SICK AUTONOMY

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ABSTRACT Complex social and economic forces have placed patient autonomy at the center of medical ethics, and thereby displaced an older ethic of physician beneficence. This development arose, and is sustained, by waning trust in the traditional doctor-patient relationship. As patients have increasingly become clients and consumers, a contract basis for medical care has put the ancient covenant of care in jeopardy. Here, a philosophical approach to harmonize the apparent conflicting claims of patient autonomy and physician beneficence is offered by demonstrating that autonomy need not be understood as protecting a threatened identity. If persons are regarded as atomistic, certain defensive notions of individualistic rights-based autonomy prevail; if a relational construction of personal identity is employed instead, then respect for autonomy becomes part of a wider morality of relationship and care. By reconfiguring trust within this latter understanding of personhood, bioethics better balances its concerns over choices and actions with those of relationship and responsibility. Neither atomistic autonomy nor the ethics of responsibility can claim hegemony, for they are mutually interdependent, and a complete account of medicine's moral axis requires that they be integrated. This reorientation is crucial for reasserting the ethos of clinical medicine, whose fundamental mandate remains the care of others.

THE MOST INTERESTING FACT about contemporary medical ethics is that it exists at all. Born as a formal discipline about 30 years ago, its initial concerns reflected complex social factors, all of which seemed to converge on a newfound suspicion of authority (Jonsen 1998). The Vietnam era was marked by the unsettling of confidence in government, education, business, and medicine. To address the suspicions raised in the moral climate of mistrust, medical ethics

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became the articulation of both an ancient moral philosophy governing the doctor-patient relationship—beneficence—and a new demand concerning the respect of patient autonomy in the guise of informed consent (Faden and Beauchamp 1986). In the explicit elaboration of these principles, their interaction and balance, bioethicists found themselves embroiled in debate as to what, indeed, medicine's ethics might be. The dominant voice became the advocacy of patient autonomy, not only because it was the most easily extrapolated from our rights-based politico-judicial culture, but because it best compensated for what was missing: trust. Whereas trust had hitherto been the implicit moral understanding governing physician behavior and patient delegation of authority, in the age of Johnson and Nixon, trust required both new definition and novel substitutes for its usual function. In short, medical ethics generally, and patient autonomy in particular, filled an ethical lacuna left by the abandonment of trust, and patient autonomy became the sacrosanct principle governing medical ethics in most dire need of protection.

Autonomy, a relatively new moral tenet, claims a dual heritage. It first derives from notions of Puritan personal religious responsibility and conscience (balanced against the obligations of persons to a community designed to serve God) (Shain 1995); a second source, again religious in origin, originates in natural law's endowment of persons with natural rights, self-governance, and the freedom to pursue their own dictates (but again, in its original Kantian formulation, one defined in relation to duties to others) (Schneewind 1998). In either tradition, autonomy was stretched between two poles: individualistic interests, on the one hand, and duties to others, on the other. This inner tension has been variously balanced in different cultures and in history. In regard to contemporary health care, Americans have opted for individual "choice." This is not idiosyncratic to medicine, for in the United States, individual rights increasingly have been regarded as sacrosanct, and correspondingly the respect for persons has shifted from one centered on communal responsibility—both the citizen's identification with the state and the state's responsibility for the citizen—to one focused on autonomy in its more atomistic interpretation (Sandel 1996). An ethos of responsibility for others ("caring") has consequently been subordinated to a preoccupation with protecting the rights of the individual. And in that realignment, the moral identity of the physician has been clouded.

