medically necessary for a child’s well-being. More generally, conflicts between parents and health-care workers arise over the use of life-sustaining medical interventions such as cardio-pulmonary resuscitation, mechanical ventilation, or artificial nutrition. Physicians sometimes undertake interventions on a severely ill or disabled child, for example, that the child’s parents see as excessively burdensome. On the other hand, parents sometimes demand interventions that physicians see as futile. Some of the starkest conflicts have come with anencephalic infants or children in a persistent vegetative state whose parents want treatment pursued, regardless of the poor prognosis, out of a belief that even unconscious life should be protected and preserved. In neonatology, such conflicts between parents and health-care workers are complicated still further, because aggressive medical interventions on premature, severely ill, or disabled newborns must often be undertaken under conditions of grave uncertainty (Arras 1984). The outcomes for such newborns often span a great range, from a full cure and normal development, to life with severe mental and physical disability, to death after prolonged and burdensome treatment.

Problems surrounding aggressive or life-sustaining medical treatment also arise for incompetent adults, and often center around conflicts between the opinions of health-care workers, the patient’s previously expressed wishes about treatment and the wishes of various members of the patient’s family. Yet the care of incompetent and marginally competent adults has also raised a much broader range of questions. Psychiatrists deal with a number of relatively specialized ethical questions about the care of mentally ill persons, many of which intersect with legal issues: questions about the conditions under which a psychiatric patient accused of wrongdoing is competent to stand trial, or when a psychiatrist is justified in breaking confidentiality, and when he has a duty to warn the victims of a potentially violent patient. Psychiatrists must also consider the question of when it is justifiable to confine or treat an incompetent or marginally competent patient against his (incompetent) expressed wishes – for instance, with antipsychotic drugs or, less commonly, with electroconvulsive therapy. The fact that many mentally ill and disabled patients live in long-term care institutions raises many questions of its own, such as the effects of institutionalization on the quality of informed consent.

While there is still fierce debate on many of these issues, over the past decade or two a fairly broad consensus has emerged in the bioethics literature about two questions that are relevant to many incompetent patients: how competence should be assessed, and how decisions should be made for patients who are incompetent. What I will do here is outline the standard approaches to these questions, and then point out several of the problems that they leave unanswered or unasked.

The Standard Models of Decision-making Capacity and Surrogate Decision-making

Decision-making capacity or competence (the legal term) is conventionally defined as the ability to perform a task – here, to make decisions about one’s medical care, or about
taking part in biomedical research (Faden and Beauchamp 1986: 290). Patients with decision-making capacity, it is widely agreed, generally have the right to make their own health-care decisions, even decisions that others believe are contrary to the patient’s interests. However, as a result of illness, disability, or immaturity, some patients do not have the mental abilities required to make these decisions. If given the opportunity, many of these patients would make decisions that are risky, dangerous, or which they simply would not otherwise make if they were thinking soundly. Assessments of competence (or capacity) protect incompetent patients from the consequences of such decisions, while also protecting the rights of competent patients to make decisions for themselves.

Most writers agree that what is most important for judging competence is how patients reach their decisions, rather than what they decide. Merely because a patient reaches a conclusion that his physician regards as unreasonable — say, refusing effective treatment for a life-threatening illness, or deciding to enroll in a risky research protocol — does not mean that the patient is incompetent. Since different patients have different values and needs, they may reach different conclusions even when presented with the same choice. While it is a matter of debate exactly what mental abilities are necessary for competence, many standards require that a patient have a relatively stable set of goals and values; be capable of understanding the consequences of the decision, including its risks and benefits; be able to reason about the relevant information and communicate a choice; and be able to appreciate how the decision will affect them personally (Dunn et al. 2006; Grisso and Appelbaum 1995; President’s Commission 1982).

Often patients are clearly not competent, but their families and physicians must still make decisions for them (Buchanan and Brock 1989). For these patients, a hierarchy of decision-making standards has evolved, based largely on commonly held notions of respect for persons. First, when patients have expressed any wishes about the treatment in question while competent (through an advance directive, for example), their surrogate decision-makers should abide by those wishes. Second, when incompetent persons have not expressed any such wishes, surrogates should rely on the “substituted judgment” standard, according to which decisions are reached according to what patients would have decided if they were able, based on the patients’ values, goals, and desires. Finally, in the event that a patient has never been competent — a small child, for example — the surrogate must make decisions based on the “best interests standard.” What the interests of a patient are is often unclear or controversial, but they are generally understood to include, at a minimum, certain basic interests such as avoiding pain and disability and having conscious life extended.

