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# The Concept of Patient Autonomy

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## *Part I: The Importance of Patient Autonomy*

If there is one concept at the center of the “bioethics movement,” it is *autonomy*. The notion that patients have a moral claim to direct the course of their own medical care and to be given reasonably full information in order to make medical decisions is the most significant challenge of the bioethics movement to conventional medicine. In the United States and elsewhere, this idea has transformed the doctor-patient relationship. Just to take one example: in 1961, eighty-eight percent of physicians would not tell patients of a cancer diagnosis<sup>1</sup>; today an overwhelming majority of American physicians feel obliged to disclose that information.

Recently, however, there has been a reassessment of the importance of patient autonomy. Some are suggesting that the focus on autonomy is a distinctively American phenomenon, a reflection of American culture’s unusual diversity and its obsession with individualism. Historically the emphasis on autonomy in the United States does coincide with a period of increasing skepticism about authority in general, especially male authority, and a time of greater receptivity to the voices of people who had not previously been in the mainstream of the medical profession; in particular, women, African Americans, Hispanics, and other minorities. These developments reinforced an American tendency to challenge physicians’ authority to make medical decisions for their patients. It is reasonable to ask whether the concept of patient autonomy should play such an important role in other societies, especially those with more cohesive and widely accepted traditions.

I would argue that patient autonomy is much more than just an idiosyncratic American (or Western) cultural trend. The moral force of patient autonomy, far from being a culturally specific notion, is based on the nature of medical decisions and on respect for the dignity of persons.

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<sup>1</sup> Donald Oken, “What to Tell Cancer Patients,” *Journal of the American Medical Association* 175 (April 1, 1961): 1120-1128

Every medical decision includes both a scientific and an ethical component, but the special expertise of physicians is limited to the area of medical science. For example, a physician's training equips him or her to determine the genetic risks a couple may face in having children. But medical training cannot address the ethical question of whether these risks imply that a couple *should* refrain from reproduction. Medical decisions include a *value* dimension often requiring that medical benefits (such as continued life and health) be weighed against not only medical risks but non-medical values as well. That more invasive surgery decreases the risk of cancer recurrence by 3% compared to less invasive surgery is a medical judgment, but whether that benefit is *worth* tolerating the cosmetic and other effects of the surgery is not a question for medical science. The importance of non-medical values is even more obvious for a patient who has religious objections to certain forms of medical treatment; for example a Muslim woman who interprets Islam as forbidding treatment by male physicians.

These considerations argue against older forms of medical paternalism, where physicians restricted the freedom of their patients on the grounds that doing so was for the patients' own good. However sincere a physician's motivation, it is hard to see why the ethical values that guide medical treatment should differ, as they so often once did, only from physician to physician rather than from patient to patient. What the bioethics movement got right in emphasizing patient autonomy was the idea that a patient's ethical values, not the physician's ethical values, should control medical treatment.

There are other good reasons for respecting the autonomy of patients. Patients who are informed about their condition and who understand the reasons for a course of treatment are more likely to follow its prescriptions. Even when a physician must impart news of a bleak prognosis, honestly informing patients gives them an opportunity to put their affairs in order, to reflect on their life as a whole, and to take the practical and spiritual measures that perhaps they alone know to be necessary. Moreover, if physicians establish a practice of withholding bad news from patients, patients will be less likely to trust the reassurances of physicians when the news is *not* bad.

Nonetheless, many criticize this emphasis on patient autonomy and claim that a physician's first obligation is simply to do what is best for his patients. To offer full information and allow patients to make crucial decisions could lead many patients to make unwise choices. Obviously the moral claim of autonomy does not apply to young children, the severely mentally incapacitated, or patients who are otherwise *incompetent* and unable to exercise autonomy. But the critic of autonomy insists that even many patients who are technically "competent" would make irrational and unwise choices if physicians do not make medical decisions for them. For example, a patient who is informed of the potentially unpleasant or harmful side effects of treatment may refuse what a physician knows to be beneficial therapy.