Given the current dominant legal and political culture based upon the protection of individual rights, autonomy as a governing philosophical principle has been prioritized in medical ethics at the expense of other ethical principles for several reasons. First, autonomy—as opposed to beneficence, justice, or nonmalfeasance—is easily applied and codified, and thus its directives are comparatively straightforward and uncontroversial. Indeed, "finding a way to apply ideals of autonomy in the clinical setting becomes a technical problem" (Root-Wolpe 1998, p. 46). Second, as a result of the erosion of trust between patient and physician, so-called "rituals of trust" have emerged as substitutes for "organic trust"

(Root-Wolpe 1998, p. 50). Informed consent has become the vehicle of such rituals, and they have assumed the legalistic form of a contract, whose formulation as a code brings clarity to what had hitherto been an implicit understanding (or covenant) of trust (May 1983; Veatch 1972, 1983a, 1983b).

Third, patient autonomy, rather than being corrosive of professional privilege, may actually re-enforce physician authority:

> Autonomy tends to be a negative right (in that a person has the right to refuse treatment) rather than a positive right (a person cannot generally demand a particular treatment). Physicians are still the translators and filterers of information to their patients, patients still generally defer to physician recommendations, and physicians remain the medical experts . . . for definitions of disease. (Root-Wolpe 1998, p. 52)

Indeed, physicians have incorporated informed consent into their practice as a means of improving patient satisfaction, and perhaps most importantly, shifting responsibility to the patient provides a potent tactic to combat malpractice suits (Root-Wolpe 1998, p. 52).

A fourth, and more insidious, interpretation maintains that the government and the medical establishment have made autonomous, informed patients into consumers as health care has been turned into a commodity or market issue (Wildes 2001). This shift of identification carries a different sense of patient responsibility, and thus avoids difficult reform or critiques of the assumptions underlying health care (Fox 1994). And finally, the power of the autonomy principle in medical ethics must also be understood in terms of its prominence as a political solution to the claims of various religious moralities in the American context. Autonomy is an instrumental, political, and moral response to the challenge of finding political harmony in a highly individualistic, pluralistic, and religious society (Fox 1990, p. 209).

But autonomy is inadequate, by itself, to account for medicine's moral calling because of two failings. First, from the patient's perspective, the notion of autonomy is frequently distorted in the clinical setting (O'Neill 2002; Schneider 1998). Patients necessarily relinquish their full autonomy to experts, and in this regard, they cannot make truly autonomous—i.e., self-reliant, fully informed—decisions, but must instead ultimately rely on the competence and good will of their health care providers to represent their best interests. Second, autonomy as a construct cannot account for the ethical responsibilities of the care giver (May 1983; Pellegrino and Thomasma 1988; Tauber 1999). The sense of responsibility exhibited by physicians and nurses arises from their commitment to care for others, not primarily from a set of rules designed to protect patient autonomy. Respect for the person in this setting is implicit to the professional role. This ethic of compassion regards autonomy as only one of a number of moral principles governing the caring relationship, among which it finds in beneficence a more resonant expression of medicine's fundamental ethos.

Thus autonomy's dominance has been widely regarded as both a judicial and philosophical problem, not only because its practical application must be balanced with other moral tenets, but because patient expectations and physician responsibilities are oriented by the dominance of one principle or another as determined by a complex sociology of clinical practice. Doctors are accountable not only to their patients, but to their employers and their investors; managed care plans and insurance companies; hospitals and professional associations; and, overriding each of these domains, the government and its laws that monitor professional competence, legal and ethical conduct, and adequacy of access (Emanuel and Emanuel 1996). As if these diverse domains of accountability were not enough, there are at least three different kinds of designs in which these relationships are enacted: a professional hierarchy, which answers the demands of professional services to provide for the well-being of the patient (e.g., licensure, certification, malpractice, etc.); an economic network, which defines health care as a commodity with certain performance standards and financial expectations and restrictions; and finally, a political domain, where policy decisions concerning health care delivery are made and executed. Physicians are increasingly aware of these mixed responsibilities, and critics are beginning to address potential ethical conflicts posed by the corporate character of medical practice (Jacobson and Cahill 2000), but this setting is only the most obvious of a more general ambiguity regarding the contemporary relationship between doctors and their patients.

