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AUTONOMY AND RIGHTS: DIGNITY AND RIGHT

*John A. Most, M.D.**

It was a nice and appealing concept. It was easy to talk of in glowing terms as long as it stayed properly in the realm of theory. But when autonomy began intruding into raw economics, first in the realm of managed care and then in the minds of those who were trying to cobble out a system of medical care for all that would, as the pundits have it, "play in Peoria," it became a cause of consternation.

The ascent to the first place of the concept of autonomy among the precepts of bioethics prefigures the tension that plagues discussion and debate about the future of medical care, its spiralling costs, and the national concern about how the bills will be paid. While it is not unambiguously conceded that a system of rationing or strict allocation will be found necessary, the realization is growing that we cannot, under any system, provide everything wanted by all comers without the imposition of some limits.

The ordination of respect for dignity emerged from the Belmont Conference in the 1970s as the first principle of bioethics. It shortly underwent a subtle transmutation. Autonomy is not, to be sure, a synonym for dignity, but a description of one of its attributes. Born of concepts enunciated by Emmanuel Kant and John Stuart Mill as the right to be let alone, autonomy has grown from the right to have nothing done to one's person without one's consent to a positive moral right to do what one wants, or to claim—exercise a right—to have whatever treatment is available. Thus, from the strength of a negative moral imperative, some have sought to extend the same power to the positive side. Which is to say, in the case of medical care, that one has a right to have anything done that one wishes. This is a utilitarian change that even Mill would have been unlikely to accept.

The probable reason for this shift of emphasis to autonomy was a reac-

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tion to the rampancy of paternalism; the notion that the doctor knows best and the patient takes whatever has been decreed.

The change in the way we think about dignity—the canonization of a single attribute and its translation into the language of rights—is now becoming troublesome. It is necessary to make distinctions. The most needed distinction concerns the essence of dignity.

Dignity is an inseparable element of humanness. It is both inherent and necessary to our humanity that we possess dignity. It is desirable that we invoke, as a quality of that dignity, the right to be let alone. As a negative moral imperative this is much more binding than its positive counterpart, the right to do what one wishes (or to claim to have done to one anything one wishes). This carries a weaker force, and one may compare it to the obligation to do no harm, which is absolute, and the duty to do good, which is binding only in situations where it is possible and feasible to do so.

Perhaps dignity was too vague a construct for the framers of the early codes of bioethics to find salable. It has an ethereal quality, evoking images of formally clad figures, even of warriors or goddesses, a likeness struck on a coin of the realm. It would be difficult to advocate any universal aspiration to this, and in the further analysis, it would be something difficult to pitch, simply because it is so vague.

But autonomy, as it has become enshrined today, is going to be hard to live with in a time of scarcity. A recounting of recent, almost back-to-back, cases from the same corner of the world will illustrate some difficulties.

Nancy Cruzan's case¹ saw an interpretation of the right to be let alone carried all the way to the United States Supreme Court, and while it was not a part of the Court's final written opinion, it was enunciated by Justice Sandra Day O'Connor and others in their quite forceful concurring opinions. This right then gained further recognition as law of the land in the Danforth legislation, which came to be known as the Patient Self Determination Act. However, it is to be noted that only the right to refuse treatment is covered.

Within months of *Cruzan*, trouble loomed on the horizon. A very old, vegetative patient named Helga Wanglie was being maintained on life support in a milieu populated by some of the principals who fought hard

1. *Cruzan v. Missouri Dep't of Health*, 110 S. Ct. 2841 (1990) (O'Connor and Scalia, J.J., concurring) (Brennan, Marshall, and Blackmun, J.J., dissenting) (Stevens, J., dissenting in a separate opinion).

for the verdict in *Cruzan*. The neurological diagnosis was certain, or as certain as any such diagnosis could be. It was even accepted by her husband, who stood firm by his demand that she be kept alive at all costs. It was his wish, and moreover it was his wife's wish, clearly stated to him and known to him. The Wanglies were devout Lutherans and held, as a matter of faith, that life should be preserved at whatever cost. (Quite incidentally, the cost of treatment was being borne by the couple's insurance carrier and could not be claimed as a burden by the caregiver). But the treatment was, in some calculus at least, futile because no recovery could be expected.

The caregivers sought to have Mr. Wanglie removed as his wife's proxy. However, the court ruled that the caregivers failed to establish a *prima facie* case. Moreover, the court determined that Mrs. Wanglie's wishes were accurately represented by her husband, and he was competent to express them. The probable appeal, or the future approach contending futility, was mooted by Mrs. Wanglie's death. She had won and, perhaps in some ghostly way, the court decision had provided her a *nunc dimittis*.

But was not Mr. Wanglie exercising his wife's autonomy? If we concede that autonomy is an unrestricted right, given the same weight as the right to not be kept alive artificially, successfully claimed by the proxy decisionmaker for Nancy Cruzan, then we are at loggerheads. The alternative is to argue through the much more arcane concept of futility, or is there a way to finesse the futility approach?

Futility is difficult to define, and thus difficult to argue. Philosophers, for example, will point out that existence is "good," even a "good of last resort," and anything which preserves existence, no matter how bleak or pointless that existence might be, cannot be deemed futile. They will be joined by a group of individuals who have been called Vitalists. Vitalists hold that life, even a life shorn of all meaning or promise, is sacred. They insist that any shred of life must be prolonged by whatever means necessary. Futility arguments are in for a rough ride in the courts, and to the courts they will most assuredly be taken.

