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.

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 to live.

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Pursuit of the low-cost strategy can mean disaster for a hospital.

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. 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 perspective. 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


goal of the operation was saving Angela, and Amy’s death was only a unforeseen, 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.