A key challenge is how to recover the "patient" in these complex settings by a reexamination of how fiduciary responsibilities apply. For patients, even when called clients, customers, or consumers, are still persons seeking aid from other individuals, physicians, who are implicitly entrusted to act on their behalf. The disaffection with managed care largely rests on the growing tension of split responsibilities of doctors, who, on the one hand, are often employed by a market-driven company seeking to reduce costs (and increase profits), and, on the other hand, have a relationship with their patients that calls upon a more ancient affiliation, where the cost issue is subordinated, if not moot. And when we look at medical tort cases, patient recourse for bad outcomes is limited by and large to malpractice, not breach of fiduciary responsibility. In other words, the law has directed complaint away from the general protections offered by fiduciary law and focuses instead on adjudicating technical incompetence and mal-execution (Rodwin 1995). Physician fiduciary responsibilities are restricted only to maintaining patient confidentiality, disclosing financial conflicts of interest, and prohibiting the abandonment of patients. Good Samaritan laws protect doctors from suits arising from nonconsensual care only in the most dire of circumstances; empathy has no legal basis whatsoever. Not surprisingly then, telling lapses in judiciary medical ethics appear as the discourse stutters when addressing the legal basis of beneficent concerns.

While medical ethics accommodates empathy under the banner of "beneficence," this hardly does justice to the moral imperative empathy commands, and the very language of medical ethics is too often inappropriate for *moral* discourse. As Carl Elliot (1999) has written:

> The law is the l*ingua franca* of bioethics. The language in which bioethics is discussed revolves around largely quasi-legal notions such as consent, competence, rights to refuse treatment, to have an abortion and so on. Many writers have targeted the language of rights and autonomy for special criticism, suggesting that we need to develop an alternative vocabulary. This is an understandable suggestion, but I also think the law's influence on bioethics has been much deeper and more subtle. It has given us a picture of morality as somehow like the law in structure—for example, as a set of rules that govern interactions between strangers. This picture of morality may work adequately as long as we are in fact talking about interactions between strangers, especially strangers whose relationship is adversarial. But it overlooks many kinds of questions that are crucial to morality, and it distorts many others. (p. xxviii)

As a result of its judicial-political-commercial contexts, medical ethics is like a lopsided table with four legs: although autonomy, beneficence, justice, and nonmalfeasance each claim consideration, autonomy usually trumps other contenders (Beauchamp and Childress 2001) to "indisputably . . . become the central and most powerful principle in ethical decision making in American medicine" (Root-Wolpe 1998, p. 43). But, as Stephen Toulmin (1981) cogently argues, authentically moral relations exist only between intimates, and consequently the discourse designed for controversy is not adequate for or befitting relations governed by rules of intimacy and commitment. Much of medical ethics is conducted with this critical contradiction and, many would say, deficiency.

So despite its apparent dominance, autonomy is under constant challenge, both in the practical life of the clinic and in scholarly discourse. I have discussed elsewhere a philosophical strategy for placing autonomy in closer alignment with the communal interests of distributive justice (Tauber 2002c, 2003); here, I wish to present a basis by which autonomy and beneficence (or responsibility) may be better balanced. Instead of using largely ineffective defensive measures to protect patient autonomy, we should instead focus on how to reconfigure the doctor-patient relationship, in order to preserve patient dignity and to foster an ethics of care without slipping into discarded paternalism (Kultgen 1995). Indeed, the fundamental challenge is to better protect patient autonomy by substituting the rituals of trust for a more meaningful relationship of care. To do so, we must explore how autonomy is a characteristic of persons, and how the understanding of personhood then determines a particular orientation about rights and duties. With such a philosophical dissection, we might better recognize autonomy's inner ambivalence as it addresses individual interests and concerns in the face of duties determined by communal demands.

