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## A Relational Approach to Autonomy in Health Care

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Respect for patient autonomy (or self-direction) is broadly understood as recognition that patients have the authority to make decisions about their own health care. The principle that insists on this recognition is pervasive in the bioethics literature: it is a central value within virtually all the leading approaches to health care ethics, feminist and other. It is not surprising, then, that discussions of autonomy constantly emerged within our own conversations in the Network; readers will recognize that autonomy is woven throughout the book in our various approaches to the issues we take up. It is, however, an ideal that we felt deeply ambivalent about, and, therefore, we judged it to be in need of a specifically feminist analysis.

In this chapter, I propose a feminist analysis of autonomy, making vivid both our attraction to and distrust of the dominant interpretation of this concept. I begin by reviewing some of the appeal of the autonomy ideal in order to make clear why it has achieved such prominence within bioethics and feminist health care discussions. I then identify some difficulties I find with the usual interpretations of the concept, focusing especially on difficulties that arise from a specifically feminist perspective. In response to these problems, I propose an alternative conception of autonomy that I label "relational" though the terms socially situated or contextualized would describe it equally well. To avoid confusion, I explicitly distinguish my use of the term relational from that of some other feminist authors, such as Carol Gilligan (1982), who reserve it to refer only to the narrower set of interpersonal relations. I apply the term to the full range of influential human relations, personal and public. Oppression permeates both personal and public relationships; hence, I prefer to politicize the understanding of the term relational as a way of emphasizing the political dimensions of the multiple relationships that structure an individual's selfhood, rather than to reserve the

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term to protect a sphere of purely private relationships that may appear to be free of political influence. I explain why I think the relational alternative is more successful than the familiar individualistic interpretation at addressing the concerns identified. Finally, I briefly indicate some of the implications of adopting a relational interpretation of autonomy with respect to some of the issues discussed elsewhere in this book, and I identify some of the changes that this notion of relational autonomy suggests for the delivery of health services.

## The Virtues of a Principle of Respect for Patient Autonomy

It is not hard to explain the prominence of the principle of respect for patient autonomy within the field of health care ethics in North America: respect for personal autonomy is a dominant value in North American culture and it plays a central role in most of our social institutions. Yet, protection of autonomy is often at particular risk in health care settings because illness, by its very nature, tends to make patients dependent on the care and good will of others; in so doing, it reduces patients' power to exercise autonomy and it also makes them vulnerable to manipulation and even to outright coercion by those who provide them with needed health services. Many patients who are either ill or at risk of becoming ill are easily frightened into overriding their own preferences and following expert advice rather than risking abandonment by their caregivers by rejecting that advice. Even when their health is not immediately threatened, patients may find themselves compelled to comply with the demands of health care providers in order to obtain access to needed services from health professionals who are, frequently, the only ones licensed to provide those services (e.g., abortion, assistance in childbirth, legitimate excuses from work, physiotherapy).2

Without a strong principle of respect for patient autonomy, patients are vulnerable to abuse or exploitation, when their weak and dependent position makes them easy targets to serve the interests (e.g., financial, academic, or social influence) of others. Strong moral traditions of service within medicine and other health professions have provided patients with some measure of protection against such direct harms, though abuses nonetheless occur. Most common is the tendency of health care providers to assume that by virtue of their technical expertise they are better able to judge what is in the patient's best interest than is the patient. For example, physicians may make assumptions about the advantages of using fetal heart monitors when women are in labor without considering the ways in which such instruments restrict laboring-

women's movement and the quality of the birthing experience from their perspective. By privileging their own types of knowledge over that of their patients (including both experiential knowledge and understanding of their own value scheme), health care providers typically ignore patients' expressed or implicit values and engage in paternalism<sup>4</sup> (or the overriding of patient preferences for the presumed benefit of the patient) when prescribing treatment.

Until very recently, conscientious physicians were actually trained to act paternalistically toward their patients, to treat patients according to the physician's own judgment about what would be best for their patients, with little regard for each patient's own perspectives or preferences. The problem with this arrangement, however, is that health care may involve such intimate and central aspects of a patient's life-including, for example, matters such as health, illness, reproduction, death, dying, bodily integrity, nutrition, lifestyle, self-image, disability, sexuality, and psychological well-being-that it is difficult for anyone other than the patient to make choices that will be compatible with that patient's personal value system. Indeed, making such choices is often an act of self-discovery or self-definition and as such it requires the active involvement of the patient. Whenever possible, then, these types of choices should be made by the person whose life is central to the treatment considered. The principle of respect for patient autonomy is aimed at clarifying and protecting patients' ultimate right to make up their own minds about the specific health services they receive (so long as they are competent to do so). It also helps to ensure that patients have full access to relevant information about their health status so that they can make informed choices about related aspects of their lives. For example, information about a terminal condition may affect a person's decisions to reproduce, take a leave of absence from work, seek a reconciliation from estranged friends or relatives, or revise a will.

Although theorists disagree about the precise definition of autonomy,5 there are some common features to its use within bioethics. In practice, the principle of respect for patient autonomy is usually interpreted as acknowledging and protecting competent patients' authority to accept or refuse whatever specific treatments the health care providers they consult find it appropriate to offer them (an event known as informed choice). Since everyone can imagine being in the position of patient, and most can recognize the dangers of fully surrendering this authority to near strangers, it is not surprising that the principle of respect for patient autonomy is widely endorsed by nearly all who consider it. Despite different theoretical explanations, the

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overwhelming majority of bioethicists insist on this principle as a fundamental moral precept for health care. Support is especially strong in North America, where it fits comfortably within a general cultural milieu in which attention to the individual and protection of individual rights are granted (at least rhetorical) dominance in nearly all areas of social and political policy.<sup>6</sup> Both Canadian and U.S. courts have underlined the importance of protection of individual rights as a central tenet of patient-provider interactions, making it a matter of legal as well as moral concern.