The problem with this objection is that it offers no reason why persons should be treated as needing protection from their irrational and unwise choices once they find themselves within the medical system and yet are thought entitled to make free choices about their own lives outside the medical sphere. It is basic to the dignity of human beings that they be afforded the opportunity to make choices about their own lives. Outside the medical setting persons face decisions every bit as important as those of patients: the choice of a marriage partner; the

selection of a career; the ongoing choice of what emphasis to give to the pursuit of competing materialistic, aesthetic, ethical, and spiritual goals; even the potentially life-and-death choice of whether to see a physician in the first place. Given the frailty of human nature, even competent adults sometimes fail to make the best choices in all of these areas. If we nonetheless deem it a matter of basic human dignity to respect the freedom of people to make their own decisions in areas where primarily their own welfare is at stake, then the burden of proof is on those who would deny that freedom to people when they become medical patients.

### *Part 2: The Problems with Patient Autonomy*

An established principle of medical ethics is that patients have a moral claim to autonomy. This is sometimes conceived as a moral “right” for patients to be informed about and to control their own medical treatment. To the extent that patients have a moral claim to autonomy, physicians have an ethical obligation to impart full information to patients and to respect the decisions that they make about their own health care. As discussed in the last issue of *Medical Updates*, I regard patient autonomy as not merely an American or Western cultural value but as an ethical principle that is basic to human dignity. Nonetheless, we should not regard the obligation to respect autonomy as absolute. Nor should we think that it requires that we do whatever patients say they want. I will discuss three challenges to the idea of patient autonomy: (1) the obligation to respect the values of the medical profession; (2) the duty to consider the important role of *families*; and (3) the duty to distinguish between a patient’s current choices and that patient’s own genuine wishes. The first two challenges suggest competing values that may outweigh the value of individual autonomy while the third challenge warns against an oversimplified view of the concept of autonomy itself. Taken together, these challenges do not negate the moral value of patient autonomy but enrich our understanding of it and place the duty to respect patient autonomy in the larger context of a physician’s moral obligations.

First, physicians have a moral obligation to the medical profession that may outweigh their duty to respect a patient’s wishes. One kind of patient request that may be thought to violate the values of the medical profession, discussed in a previous issue of this journal, is a request to be helped to die.<sup>2</sup> Many would argue that a patient’s right of autonomy does not extend to assistance in dying. But requests from patients that conflict with values of the medical profession are not limited to requests for assistance in dying.

Physicians are members of a profession with its own inherent values, and it would be a mistake for them to view themselves, in a business model, simply as providers of services to a client. An extreme example, just to make the point, would be a patient who offers to pay a physician to have his arms amputated, though there is no good medical reason for the procedure. To amputate a person’s arms simply because he requests it and is willing to pay for it would not

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<sup>2</sup> See H. Hathout, “Ending Life: An Islamic Perspective” and E. Baumgarten, “Should Doctors Help Patients Die? A Philosophical Perspective,” *Medical Updates on Therapy Diagnosis and Prevention*, September 1997.

be a failure to practice good medicine; it would not be practicing the *profession of medicine* at all. Other patient requests may raise more subtle issues; for example, a young woman who requests a tubal ligation because she has decided she never wants to have children.

A more frequent and problematic occurrence is a dying patient's (or the patient's family's) asking, in desperation, for a treatment which physicians judge to be *futile*. A treatment may be deemed "futile" not only where it is physiologically impossible to implement but where it offers no hope of benefiting the patient.<sup>3</sup> If performing procedures that will do no good is contrary to the values of the medical profession, then the right of patients to autonomy does not imply that a physician must honor their requests for futile treatments.

However, we need to be careful when appealing to "futility" as a reason for denying treatment. It is tempting to invoke "futility" to deny a requested treatment not only when it offers *no* benefit to a patient but also when it is judged to offer only a *slight chance* of benefit and is thought, all things considered, to be an unwise (and even unjust) use of a society's scarce resources. The problem is not that one must accede to every patient request for expensive treatment but, rather, that one must carefully distinguish between refusing treatment because it is genuinely futile and refusing treatment when a small chance of benefit does not seem to be worth the costs. The just distribution of scarce resources is a legitimate ethical issue in medicine, but we should not obscure tough judgments about scarce resources by labeling a requested treatment as "futile" when one is actually weighing the costs versus the benefits of a treatment option. The two issues must be kept separate.