TWO FACES OF AUTONOMY

Two notions of selfhood determine different conceptions of autonomy: the "social self" and the "atomistic self" (Sandel 1982; Taylor 1989). The proponents of the social self school maintain that persons are fundamentally social, i.e., identity is conferred by the myriad relations of gender, class, socioeconomic status, religion, age, etc. To be sure, there is a biological substrate of personality and cognitive abilities, but these are formless until socialization ensues and molds the potential of character into a person. From this perspective, it is meaningless to attempt to dissect away the prevailing social, cultural, historical, and psychological contingencies that make up human experience to reveal a core self, an identity that somehow resides inured from experience (Mead 1934). Alternatively, those who advocate an "atomistic self" conception maintain that underlying our social identities is a deeper inner sense of identity, one that is, in a sense, isolated and inviolate. In this view, persons have complementary identities, individual and cultural, and the former confers a uniqueness distinct from the social roles played.

From these different orientations, autonomy assumes different meanings. Atomistic autonomy begins with an assumption of human separateness, where freedom is fundamental. So, if the self is so-defined—i.e., self-reliant and severely independent—autonomy exercises radical self-direction, and the array of competing communal principles that both identify the self and empower it to act are thereby subordinated. On the other hand, if the self is understood as a confluence of relationships and social obligations that are constitutive to identity, then autonomy loses its hegemony and may readily be coordinated with other moral principles governing the self acting within a social context. This generally takes the form of recognizing that autonomous choices must be made in response to obligations, duties, and responsibilities. (Ironically, perhaps, this was autonomy's original commitment as understood by Kant [O'Neill 2002; Schneewind 1998].) And here, the ethics of responsibility assume a prominent position, for care begins with an assumption of human connectedness, and its goal is to correct detachment, for in this view relationships are fundamental and must be protected (Gilligan 1982; Noddings 1984). In short, the contested understanding of patient autonomy rests upon differing presuppositions about personhood, and the task is to find their reconciliation.

One approach is to understand that "autonomy" may be regarded as a primordial product of social relationships, and not necessarily only a consequence of a severe individualism (Clement 1996; Mackenzie and Stoljar 2000). According to "relational autonomy," isolated persons are not only incomplete individuals, but their isolation beleaguers them with burdens that actually impede their self-actualization. Accordingly, autonomy is "not merely an internal, or psychological characteristic, but also an external, or social" one (Clement 1996, p. 22). This insight highlights a fundamental social fact: no one is fully autonomous, inasmuch as everyone relies on a vast social network to provide goods and services, and each of us enjoys (or regrets) complex and numerous interpersonal relationships. Thus an "autonomous individual" is not some Robinson Crusoe stranded alone on an island, but rather a person who *exercises* autonomous choices. Thus we distinguish "autonomous persons" from "autonomous acts." The latter is a characteristic or property of persons, and the former is a nebulous ideal that has no bona fide standing in the real world of social relations. So part of the murky philosophy enveloping "autonomy" is cleared by recognizing that none of the criteria defining autonomy precludes interdependence: (1) decision-making must be one's own, and free of coercion; (2) to fulfill the first requirement, one must critically reflect on one's choices to ensure that they are solely self-motivated; and (3) autonomous choices bequeath responsibility for those choices. Given the everyday limits and opportunities of social intercourse, autonomy must be placed within a construct in which supporting relationships enable individuals to achieve various degrees of autonomy and thereby act freely by the criteria presented above. The dependency of patients is a paramount case of such reliance on others.

By emphasizing the ultimate relational character of autonomy, free choice and responsibility are seen as complementary to each other and thus mutually interdependent. This is an important corrective, for the focus on an excessively individualistic account of autonomy ignores the social conditions necessary for self-determination, with the result that moral knowledge and action are seen as exclusively individual achievements, products of rational reflection independent of their social locus. The ethic of care offers a corrective to this severely atomistic orientation by emphasizing moral knowledge as the product of the interdependence of persons and their mutual negotiation of options and actions.

