

Disclosing Rationing Decisions: A Reply to Paul S. Appelbaum

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IN “INFORMED CONSENT TO RATIONING DECISIONS” (Hall 1993), I take up the neglected issue of how informed consent legal doctrine might apply to implicit rationing decisions, that is, to withholding marginally beneficial treatment on account of cost. I argue that such decisions need not be disclosed to patients in all circumstances, and I set forth the legal rationales in terms of the existing concepts of bundled consent and waiver of consent. In his reply to my article, Paul S. Appelbaum (1993) confronts me with a stern challenge. He asserts that my theory of economic informed consent would allow the physician in the infamous *Wickline* case¹ not to warn his patient that, in order to avoid losing her leg, she needs four days of hospitalization beyond what her insurer would approve. Neither I nor my theory supports his assertion. I will explain why and discuss as well why my lack of support for the *Wickline* physician’s action does not undermine my argument.

To start with, I do not argue, as Appelbaum apparently assumes, that *no* rationing decision need ever be disclosed. I argue the much weaker case that *some* rationing decisions need not be, in circumstances where insurance subscribers knowingly select a payment scheme that encour-

¹ *Wickline v. State*, 228 Cal. Rptr. 661 (Cal. App. 2 Dist. 1986).

ages their doctors to make economizing decisions. This qualifying circumstance presently does not exist, and did not exist in *Wickline*. Moreover, as Appelbaum acknowledges, the doctors in *Wickline* apparently considered the shortened hospital stay ordered by the insurer to be a departure from the standard of care. I argue only for nondisclosure of some treatment variations that are *within* the existing standard of care, not for concealing any nontreatment decision, however substandard, that is motivated by economic gain.

Finally, *Wickline* involved the situation of disagreement between the doctor and a third-party, fee-for-service insurer. I envision primarily a setting in a health maintenance organization (HMO) where the doctor effectively *is* the insurer. In this setting, the doctor's medical decisions— influenced as they are by economic considerations (a fact that should be disclosed to the patient upon enrollment)—determine insurance coverage. *Wickline* involved a treating physician in adamant disagreement with the insurer's physician. In the HMO setting, the treating physician does what she thinks is right. In such a setting, I argue that the doctor need not disclose that *other* doctors might be inclined to do more.

To make these differences more tangible in the context of Ms. Wickline's tragic loss, I will take some liberties with the facts:

Suppose Ms. Wickline is insured by a group-model HMO she chose from a multitude of options at her health alliance, knowing that its primary care physicians are paid a salary and that financial incentives are used to minimize specialist referrals and hospitalization. Suppose also that, instead of being discharged after only four days, she is kept in the hospital the full eight days recommended by her physicians, but she still suffers an amputation because she ignores signs of serious problems after she is discharged (as the case description suggests she did). Should she have been advised by her physicians that spending an extra day or two in the hospital would lessen the risk of complication after discharge, but that she would have to pay for such extended care on her own?

Dr. Appelbaum presumably would say yes. Moreover, he would apparently go further and maintain that the doctors are subject to tort damages even though it is highly unlikely that Ms. Wickline would have chosen to remain in the hospital had she been informed (Appelbaum, Meisel, and Lidz 1987, 123). I argue only that the law need not go to these extreme lengths in search of idealized patient autonomy, just as it

has stopped short of perfection in many other respects. (The latest example can be found in the California Supreme Court's recent decision² that doctors need not specifically disclose the low chance of success of a demanding treatment regimen for cancer that failed. The court held: "The [clinical contexts] in which physicians and patients interact and exchange information . . . are so multifarious, the information needs and degree of dependency of individual patients so various, and the professional relationship itself such an intimate and irreducibly judgment-laden one, that we believe it is unwise to require as a matter of law that a particular species of information be disclosed.")

It would be impossible to operate a system of universal and affordable health insurance under the threatening legal climate Appelbaum envisions. Some sacrifice of legally enforceable autonomy is necessary if a system of comprehensive insurance is to be maintained. Perfect autonomy would be achieved if insurance were banned and patients were forced to pay for all of their care out of pocket, for then each patient would have to authorize the cost-benefit trade-off for each discrete treatment decision. However, we have a strong desire for some form of insurance in order to guard against the exigencies of poor health and the anxiety of having to think about money during the stress of illness. To keep insurance affordable, we must yield the right to demand all conceivably beneficial care regardless of cost. Therefore, we must adopt what I refer to as the patient welfare compromise of insured-but-rationed health care. This patient welfare compromise creates the ethical bind that, in order for affordable insurance to exist, some degree of financial autonomy must be relinquished to physicians or others.

The very nature of insurance makes it impossible to consult patients directly about their values at the time of treatment while preserving the patient welfare compromise. After purchasing insurance, a patient no longer has the incentive to evaluate fully the cost effectiveness of various treatment options. Insured patients have a strong free-rider incentive to order more care than they would be willing to insure against if the choice were put to them at the time of their enrollment decision. Put another way, an ethic of absolute autonomy enforced in the presence of insurance makes insurance unaffordable, which forces an increasing number of people to go without insurance at all. For this reason, we can no longer give full force to the notion of patient autonomy as it has been

² *Arato v. Avedon*, 23 Cal. Rptr. 131, 858 P.2d 598 (Cal. 1993).

conceived of by conventional bioethics—from the perspective of the presently ill, but fully insured, patient.

Appelbaum's strongest attack on my position questions the meaningfulness of any enrollment-time disclosure of financial incentives and rationing rules. However, this criticism applies with virtually the same force to the treatment-specific disclosures he advocates. I quote at length from his argument, substituting only his desired disclosures for mine:

. . . Note that postulating an effect of disclosure at the time of [treatment] depends on an interrelated set of highly questionable propositions: that disclosure is made in language sufficiently clear for a layperson to understand; that [patients] are alerted to the importance of the information, such that they attend to its presentation, whether oral or written; [and] that persons unsophisticated about medical concepts are able to appreciate the implications of the information for their [present] medical conditions. . . .

Even were all these desiderata to be achieved—an accomplishment students of informed consent in the real world would recognize as little short of miraculous—considerable doubt would remain as to whether patients still would grasp the impact of economic factors on their care. . . .

Only a cockeyed optimist is likely to respond to these queries in the affirmative. . . .

I conclude, therefore, that disclosure at the time of [treatment] of an insurer's limitations on coverage based on economic considerations is unlikely to leave subscribers meaningfully informed about the ways in which their doctors' recommendations are being affected by concern over costs. . . . (672–3)

If real-world constraints on patients' attention spans, analytical abilities, and experience base limit the effectiveness of disclosure, what are we to do? Prohibit the doing of that which is being disclosed, or proceed in the face of epistemological imperfection? When the issue is whether to treat, we accept the validity of disclosure despite actual deficiencies in patient understanding because the only alternative is to withhold desired treatment. When the issue is whether to decline treatment, this solution is equally compelling because the only alternative is to force unwanted treatment. It is only when we confront the issue of whether to waive or to alter the required disclosure that Appelbaum imposes his objections to the effectiveness of consent. It is self-defeating to require that, in order

for waiver of consent to be informed, the person must be told and must understand all the information that he or she is asking not to be told.

Appelbaum's final objection is that enrollment-time consent is not freely given because the choice among insurance options is often severely constrained. This is an important and potentially disabling objection to my theory, which I deliberately left to future discussion. I did so with the hope that this objection would soon be mooted by the enactment of comprehensive managed competition reform, which would give everyone the same choices presently offered by large firms to their employees. That happy event would save us all considerable agonizing and work.

References

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