The problem of competent irrationality

Some patients understand all the important aspects of their decision, including its risks and benefits, yet still make decisions that seem irrational (Brock and Wartman 1990). Sometimes these decisions are irrational even from the perspective of the patient’s own goals and desires. For example, an apparently competent diabetic patient being asked to consent to the amputation of a gangrenous toe might refuse, even if avoiding death is more important to him than avoiding the amputation, and even if he realizes that his refusal is threatening his life. What are we to make of such a choice? Doctors and
nurses, not to mention family members, are understandably reluctant to abide by a patient’s decision when that decision is irrational, especially if it is also self-destructive. Yet irrationality is a part of ordinary life. At times we all deceive ourselves, take poor risks, make impulsive decisions, act out of fear or anxiety, downplay future risks or benefits in favor of present ones, and otherwise behave in ways that seem unreasonable, idiosyncratic, or odd. Should an irrational decision be given the same degree of respect as a rational decision?

A related problem revolves around the question of which mental abilities are relevant to competence. Severely depressed patients may be capable of reasoning and deliberating about a decision, yet make very poor decisions, at least partly because of their depression (Elliott 1997). They may understand the risks of their decision, for instance, yet simply not care about them. Is a severely depressed person who wishes to die competent to refuse life-saving treatment? Similarly, people with addictions may want to resist a desire and understand that giving in to the desire is contrary to their own self-interest, yet still find the desire extraordinarily difficult to resist (Charland 2002). Is a heroin addict competent to consent to a research study involving the administration of heroin?

The decisions of children raise similar problems. The decision of a child may be influenced by the views of his or her parents or by other factors to such an extent that a clinician might reasonably question whether that decision is truly the child’s own. A 12-year-old child of parents who are Jehovah’s Witnesses may refuse a life-saving blood transfusion and, further, may appear capable of understanding both the religious reasons why Jehovah’s Witnesses regard blood transfusions as morally wrong and the brute medical facts relevant to that decision. Yet it may still be unclear whether the child’s refusal is competent. This is partly because it is unclear where the point lies at which a child’s decision becomes truly authentic and autonomous, and partly because it is unclear what sort of factors should cause one to question a child’s competence. Some clinicians might see fear, guilt, and the influence of the child’s parents as reasons to question a child’s competence, while others would see them as parts of ordinary decision-making.

The problem of personal identity

The standard way of making decisions for incompetent but previously competent patients has come to be the patient’s previously expressed wishes. Yet many neurologically damaged or demented patients are not, in some sense, the same persons they were before the damage or dementia. This is especially obvious for patients who are permanently vegetative, where the patient’s higher brain functions are absent, but it is also true for patients with other types of cerebral damage, such as stroke or trauma. The patient’s personality and values may have changed dramatically: his memory of his past life may be impaired; his intellectual and other mental abilities may be severely damaged. When this broad gap in identity separates the patient’s current and past selves, it becomes a matter for debate how much weight should be given to the wishes, values or desires of the patient as he was in the past. Should the patient’s previously expressed wishes prevail even when they seem to run squarely against his current interests?
Sometimes we may have reason to think that the person would have changed his mind if he could be made aware of subsequent events and developments – for example, a man in a persistent vegetative state from traumatic injury who, before his injury, had never been sick in his life, who had expressed a lifelong wish to have his life extended as long as possible regardless of the circumstances, but whose family feels would have changed his mind if he had ever been in a hospital intensive care unit. At other times the patient’s wishes and values in the past may directly contradict his present wishes and values (Dresser 1995; Nelson 1995). Take, for example, a writer who has devoted her life to matters of the mind, and for whom the mental deterioration associated with Alzheimer’s disease has always seemed the cruelest way for a life to end. She has told her son that if her mental faculties were to deteriorate, she would rather have euthanasia. What she regards as most humiliating of all is the lack of awareness of one’s condition that dementia brings. Yet when her mental faculties eventually deteriorate, she seems perfectly content with her life. She has no memory of her earlier wishes, and as far as anyone can determine, she would not now want her life to end. What value should we place on the wishes and values of a patient’s previous self, and what should we place on those of the current self?

The problem of involuntary “altruism”

It is an article of faith in pediatric hospitals that medical decisions for a child should serve that child’s best interests. Yet some medical interventions are clearly not in the child’s interests, and in fact are designed for other purposes. For example, surgeons often transplant kidneys or bone marrow from children too young to consent, usually matched siblings of the transplant recipient. Unlike the conventional medical interventions for which parents are asked to consent on behalf of a child, transplantation from child donors exposes children to risks that are not balanced by commensurate benefits – or at least not benefits to them personally (Dwyer and Vig 1995). This problem parallels a problem in certain types of clinical research, where children undergo risks or discomforts not for their own benefit, but to generate scientific knowledge that may eventually benefit others. For example, Phase 1 cancer trials are designed to test the safety and toxicity of new regimens for the treatment of cancer. The subjects in Phase 1 pediatric cancer trials are usually children whose cancer has a very poor prognosis and for whom standard therapy has not been effective. These trials are not designed to test the effectiveness of the new therapy, and the chance that children enrolled in the trials will experience any therapeutic benefit is relatively small. As with parents of living organ donors, parents of potential subjects in clinical research that has a poor risk–benefit ratio are asked to expose their child to risks, harms, or discomforts for the sake of someone (or something) other than themselves.