In summary, autonomy may be configured from two different conceptions of personal identity. If individuals are thought of as radically individualistic, or atomistic, then a particularly jealous understanding of personal rights is asserted. On the other hand, if the self is understood as arising from social relationships and the cultural context defines moral options, then autonomy rights are defined in a more complex manner, in terms of moral obligations, duties, and responsibilities (Baier 1994, 1997). It is plain that each orientation has its own claim to defining personal identity and the moral agency bequeathed by that conception. The lesson to be drawn is that "autonomy" has no singular definition or standing, and thus it must find its place in the flux of social demands and claims that balance the needs of individuals and their society in a complex dynamic relationship. Neither atomistic autonomy nor the ethics of responsibility can claim hegemony, for they are mutually interdependent, and a complete account of the moral axis in patient care requires that they be integrated. It seems clear that *both* ethics capture something real and important about morality, and that insisting on ranking these principles trivializes the contributions of the principle deemed less basic (Clement 1996).

TRUST

The major question underlying medical ethics is the very definition of moral agency, the elusive interpretation of the self, which is historically conceived in a polarized construction: at one end is an atomistic notion of personhood, in which personal autonomy must be jealously protected, and, at the other end is a social conception of the person, whose identity and associated freedom and autonomy cannot be understood independent of those relationships which are constitutive of individuality. From this debate emerges the philosophical problem of trust, which offsets autonomy—or to put it another way, trust accompanies dependency and thus serves as the countervailing balance to independence. The insecurity engendered by the dependence of being ill is a hallmark of human experience, but the ways in which Americans now deal with that insecurity, which in other terms is an assault on their selfhood, is new. Informed consent and patient rights are the manifestation of that different response, which is oriented by the dominance of the atomistic understanding of selfhood.

The quest for patient autonomy is a symptom of a deeper problem, the loss of trust. At least traditionally, clinical care was built on trust, the commitment of physicians to serve their patients, and the patients' expectation that their best interests will be ministered to. Autonomy sets its sights on another agenda altogether, one marked by freedom and independence that was forged in the fires of advocacy and conflict, dynamics foreign to medicine. In the face of the rising tide of patient rights, medicine has been forced to adjust to this interloper. Thus a basic challenge in medical ethics is to conceptualize autonomy and trust so that they are mutually supporting.

But prescriptions are not readily forthcoming, for the problem of trust is a culture-wide phenomenon (Seligman 1997). Advocacy of patient rights is a particular *response* to mistrust, as contemporary medicine has been caught up in a general social crisis, in which each of our basic institutions—government, education, medicine—has been forced to adjust to a new balance of power and expectations between power brokers and their constituency (in this case health care practitioners and patients). Autonomy-based medical ethics originated from disgruntled patients and their advocates, who reacted against what they regarded as physician arrogance and drew upon legal precedent to demand informed consent in medical practice. The pendulum has swung forcefully and unwaveringly towards patient autonomy against the older tradition of physician paternalism (Katz 1984). This assertion of a new doctor-patient relationship has reoriented medical practices to the revised needs of individual patients, and legalistic contracts have dominated older covenants primarily because patterns of trust had been broken. As Robert Root-Wolpe (1998) wryly observes, "informed consent is the modern clinical ritual of trust" (p. 48). He might have added, medical ethics is an expression of the erosion of trust between physician and patient and no ritual can fill that lacuna. Efforts to assure patient autonomy and offer protections against possible abuse have failed to reestablish trust. Onora O'Neill (2002), after exhaustively reviewing the relevant surveys and studies, correctly observes that public trust in medicine "has faltered *despite* successes, *despite* increased efforts to respect persons and their rights, *despite* stronger regulation to protect" (p. 11), and then she asks the next expected question: why?

