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David Orentlicher University of Nevada, Las Vegas -- William S. Boyd School of Law

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Commentary: Organ Retrieval from Anencephalic Infants: Understanding the AMA's Recommendations

David Orentlicher

In the case study about anencephaly and organ donation, the consulting ethicist, James Reagan, relates an important instance about the influence of professional guidelines in ethics. Within months of their publication in the Journal of the American Medical Association, the AMA's new recommendations on organ retrieval from anencephalic infants nearly resulted in a parental donation of life-sustaining organs from an anencephalic newborn.

While one could discuss this case in terms of the role of the ethics consultant when physicians propose illegal action, the importance of professional guidelines in ethics,² or in terms of the argument that anencephalic infants are not likely to be meaningful sources of transplantable organs,³ I want to focus on two other points. First, the advocates for organ retrieval in this case incorrectly cited the AMA's recommendations as support for their proposed course of action. Second, the incorrect citation of the AMA's recommendations tells us something about ethical decision making in medicine, that such decision making is driven more by personal values than medical or ethical principles and that decision makers disguise the influence of their own values by pointing to external influences that are plausible but not actual explainers of their actions.

Mr. Reagan mentions at several points the desire of the physicians, parents, and others at the hospital to proceed with organ retrieval from the newborn before she died, as "consistent with the AMA's recommendation." Yet, the proposed retrieval would have violated the AMA's guidelines. While the guidelines in effect at that time stated that it is ethically permissible to retrieve life-necessary organs from anencephalic infants,⁴ the guidelines also stated that the law would have to be changed before organs could be

Journal of Law, Medicine & Ethics, 23 (1995): 401–02. © 1995 by the American Society of Law, Medicine & Ethics. retrieved from living anencephalic infants.⁵ The AMA's Council on Ethical and Judicial Affairs recognized that, even with its new ethical guidelines, organ retrieval from an anencephalic infant was still legally prohibited before the infant's death. Accordingly, the council indicated its hope that the new guidelines would spark public discussion and consensus in favor of changing the law.⁶ However, the council acknowledged that organ retrieval would not be possible in the absence of such a change.⁷

That the physicians misread the council's guidelines is surprising. It is a serious misreading that could have had severe consequences. Given the controversy over the guidelines, one would expect physicians to act very carefully before proceeding with organ retrieval from an anencephalic infant. Moreover, if the desire to avoid legal liability is as great an influence on physician behavior as is commonly asserted, then one would expect the physicians here not to have reached a decision without first consulting a lawyer. Yet, at least one physician was ready to proceed without even an ethics committee consultation, and it was the hospital's chief executive officer who sought the opinions of both the ethics committee and the hospital's legal counsel.

While the physicians were not acting consistent with the AMA's guidelines, they were acting consistent with a considerable and growing body of data indicating that physician decision making on ethical matters is driven much more by physicians' personal views than by any external ethical guidelines or principles. For example, when decisions are made whether to discontinue life-sustaining medical treatment, the personal values of the patient's physician regarding life-sustaining treatment are much more decisive than principles of patient autonomy. Rather than serving as guides to physician behavior, external ethical guidelines and principles are used by physicians to justify the decisions they have reached based on their own moral compasses.

Physicians do not openly acknowledge the role of their personal views. They explicitly justify their decisions either with external principles or with other external considerations that are accepted as "objective" bases for decision making. When physicians do not agree with a family's request to discontinue life-sustaining treatment for a patient, physicians might argue that the family's request is not truly consistent with the patient's wishes, or they might argue that legal considerations prevent them from complying with the family's request.¹¹

Yet, as this case suggests, such "objective" factors are anything but that. They are relied on only when it is useful for the physician to do so. Physicians may cite concerns about tort liability, for example, when such concerns support an outcome consistent with the physician's views. However, physicians often ignore liability concerns, as they did in this case, when such concerns would not support the physician's views. Tort liability or other external considerations, in other words, are not explainers of, but are rationalizers for, physician behavior.¹²

This is not to say that physicians consciously impose their own values or that they act differently from other professionals. Judges decide cases before them similarly. They reach a conclusion about the appropriate outcome and then justify their conclusion on the basis of the legal principles or precedents that support their conclusion, distinguishing or ignoring legal principles that support the opposite outcome.¹³ The important point is that patients must recognize that their care is heavily influenced by their physicians' personal views and that they may want to take this fact into account when choosing their physicians.¹⁴

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Public Sector Managed Care: A Forum on Corporate Responsibility, Ethics, Law, and Policy

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Location: Inn and Conference Center,

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