When competent adults take risks or undergo harms for the sake of others, we ordinarily consider their actions not morally obligatory, but altruistic or supererogatory – beyond the call of duty. Certainly they are not things that an adult should be forced to do. Yet if this is true, on what grounds can we justify such interventions on young children? Many of the justifications given in the past have a notably ad hoc feel about them. For example, some writers have argued for organ transplantation from living siblings by appealing to the psychological benefit that the sibling would gain from...
donating. On these grounds, a case is made for donation as an intervention that is in the best interests of the donor. Yet while there is no doubt some sense in which a child, at least an older child, might benefit by being volunteered to help his or her brother or sister, it is precisely because undergoing such risks are ordinarily not regarded as being in an adult’s interests that they are seen as altruistic (Crouch and Elliott 1999).

Other writers have appealed to a sort of hypothetical autonomy, suggesting that a child can be “volunteered” if at a later point she would come to see the intervention as ethically justifiable, or if the intervention is something for which she would have a moral obligation to volunteer if she were able (McCormick 1974). Yet what a child will come to see as morally acceptable will depend on the interests and character he or she develops, and often these things cannot easily be predicted (Ackerman 1979). Moreover, at least some of the interventions in question, such as Phase 1 trials, are not generally regarded as something in which adults have a moral duty to take part. If taking part is not obligatory for adults, the argument that it is justifiable for children is radically weakened. If we admit that an adult stands on solid moral ground in refusing to take part, then the ground for “volunteering” a child unable to consent seems much less firm.

The problem of the moral imagination

Deciding what kinds of medical care an incompetent patient ought to receive often means trying to decide what kind of care would be in the patient’s interests. How aggressively one should treat a newborn with severe spina bifida; whether a mentally retarded adolescent with cancer should undergo a burdensome course of chemotherapy with uncertain efficacy; determining the point at which a patient with schizophrenia should be treated against his will; deciding whether to treat pneumonia in a child with cerebral palsy and profound neurological impairment: understanding the interests of such patients requires a kind of imaginative leap. Like anthropologists who must try to understand cultures vastly different from their own, health-care workers must try to understand patients whose lives differ dramatically from theirs by virtue of illness or disability.

Imaginatively sharing another person’s particular, subjective point of view, however, requires imagining a logical impossibility. It asks the question: what would it be like for me, if I were someone else? The most problematic cases arise when we must imagine what life is like for a person whose mental life appears radically different from our own, as a result of mental retardation, mental disability, or mental illness. This kind of imaginative leap requires us to imagine what it would be like not to have the mental abilities that we have, including those by virtue of which we are able to imagine. Adam Smith thought that in imagining what the experience of the mentally impaired is like, a person is tempted to “imagine what he himself would feel if he were reduced to the same unhappy situation, and what is perhaps impossible, regard it with his present reason and judgment” (Smith 1982: 12). There are at least two serious dangers to this sort of exercise. One danger comes with trying to imagine the experience of the permanently unconscious, such as anencephalic children or permanently vegetative persons. This is the danger of imagining, in Nagel’s words, that “there is something that it is like” to be permanently unconscious, and making a misguided judgment as to the permanently unconscious person’s quality of life.
The other serious danger is that of underestimating the quality of a mentally impaired or disabled person’s life. The fact that I would not want to live such a life, or the fact that I would not regard my life as worthwhile if I were to lose my mental faculties, says little about the quality of that person’s life. For Hauerwas, the “crucial point is that the retarded do not feel or understand their retardation as we do, or imagine we would, but as they do. We have no right or basis to attribute our assumed unhappiness or suffering to them” (1986: 67). The reality of these dangers has been made evident by the willingness of physicians and hospitals to deny treatments to patients on the basis of their mental disabilities, such as the often mild mental handicap associated with Down syndrome.