Obviously, there are many answers, but I believe any set of explanations must include how autonomy, as understood in its atomistic definition, cannot substitute for trust in clinical care, because the disparity of power between patient and doctor is just too great. Patients cannot avoid delegating authority, entrusting themselves to others, and then fretfully hoping that their best interests will be protected (Schneider 1998). In contemporary America, such faith in powerful others is increasingly regarded as inadequate, and legalistic solutions have been imposed. I would hardly oppose such protective measures, but they do not really address the underlying moral problem. And here we come to the heart of my concern: if physicians allow the power politics of rights to dominate the ethics of care, they inadvertently lend support to the forces undermining their own ability to attend to their patients. The relational ethics outlined here is an approach to bring physician and patient into closer moral proximity, emphasizing the reciprocal exchange of trust and obligation that cannot be divided in the doctor-patient dyad.

No doubt patient autonomy has legitimate standing in medical ethics, and the challenge is not to assert its premier position, but rather to find its rightful place among the various principles governing medical practice. To do so, a libertarian interpretation of autonomy that assumes a Platonic ideal "Form of Independence" must be discarded as too simplistic. In deliberations dominated by this form of the autonomy principle, the individualistic autonomy "template" overdetermines medical ethics by legal and commercial interpretations. Alternatively, the social identification of persons informs relational autonomy with an ethic that balances responsibility and duties with self-governance. This construction places moral action within a context of persons acting in relation to each other, so that autonomy is matched with responsibility. This coupling occurs both within the action of an individual (who must balance self-interest with responsibility to others), and in the actions of two persons, where one may delegate choice to another, who then in response (i.e., responsibly) addresses those interests or needs.

CONCLUSION

The prescription of patient autonomy could hardly repair the ills that afflicted health care in the 1960s, and there is little reason to suppose it might have. Autonomy is only one element in the mosaic of moral praxis, and whether regarded from political, legal, or cultural perspectives, autonomy's meanings are in large measure defined by how individual rights are configured in balance with other moral principles, such as beneficence and distributive justice. This dialectical relationship of autonomy with other communal moral precepts has been evident throughout American history and in virtually all expressions of contemporary American life (Sandel 1996). To be sure, autonomy serves a vital judicial-legal function in our system of medical law, and this may well account for its continued importance, but the moral depth of our notions of respect for persons more directly reflects a deep social and religious commitment for the welfare of others. Ironically, patients under the individualistic autonomy model assume a defensive posture, one at potential odds with those moral concerns most prominent for the doctor or nurse, whose primary ethical affiliation is to care—beneficence—or, in another format, responsibility (Pellegrino and Thomasma 1988; Tauber 1999).

The conundrum of autonomy in medicine arises from a faulty extrapolation of a particular form of American political and judicial individualism, where a relational dialectic is obscured or even ignored. My concern is not that patients should not or cannot exercise autonomous choices, but rather that "informed consent" is a ritual that too often has little substance and instead becomes a conceit, or at best an aspiration (Schneider 1998). Given the disparity between the knowledge and technical expertise of doctor and patient, the basis of cooperative decision-making ordinarily is an irredeemable obstacle to full patient participation in deciding clinical options. So my worry is that there is not enough patient autonomy—true self-governance—and more saliently, that there cannot be, given the authority of physician experience.

Given this perspective, and my abiding commitment to protect freedom of choice, I endorse a patient-centered medicine (Barbour 1995; Tauber 2002a), which places the physician as an advocate of care, a facilitator who identifies moral concerns and then helps address them (Tauber 2002d, 2002b). Precisely because informed consent and freedom of choice are crucial to the care of the ill, physicians must develop an increased moral self-reflection and strengthen their fiduciary responsibility towards their patients. Fundamental to this realignment is a medical ethics that focuses upon the problem of trust, one that configures a philosophy of medicine based on recognizing that the key issue in clinical care is not the protection of some severe form of individualism, but rather the exercise of autonomous choice within a moral context of trust, understanding, and enabling. This formulation not only offers the opportunity to recapture medicine's ancient moral imperative, but it more appropriately addresses the reality of clinical care.

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