A Life-and-Death Decision: The Lakeberg Twins

BY CHARLES J. DOUGHERTY, PhD

No one can fail to sympathize with the difficult choice Kenneth and Reitha Lakeberg faced after the birth last June 29 of their conjoined twins, who shared one liver and one heart. People of goodwill everywhere hope for the best possible outcome for the survivor, Angela Lakeberg. But the decision to separate the twins raises several disturbing ethical questions. Was justice served by allocating so much money for such a small chance of success? What was the quality of the informed consent involved? And what is the moral status of an operation whose direct result was the death of the other twin, Amy Lakeberg?

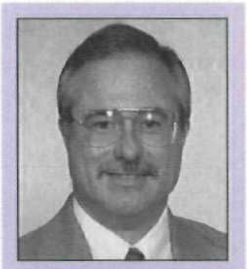
The twins were born and cared for initially at Loyola University Medical Center in Chicago. Loyola physicians said the twins had no chance of surviving conjoined, but one twin might have a 1 percent chance of survival *beyond infancy* if they were separated surgically. Because the doctors at Loyola advised against such surgery, the Lakebergs took the twins to Children's Hospital of Philadelphia. Surgeons there separated them, reconstructing the liver and heart for Angela. Amy died.

The bill for seven weeks of care at Loyola—*before* the Philadelphia operation—is reported to be more than $300,000. The total bill will easily reach $500,000 and likely much more. This is an exceptional cost—not for Angela's life, which is priceless—but for the 1 percent chance of survival past the few months any similar twin has ever lived after this kind of operation.

A Just Allocation of Resources?

The fact that the Lakebergs are uninsured is not the issue. Nor does the central problem lie in the fact that Kenneth Lakeberg has admitted illegal drug use and diversion of funds donated for the twins. The consequences of a father's faults ought not to fall on his children.

The central problem is that it is inconceivable that any national plan to ensure healthcare for all Americans would cover this great an expense for this small a chance for success. Justice in the allocation of limited resources would forbid it, since the nation has too many unmet basic healthcare needs. How many low-birthweight deliveries could be prevented, for example, if the money spent on the Lakebergs went to fund more adequate prenatal care? Just now such a linkage between one healthcare investment and another is tenuous; universal coverage will make it explicit. Perhaps surgical research funds or private donations will be available for such high-cost, high-risk procedures in the future. But they could not be covered in any reasonable national benefits package. That would be unjust.



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Adequate Informed Consent?

There are problems too in determining—especially from a distance—whether the informed consent given by the Lakebergs was adequate. Did they fully appreciate the experimental character of the operation? While declining to offer any estimate of the odds for survival, the cardiac surgeon in Philadelphia was quoted to this effect: "If there is long-term survival [for Angela], this would be unique." But he refused to call the operation hopeless. He told reporters, "If we thought there was no chance of reconstruction, we would not have made this an option to the family." Presumably, then, any chance whatsoever represented a medical option for the family—an impossible standard for surrogate decision making.

Valid Consent?

There is also a deeper issue of consent that leads to the third major problem. Can parents give morally valid consent for an operation that directly causes the death of one of their children?

The same operation that gave Angela her small chance took her sister's life. This result was not an accident; it was part of the plan of the surgery. Before the operation, nurses painted Angela's fingernails pink but left Amy's unpainted, a poignant symbol of who was to be given a chance

Continued on page 30

Continued from page 23

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ronment in hopes of retrieving valuable information early enough to effect appropriate responses to threats and opportunities.

PRESCRIPTIVE ADVICE

The use of textbook approaches to gaining competitive advantages in a typical manner may lead healthcare managers astray. For example, much of conventional managerial wisdom is built on the cost-benefit analysis. The common make-or-buy decision is a variation of this analysis. This concept underpins traditional competitive strategies regarding the outsourcing of all services too costly to handle internally. This economic-based directive assumes that a firm's production process can be easily disaggregated to minimize costs in each functional area. Such an assumption is ridiculous in the healthcare setting. Healthcare administrators must consider the interrelationships of many factors that do not lend themselves to economic analysis. Pursuit of the low-cost strategy can mean disaster for a healthcare institution.

Conventional competitive strategy also includes typologies to help managers organize their thinking and formulate competitive responses in the marketplace. One such popular typology is the Defender/Analyzer/Prospector/Reactor model developed by R. E. Miles and C. C. Snow.[2] Although healthcare institutions were used in the formulation of this model, its conventional use can exacerbate preexisting problems for healthcare administrators. The hazard in the use of this diagnostic system is the implicit assumption of a one-dimensional competitive prospective. Consideration of the three-dimensional outlook can result in apparently contradictory answers. But such contradictions may, in fact, be the most accurate assessment of a firm; that is, a defender profile may be apt in one area of the institution, whereas some other profile best describes another area.

