Paul S. Appelbaum, "Comment on the Case of Mr. A.B.," *The Journal of Clinical Ethics* 18, no. 4 (Winter 2007): 402-3.

Comment on the Case of Mr. A.B.

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The "ethical dilemma" in this case arises from a thoroughgoing misconception about the obligations of physicians and hospitals in obtaining patients' informed consent. To understand why the extended handwringing over whether to disclose information about the death of the patient's daughter was misplaced, we need to return to the fundamentals of the law and ethics of informed consent.

The doctrine of informed consent to medical treatment evolved in the U.S. courts in the mid-twentieth century. It grew out of the earlier requirement that physicians obtain patients' "simple consent" for invasive medical procedures, that is, that patients be informed in advance of the nature of the procedures to be undertaken and indicate their agreement with the proposed interventions. For roughly 200 years, courts operating in the Anglo-American legal tradition had found disclosure merely of the nature of the procedure that was being recommended by the physician — and the patient's subsequent consent — to discharge the entirety of a physician's obligation to provide information to the patient.

By the middle of the twentieth century, however, American courts began to recognize that the choices facing patients had grown considerably more complex since the days when the simple consent rule had been formulated. In many medical situations, patients had to choose among multiple treatment alternatives, with varying sets of risks, disadvantages, and benefits. For patients to make truly meaningful choices, they needed the kind of detailed information about the possibilities for treatment that ordinarily only their physicians would possess. Hence, the courts placed the burden on physicians to disclose information about the nature of the patient's condition, the nature and purpose of the proposed intervention, the risks and disadvantages of that approach, the possible benefits of the treatment, and possible alternatives to the proposed treatment, along with their risks and benefits.[1]

Hence, informed consent to treatment is largely based on judge-made law, driven by concerns of the judiciary, not by the theories of ethicists, who came along after the fact to offer theoretical ethical justifications for the new set of practices. (Rules regarding informed consent to research evolved separately, with little interaction between these two seemingly related areas.) Ethicists often focused on the importance of patients' decisional autonomy, and the desirability of enhancing that autonomy by providing patients with sufficient information so they could apply their values to the choices they faced. In this dominant ethical formulation, the role of physicians is to offer medical information to patients, who then use this information — in the context of what they know to be their life situations and in light of the preferences they have — to reach decisions about treatment.

Whether the medical information disclosed to patients should be limited to the categories mentioned above or expanded to include other issues has been debated in recent years. Among the suggestions for additional disclosures is information about the physicians' previous experience with patients facing similar medical issues; the success rate of the physician and/or facility in performing the recommended procedure; the cost of the procedure, even if the patient's insurer will be bearing that burden; and aspects of the physician's own situation that might influence patients' choices (for example, whether a surgeon is HIV positive or a hepatitis carrier). Except when such additional disclosures have been statutorily mandated, the courts have been reluctant to impose additional disclosure burdens on physicians — even when the disclosures related to information that was uniquely available to them.

In this case, the question was raised as to whether the physician was obligated to tell the patient about the death of his daughter. Note that, unlike data about the risks and benefits of the CABG procedure itself, this is not information that was held uniquely by the physician or the other medical personnel. Indeed it was obtained from the patient's family, with the explicit request that it not be communicated to the patient. Information pertaining to the death of a patient's loved one is beyond the scope of disclosure suggested by any reasonable legal or ethical formulation of the doctrine of informed consent. It is the sort of information that is generally communicated by families or other intimates, not by physicians. Whether the family in this case was ethically justified in withholding this information from the patient goes beyond my discussion here. But however one would resolve that question, the choice — and the potential burden of having made an incorrect choice — rests with the family, not the physician or the hospital.

To be clear, because this seems to be at the core of the confusion in this case, it is not the obligation of the physician to disclose all information material to a patient's decision, as this datum arguably may have been. Physicians must disclose relevant medical information, and no more. This case actually provides a good example of the problems that physicians can create when they violate that dictum. For disclosure of the death of the patient's daughter to have been made over the family's objections would not only have caused distress to the patient at a critical time, but would have constituted a major intrusion into the autonomy of the family unit. The patient, perhaps resenting the family's decision, may have been alienated from them at precisely the time when their support was most needed. The repercussions of that perturbation of the family's dynamics are too complex even to be foreseen, but may have extended well into the future.

More than two years later, we are told, staff members at this facility are still in anguish over whether the right decision was made. But the worry is misplaced. It derives from what is at core an assumption that it is the burden of the medical profession to assume responsibility for all aspects of their patients' lives. Ironically, a doctrine meant to undercut medical paternalism here was used to argue in favor of overweening medical paternalism — with physicians and other medical staff assuming the responsibility most properly resting with the patient's family. It is time to reassure those staff members who continue to experience "lingering discomforts" that they can put their concerns aside. The right choice was made here — perhaps not for the right reason, but the right choice nonetheless.

NOTES

1. J.W. Berg et al., *Informed Consent: Legal Theory and Clinical Practice,* 2nd ed. (New York: Oxford University Press, 2001).