An answer might be found by examining the goal of medicine and, further, by seeing how it satisfies the principle of respect for dignity. One can cast the goal of medicine as being the relief of suffering, insofar as it can be done. It is a large order, and it has been made only a bit larger by Callahan,² who adds to it the attainment of a normal life span. The modi-

2. DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1987).

fication is acceptable, however, and adds no appreciable difficulty. One might point out here that the approach of the World Health Organization (and others) would insist on making medicine responsible for everything from the vacillations of the Gizeh and the Bundesbank to the Ivory Trade. To be sure, suffering is not solely the provenance of illness, but physicians will be kept quite occupied if they stick to what they know and do best. The ancient admonition "to cure sometimes, to heal often, to comfort always" is still a tall enough order.

Cassell³ reminds us that it is precisely the attack on the integrity of the person that produces suffering. It is in the unhinging of the individual and his personal integrity that suffering is produced. An analogy might help. The person who enters an emergency department following the loss of the tip of his left little finger is certainly in pain. Is he suffering? If he is a concert violinist, that loss is rightly seen by him as the end of a career, the disintegration of his person. He will be in pain, but more to the point, he will be suffering. The relief of suffering then, ties in neatly with respect for the dignity of the individual. Suffering is a personal and an individual emotion.

Are we at odds with rights? What rights are inherent and which are granted by society? If we view rights in the perspective of what is right, we have a different but compatible perspective. It would seem that Michael Walzer⁴ was doing just this when he spoke of what was right for society to do. He spoke of the obligation society bears to provide to its members a decent level of medical care. This statement is pithy indeed, but we can tease out of it the components that will fit a proposed scheme very nicely and satisfy the respect for dignity that is mandated. It does not, however, blend easily with autonomy.

Civil rights are those rights that are bestowed by laws enacted by a society. That society must agree to share certain very basic beliefs, values, and responsibilities that have to do with the natural law. The natural law has more to do with the right. Thus, the society which bestows rights must do so informed by and structured by the natural law which is to say, the right.

Because rights imply a claim on society, that same society must agree to honor those claims (otherwise the rights become, in effect, non-existent). So the effectiveness of these rights depends both on the willingness

3. Eric J. Cassel, *The Nature of Suffering and the Goals of Medicine*, 306 *NEW ENG. J. MED.* 639 (1982).

4. MICHAEL J. WALZER, *SPHERES OF JUSTICE* (1983).

and the ability of that society to honor them. One thing is immediately apparent. Society cannot bestow, or honor, rights which will, if they are claimed, destroy that society. Thus, society can and must ask for some sacrifice of individual good for the common good. This is a basic societal concept of right.

Arnold J. Toynbee in his work, *A Study of History*,⁵ opined that civilizations fall because they overdo the elaboration of their best idea. The idea of the rights of the individual is arguably one of the best of democracy, and perhaps of western civilization.

Now it would be ideal if, in claiming a right, the individual would think first of duty to society. But this is to expect, and to ask, a standard of altruism to which few, precious few, would rise. So society, then, is in effect forbidden to honor claims which are not right (good) and is, at the other end of the spectrum, strongly enjoined to respect those which best contribute to the common good. Only an absolute good, then, is absolutely binding, but of course gradations occur. And as the good descends from that absolute (whatever that may be, if it even exists), society has a lesser duty to honor such claims and may abridge them in ways which best protect the good of all its members. It is derivative then that members have a corresponding duty to limit their claims so that the integrity of the society is preserved.

The attention given to autonomy can be seen to come from an atomization of the individual, a process that encourages the individual to seek his own perception of good to the derogation of the society.

Does this advocate communitarianism? Not really. The communitarians adhere to a concept that community is composed of egos. Classical philosophy, however, would instruct that the "we" is more fundamental than the "I" (the "ego"), rather than being derived from it. Society returns more to the "we" than we can ever contribute to it. The Samaritan is rewarded more by the wounded man than the wounded man is rewarded by the Samaritan.

Rather than sacrificing anything by returning to a philosophy of individual dignity, society enriches itself by turning to its members for a notion of societal obligation. Can we expect them to do this of their own volition? We need not. Society can and must regulate what is to be given so that it has the resources to honor claims, and to honor all similar claims in a similar way, a favorite and valued instruction of Margaret Somerville. It is only by setting limits that it can do so.

5. ARNOLD J. TOYNBEE, *A STUDY OF HISTORY* (1947).

Will limits thus set be equitable and just from their inception? We would hope that they would be, but we can only strive. As inequities come to light, they can be righted, but it is incumbent on society to make a start.

It must be aware from the outset that, as C.S. Lewis⁶ put it so insightfully, "Every power man has is a power over man." This imposes the gravest obligation to act wisely. Wisdom in intent will provide the first steps. To act otherwise would subvert the negative moral imperative so important to the best construct of autonomy: first, do no harm.

What is the pertinence to the footsoldier, to the man who serves in the frontlines? The primary doctor, and I avoid the handle "provider" as being just one step above the previously proposed "vendor," is dedicated to patient advocacy. He has survived having this assailed as paternalism, but his ethic is, or should be, that of advocate for his patient. He both respects that patient's autonomy and realizes that it must be limited. But limited by whom? Not by him. His role must be to press for whatever is available that will be in the patient's best interest. But he can recognize limits, and does, in fact, within the present system. Some things are out of reach, simply unobtainable, and will be thus represented by him. He is comfortable with that role.

Because it is the continued ability of society to provide for its members that is at stake, it must be that same society which clearly sets those limits, realising that to attempt to do more would impair society's ability to provide the decent care which is society's responsibility. The physician can then say with honesty, "I will do everything that I can" and honor that Hippocratic mandate within the properly set bounds of a just and equitable system.

6. C.S. LEWIS, *MERE CHRISTIANITY* (1958).