In lieu of conventional competitive approaches, we recommend that healthcare managers begin with a three-dimensional competitive analysis, focusing on consumers, customers, and clients. Following this, traditional typologies and management theory can be useful, but with the vital caveat of *simultaneous* consideration of hospital strengths and weaknesses in *each* competitive arena. Resources should be focused on the strengths of an institution, but the goal should be an optimal mix of resource allocation among all three arenas. □

NOTES

1. A. C. Enthoven, "Managed Competition in Health Care and the Unfinished Agenda," *Health Care Financing Review*, Annual Supplement, 1986, pp. 105-119; D. E. Farley, "Competition among Hospitals: Market Structure and Its Relation to Utilization, Costs and Financial Position," *Research Note 7*, Hospital Studies Program, Department of Health and Human Services, 1985; R. Feldman and B. Dowd, "Is There a Competitive Market for Hospital Services?" *Journal of Health Economics*, vol. 5, no. 3, 1986, pp. 277-292; W. Higgins, "Myths of Competitive Reform, *Health Care Management Review*, vol. 16, no. 1, 1991, pp. 65-72; G. C. Pope, "Hospital Nonprice Competition and Medicare Reimbursement Policy," *Journal of Health Economics*, vol. 8, no. 2, 1989, pp. 147-172; M. Coyle, "Is Competition Compatible with Gospel Values?" *Health Progress*, March 1992, pp. 16-18.
2. R. E. Miles and C. C. Snow, *Organizational Strategy, Structure, and Process*, McGraw-Hill, New York City, 1978.

Continued from page 16

to live and who was to die.

During the operation, the single liver and six-chambered heart the twins shared were taken from Amy and refashioned for Angela. When the shared heart was divided, Amy died. The operating team—six surgeons, four anesthesiologists, eight nurses, and one technician—did not pause to acknowledge the event. "We were aware at that phase what was happening," commented one of the surgeons. "But minutes really count, and you have to press ahead as fast as you can."

To see the ethical issue here more clearly, imagine a slightly altered scenario. Suppose that identical twins are born. They are not conjoined, but both have severe heart defects—each has a failing three-chambered heart. Doctors determine that both will soon die. But they offer one long shot. If the heart is removed from one child—not after her death, but while she is living—it could be used to repair the heart of the other. Wouldn't such a suggestion be rejected out of hand as a clear case of killing one patient to try to help another? Wouldn't such an operation be a clear violation of the parents' and doctors' duties to the child whose heart was taken? How different is this from what was done to Amy Lakeberg?

It is not sufficient to reply that the end justifies the means, that both twins would have died had Amy not been killed. Patients die every day, and we do not countenance killing others to buy them more time. Nor is it acceptable to say that Amy was not really a person because she shared vital organs with her sister. She had her own name, her own personality (reportedly the feistier of the two), and she was buried alone—all marks of an individual human person.

DOUBLE-EFFECT ANALYSIS

Can double-effect analysis avail in this situation? Perhaps the directly intended

goal of the operation was saving Angela, and Amy's death was only a foreseen, but unintended, consequence.

But this analysis will not work. Three other criteria must be met in addition to having the proper intention. First, a valid double-effect analysis requires that the act itself be morally good or neutral. This act, the reconstruction of the shared heart for Angela alone, could hardly be construed as morally neutral from Amy's point of view. It took a beating heart from her chest and in that act caused her death. Second, on double-effect grounds the evil effect—Amy's death—cannot be the means for the good effect, Angela's chance at life. But Amy's death at the moment of the removal of her share of the single heart was the means for Angela's survival. Finally, depending on Angela's fate, there may not be a proportional relationship between the good and evil created. Angela's life may still be short, and possibly harder than it might otherwise have been. Double-effect analysis cannot justify this operation.

Accepting Death

What should have been done for Amy and Angela? Certainly, the Lakebergs faced a terribly difficult situation—a *Sophie's Choice*—that properly evokes public sympathy. But, in my opinion, they should have taken the advice of their doctors at Loyola University Medical Center. The twins should have remained together. They should have been kept as comfortable as possible. Their deaths should have been accepted. This would have meant choosing to lose a very small, exorbitantly expensive chance of giving Angela more time. But this choice would have reflected an informed consent sensitive to the interests of both patients. And it would have been far more respectful of Amy. □