The problem of asymmetrical relationships

One serious criticism of the “best interests” standard of decision-making for children is that by focusing solely on the child it overlooks the role of the family (Nelson and Nelson 1995). This can leave us with a kind of misplaced individualism, as if the only ethically important considerations are those that have to do with the child himself – intrinsic abilities like his intellect, his awareness, his physical abilities, and so on. But this is an odd way to look at children, since what is most striking about children is not their intrinsic abilities but their dependence. Children exist in relationships of dependence on their families, and with time those relationships become deeper and richer and more complex. It seems ungainly to try to consider children’s interests apart from the interests of their families because their interests are bound up together. This is more than simply saying that parents are best placed to judge the interests of their child; it is saying that very often their interests are the same. It would not be exaggerating to say that very often the worst thing that could happen to parents would be for something to happen to their children.

Because of these kinds of questions, bioethics has begun to pay more attention to families, and has tried to locate our ethical thinking about children within the parent–child relationship. Some writers have argued that what is morally important about children cannot be reduced solely to their intrinsic capacities, but instead needs also to take account somehow of their relationships with others. What matters morally about children is connected to the fact that they are loved by their parents, and what we value about human beings is not just their intellect but also their capacity for these deep human relationships.

But with some children – for example, those who are left with profound neurological damage from traumatic and anoxic brain injury – these relationships are often completely asymmetrical. Many of these children will never be able to experience the kind of love that they are given, and they will never be able to give it back. Many will never even be able to recognize their parents. What sort of respect and value should we place on these kinds of relationships? Many families seem to have made a place in their lives for such profoundly damaged children, and when it comes to questions about medical care, they want the child treated very aggressively, even when the treatment is very burdensome or painful. Here health-care workers are often torn between a desire to respect the parent–child relationship and the realization that the child is not really a participant in that relationship. Often parents of such children make such tremendous
emotional sacrifices for the child, and labor under such guilt about their responsibility for the child’s care, that physicians wonder whether it is ethically justifiable to place all the burden of decision-making on the parents.

The problem of meaning and the profoundly damaged child

Human activities and discourse are played out against a backdrop of understandings—some widely shared, some rather more fragmented—about what counts as a good life. These are not necessarily a matter of choice for us, or not entirely: they are the framework of tradition and culture within which our choices are made. Part of this framework concerns understandings about what might be called the meaning and significance of life: questions about the way in which we make sense of our lives, what gives our lives significance, beliefs about how one ought to live, stories that we tell ourselves about successful lives and failed ones (Taylor 1989). Different cultures and eras have answered these kinds of questions in different ways, of course, and many individuals will answer them differently even within contemporary Western culture. Yet some widely shared Western views may call into question the meaning of the life of a person with profound neurological damage. These questions present deep problems for decisions about the conditions under which such lives should be prolonged.

For example, when we in the West talk about what gives our lives meaning, and the reasons we have chosen to do what we have done with our lives, we often find common ground between us. Many of us talk about the people we love, such as our families, and we also talk about our work—about a calling or a sense of mission, the satisfaction of artistic creativity or taking part in a broader social or political movement. Charles Taylor (1989) calls this emphasis on family and work the “affirmation of ordinary life.” Moreover, this view locates meaning at least in part within the individual himself. That is, we ordinarily think that the meaning of our lives has something to do with us as individuals and the choices we make— with discovering and following a calling, with looking inward and finding one’s own special character or talents, with developing a relationship with God and so on.

What is important to realize, however, is that this kind of life is inaccessible to many people with profound neurological damage. If a person is incapable of appreciating and sustaining the emotional bonds of family, and incapable of finding meaning through work, she will not be able to live the kind of life that is widely regarded in our culture as meaningful. It could be otherwise, of course—for example, in a culture in which meaning is found through occupying one’s place in the natural order of things, or in which all life is seen as glorifying God, or in any number of other cosmologies. But these are not our Western cosmologies. This may help to explain why such profoundly damaged lives seem so tragic to us, even when we realize that the disabled child is not actually in pain. There is a gap between the kind of life through which the rest of us achieve those goods that make it worthwhile, and what we see as the trajectory that this child’s life will inevitably take.

This struggle to find meaning in such profoundly damaged lives places us in a difficult position when it comes to clinical decisions. On the one hand there are extremely powerful moral ideals in our culture that make us very reluctant to deny these children beneficial medical treatment. Our tradition of rights and equality makes
us wary of withholding treatment from a person because of her intelligence. Moreover, we realize that these are the most vulnerable and dependent of human lives, and that they may have deep significance for other people, such as the child’s family. Yet these ideals lead us into a kind of ethical double-talk. We feel as if these lives deserve respect, yet, at the same time, they fail to meet the criteria by which we count our own lives as meaningful. We want to protect vulnerable lives, yet our own measure of the good life for ourselves does not include a life like this.

This is not to say that we can simply decide to discard or change the broader framework of culture and tradition within which such choices are made. It is only to suggest that we are unlikely to achieve a lasting or ethically satisfying resolution to these choices unless we take these broader questions seriously.

References


Further reading