Further, the principle requiring respect for patient autonomy helps to resolve problems that arise when health care providers are responsible for the care of patients who have quite different experiences, values, and world views from their own; under such circumstances, it is especially unlikely that care givers can accurately anticipate the particular needs and interests of their patients. This problem becomes acute when there are significant differences in power between patients and the health care professionals who care for them. In most cases, the relevant interactions are between patients and physicians, where, typically, patients have less social power than their physicians: doctors are well educated and they tend to be (relatively) healthy and affluent, while the patients they care for are often poor, and lacking in education and social authority. In fact, according to most of the standard dichotomies supporting dominance in our culture-gender, class, race, ability status-odds are that if there is a difference between the status of the physician and the patient, the physician is likely to fall on the dominant side of that distinction and the patient on the subordinate side. The tendency of illness to undermine patients' autonomy is especially threatening when the patients in question face other powerful barriers to the exercise of their autonomy, as do members of groups subject to systemic discrimination on the basis of gender, race, class, disability, age, sexual preference, or any other such feature. A principle insisting on protection of patient autonomy can be an important corrective to such overwhelming power imbalances.

Moreover, physician privilege and power is not the only threat to patient autonomy. Increasingly, the treatment options available to both patients and physicians are circumscribed by the policies of governments and other third-party payers. In the current economic climate, those who fund health care services are insisting on ever more stringent restrictions on access to specific treatment options; physicians find themselves asked to perform gate-keeping functions to keep costs under control. In such circumstances, where patient care may be decided by general guidelines that tend to be insensitive to the particular circumstances of specific patients, and where the financial interests of the institution being billed for the patient's care may take priority over the patient's needs or preferences, the principle of respect for patient autonomy becomes more complicated to interpret even as it takes on added importance.

The principle of respect for patient autonomy can also be seen as an attractive ideal for feminists because of its promise to protect the rights and interests of even the most socially disadvantaged patients. Feminist medical historians, anthropologists, and sociologists have documented many ways in which health care providers have repeatedly neglected and misperceived the needs and wishes of the women they treat.7 The ideal of respect for patient autonomy seems a promising way to correct much that is objectionable in the abuses that feminist researchers have documented in the delivery of health services to women and minorities. Most feminists believe that the forces of systematic domination and oppression work together to limit the autonomy of women and members of other oppressed groups; many of their political efforts can be seen as aimed at disrupting those forces and promoting greater degrees of autonomy (often represented as personal "choice") for individuals who fall victim to oppression. For example, many feminists appeal at least implicitly to the moral norm of autonomy in seeking to increase the scope of personal control for women in all areas of their reproductive lives (especially with respect to birth control, abortion, and childbirth, often discussed under a general rubric of "reproductive freedom" or "reproductive choice").

In a world where most cultures are plagued by sexism, which is usually compounded by other deeply entrenched oppressive patterns, fundamental respect for the humanity, dignity, and autonomy of members of disadvantaged groups, though extremely fragile, seems very important and in need of strong ethical imperatives. Feminists strive to be sensitive to the ways in which gender, race, class, age, disability, sexual orientation, and marital status can undermine a patient's authority and credibility in health care contexts and most are aware of the long history of powerful medical control over women's lives. They have good reason, then, to oppose medical domination through paternalism. Promotion of patient autonomy appears to be a promising alternative. Understood in its traditional sense as the alternative to heteronomy (governance by others), autonomy (self-governance) seems to be an essential feature of any feminist strategy for improving health services for women and achieving a nonoppressive society.

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## Problems with the Autonomy Ideal

Nonetheless, despite this broad consensus about the value of a principle of respect for patient autonomy in health care, there are many problems with the principle as it is usually interpreted and applied in health care ethics. As many health critics have observed, we need to question how much control individual patients really have over the determination of their treatment within the stressful world of health care services. Even a casual encounter with most modern hospitals reveals that wide agreement about the moral importance of respect for patient autonomy does not always translate into a set of practices that actually respect and foster patient autonomy in any meaningful sense. Ensuring that patients meet some measure of informed choice-or, more commonly, informed consent-9 before receiving or declining treatment has become accepted as the most promising mechanism for insuring patient autonomy in health care settings, but, in practice, the effectiveness of the actual procedures used to obtain informed consent usually falls short of fully protecting patient autonomy. This gap is easy to understand: attention to patient autonomy can be a time-consuming business and the demands of identifying patient values and preferences are often sacrificed in the face of heavy patient loads and staff shortages. In addition, health care providers are often constrained from promoting and responding to patients' autonomy in health care because of pressures they experience to contain health care costs and to avoid making themselves liable to lawsuits. Moreover, most health care providers are generally not well trained in the communication skills necessary to ensure that patients have the requisite understanding to provide genuine informed consent. This problem is compounded within our increasingly diverse urban communities where differences in language and culture between health care providers and the patients they serve may create enormous practical barriers to informed choice.

There are yet deeper problems with the ideal of autonomy invoked in most bioethical discussions. The paradigm offered for informed consent is built on a model of articulate, intelligent patients who are accustomed to making decisions about the course of their lives and who possess the resources necessary to allow them a range of options to choose among. Decisions are constructed as a product of objective calculation on the basis of near perfect information. Clearly, not all patients meet these ideal conditions (perhaps none does), yet there are no satisfactory guidelines available about how to proceed when dealing with patients who do not fit the paradigm.