Health Care Decisions in Minors: Ethical Dilemmas

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"Every human being of adult years and sound mind has a right to determine what shall be done with his own body. A surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages."

These words were written in 1914 in the case of *Schloendorff* v. *Society of New York Hospital* by Justice Benjamin Cardozo, later an Associate Justice of the Supreme Court, but at that time sitting on New York's highest appellate court. The principle he enunciated is certainly well known to all of us involved in health care, even if we sometimes struggle to decide if a particular adult is of "sound mind" to make decisions.

But what about children, do they have the same right to decide what will be done with their bodies? The law's answer is "no." Children do have a right of self-determination, but it is exercised in a different way. In the 1979 case of *Parham* v. *J.R.*, which dealt with the involuntary hospitalization of a minor at the request of his parents, Chief Justice Warren Berger wrote: "The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. . . . Most children, even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment."

For minors less than 18 years old, health care decisions are made by someone else on their behalf, usually by their parents unless there is a court-appointed guardian. For an incompetent adult most states apply a somewhat different "substituted judgment" rule, by which the decision maker is supposed to do what the patient would presumably do if he or she were competent to decide. This principle guides the January 2007 Pennsylvania statute on advance health care directives and decision making for incompetent patients, which stipulates that the patient's representatives generally are required to make decisions based upon the following order of criteria: foremost, any clearly expressed instructions of the patient while competent; next, the patient's preferences and values (including religious and moral beliefs); and third, the best interests of the patient. "Best interests" must take into account the following objectives: preservation of life; relief of suffering; and preservation or restoration of function.

There is no requirement that decisions for children must apply the "substituted judgment" rule, and for infants and preteen minors, the rule would not even be feasible. Thus, parents are likely to make decisions based upon their own desires, preferences, and values, which determine their view of their child's "best interests." Although this practice generally works well, the right of parents to make medical decisions for their children is not without limits. Virtually every state reserves the right to intervene when a child's life, health, safety, or welfare is at risk. Though an allegation of child abuse is the classic and obvious example, similar principles apply when a parent's health care decisions are perceived as jeopardizing the child's wellbeing, and Pennsylvania statute authorizes physicians and hospitals to take minors into protective custody if they have reason to believe that a child's health and welfare are being jeopardized by their parents' decisions.

Sometimes these decisions may appear obvious, such as when a physician believes that a minor patient needs blood or blood products to survive, but the parents' deeply held religious beliefs oppose their use. To the extent that all reasonable alternatives have been exhausted, the physician faces the ethical dilemma of either following the parents' instructions and risking the child's death, or acting contrary to the parents' directives and taking the relatively low risk of a blood transfusion to achieve a very worthwhile outcome, the survival of the child. In these cases hospitals may use their statutory authority to take protective custody of the child and to administer blood. In Pennsylvania this action is ordinarily taken in

concert with the local child and youth agency, which petitions a judge for a court order that authorizes blood transfusion.

Other health care decisions for minors can be far more difficult, as when the child's life is not at risk. For example, a parent may refuse surgical intervention for a child with a severe but correctable deformity, such as a cleft palate or club foot. When the outcome is uncertain, the decision may be even more difficult, as when an acutely ill child has advanced cancer and an uncertain prognosis at best. If the minor's parents refuse chemotherapy, whether for religious or other reasons, it may be difficult to determine that their refusal rises to the level of abuse, even though others might make a different decision.

The most difficult decisions arise when health care providers recommend a treatment that not only contradicts the ethical, moral, or religious beliefs of the parents, but could undermine the child's relationship to the family. Such decisions may also place tremendous burdens on the family to provide and/or pay for ongoing care.

There is no simple solution when health care providers feel that medical decisions made by parents are not in the minor's best interest, but some principles are always helpful:

- Maintain an ongoing dialogue with the parents in order to avoid misunderstanding their directions and their rationale;
- Avoid confrontation; parents' emotions are understandably strong;
- Explore any alternatives to the Doctors' recommendations that might be acceptable to the parents or might alter their decision;
- Consider if consultation with the hospital's ethics committee might be helpful to doctors or parents, either separately or together.

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