A second challenge to the idea of patient autonomy is that it ignores the importance of the family. The role of the family is receiving more attention even in the United States, where medical ethics generally emphasizes the rights of individual patients.<sup>4</sup> Consider the following case:

A cognitively competent 52-year-old man from a Vietnamese family is diagnosed with aggressive T-cell lymphoma. The physicians recommend chemotherapy and want to obtain the informed consent of the patient, but the family insists that it is against their cultural values for anyone to be told a bleak prognosis.<sup>5</sup>

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<sup>3</sup> There is much discussion in the medical ethics literature about the concept of *futility*. See, for example, Joanne Lynn and James F. Childress, "Must Patients Always Be Given Food and Water," *The Hastings Center Report* 13 (October 1983), 17-21.

<sup>4</sup> See, for example, John Hardig, "What About the Family?" *Hastings Center Report*, 20 (March-April 1990): 5-10.

<sup>5</sup> This case is discussed in Joseph M. Kaufert and Robert W. Putsch, "Communication through Interpreters in Healthcare: Ethical Dilemmas Arising from Differences in Class, Culture, Language, and Power," *The Journal of Clinical Ethics*, Vol. 8 (Spring 1997), 71-87.

Respecting autonomy would dictate the full disclosure of information since patients can make choices about their health care only if they are fully informed. But the right of patients to full disclosure of information and to free and informed consent to any medical procedure conflicts with the idea of many cultures that bad news should not be given to patients and that it is families, rather than patients, who should control medical information. In the United States it is not only many *patients* who retain values rooted in a culture that may be less individualistic than that of mainstream America; it is many *physicians* practicing in American hospitals who retain the more family-oriented values of their culture of origin. In many cases, then, there are two intertwined moral values that compete with the obligation to respect patient autonomy: the duty to respect the needs and interests of families and the duty to respect a diversity of cultural viewpoints.

One partial way to reconcile individual and family values is to recognize that often patients themselves want their families to make decisions for them and would even choose to waive their right to be informed about their prognosis. We need to develop ways for individuals to convey *early* in their care the degree to which they want to be informed about, and retain control over, their treatment. Some patients may exercise their autonomy by *choosing* to let others make decisions for them. We can show the most sensitive regard for patient autonomy by respecting the diversity of ways in which patients choose to exercise it. This is not a license to ignore a patient's wishes in favor of the family's. It is an imperative to go beyond autonomy as an abstract concept and to develop creative procedures for determining how to respect the choices of real patients who exercise their autonomy not as isolated selves but as human beings embedded in a variety of family and cultural contexts.

A third challenge to a simple notion of patient autonomy is that it fails to recognize that a patient's current choice might not represent what even the patient himself *truly* wants. The effects of illness, or of the treatment itself, could distort a patient's perceptions. Even though such a patient's capacities might not be compromised to the point that he would be considered incompetent, he might, for example, refuse a treatment that his "true self" would have accepted. In such circumstances, respecting autonomy is not a simple matter of acceding to the patient's currently expressed wishes. A physician who has a longstanding relationship with a patient may be in a good position to act on behalf of the patient's own enduring values, overriding that patient's currently expressed wish. In a sense the physician is acting in the hope of receiving retroactive consent from the patient. Needless to say, this provides no sanction for physicians to act contrary to a patient's expressed will by imposing *their own* values on the patient. The burden is on the physician to show that there is some evidence that the patient himself does not *truly* want what he is asking for (or truly does want the treatment he is refusing). To avoid an overly simplistic notion of respecting patient autonomy, we will need to do more to learn about the underlying values of our patients. Family conferences are helpful, but we also need to expand the standard "medical history" to include a greater understanding of the human person behind the patient.

In sum, patient autonomy is an important ethical principle in medicine. However, it should neither be conceived as a value that necessarily overrides all others nor as a simplistic directive always to comply with the expressed wishes of our patients.

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