Perspective: The Ethics and Economics of Heroic Surgery

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The Ethics and Economics of Heroic Surgery

BY PETER RATIU AND PETER SINGER

A brief report in the 10 August 2000 issue of the *New England Journal of Medicine* described a case of conjoined twins and their separation at Children's Hospital in Boston, Massachusetts. That report described the extraordinary surgery, immediately after birth, made possible by the use of computer-aided presurgical planning.[1] The media picked up the story, and a first page article appeared in *The New York Times* on the same day.[2] Two days earlier, on 8 August, conjoined twins were born in Malta in a case that stirred even more media attention. Eventually they underwent surgical separation in the United Kingdom against the parents' wishes.[3]

Reflecting on the case presented in the *New England Journal of Medicine* has led one of the coauthors of that report to enlist a bioethicist to help consider its ethical aspects. This essay is the outcome of that joint endeavor.

The two cases are similar in important ways. Although the U.K. twins were conjoined at their pelves while the Massachussetts twins were conjoined at their chests and abdomens, in both cases, one of the twins was perfused with blood pumped by her twin sister's heart. This phenomenon is known as twin reversed arterial perfusion, and had not previously been reported in the medical literature in conjunction with conjoined twinning. Also, in both cases, both twins would ultimately have died had they not been separated. Finally, the expected outcome of both cases was comparable and is so far confirmed by the facts: one twin was sacrificed in the surgery, and the surviving twin will have a relatively normal development and lead a healthy life, although she may not be entirely free from complications.

Both surgeries are without question remarkable accomplishments, and the use of computer-aided surgical planning in the Massachusetts case was a great technical advance. Yet while the individual cases seem to have turned out successfully from a medical perspective, they also have troubling social implications. "We want other parents with this problem to try to save their kids," said the father of the twins described in the *New England Journal of Medicine*.[2] He will probably have his wish.

In the Massachusetts case, the parents accepted the need to bring about the death of one twin in order to save the other. We agree that, if the choice is between saving one twin or allowing both of them to die, it is, other things being equal, better to save one. But it is never the case that everything else is equal. Other factors are always involved. Perhaps most importantly, there are always *other cases*—other patients, other children, other social needs. What is striking about these cases are their implications for the allocation of scarce public health care resources.

The New York Times reported that the treatment of the Massachusetts case cost "more than $500,000, partly paid by the Medicaid programs in Massachussetts and New Jersey, and the rest absorbed by the hospitals." We believe that the cost may actually have been much more, given that it involved three surgical procedures and six months of hospital care, most of it in the intensive care unit. Assume, nonetheless, that the cost of the procedure was approximately $500,000.

Much has been written both about escalating health care costs and the need for their containment, and about the questionable practices that health maintenance organizations and third party payers employ to limit costs. Yet there is now a widespread consensus that *something* must be done to limit health care costs. In a recent U.S. Supreme Court case involving a suit by a patient who was denied necessary tests, Justice David H. Souter bluntly declared that rationing health care was a legitimate public

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goal.[5] The case of the Massachusetts twins illustrates the difficulties that stand in the way of solving this problem, given how health care decisions are currently made.

It is not difficult to estimate the significance of $500,000 for health care. It could pay for the cure for 2,500 cases of tuberculosis in Haiti or for twenty-five cases of tuberculosis in the United States.[6] It could cover the cost of drugs for seventy-seven elderly couples with needs like those of Robert and Sarah Bergeon, a couple recently featured in *Newsweek* who live on a yearly income of $21,000 and spend $6,500 annually on medication.[7] From the perspective of the taxpayer-funded health care system, separating the newborns could make sense only if the life of the surviving infant was of greater value than all the other lives that $500,000 could have saved or improved. This assumption seems doubtful to us. But since no one involved in the decision was responsible for taking on the perspective of the health care system as a whole, no one had any interest in questioning the assumption, and there was no need for it to be defended.

Is it always imperative to try to save the life of a newborn infant?

Could those in charge have reached a different decision? Clinicians feel that they are bound to act in the best interests of their patients, and rationing health care runs contrary to this principle. Also, the patient is the one present, not an assortment of tuberculosis patients from Haiti or elderly American couples on Medicare. Further, the highly trained clinicians and researchers of a leading tertiary care hospital are likely to feel other motivations that reinforce their desire to help their patients. They will be eager to rise to the challenge of a difficult case that might lead to a publication in a prestigious journal. And finally, if it had been decided not to undertake the operation, there is no guarantee that the money saved would have been used for more cost-effective alternatives. The medical community has a long history of wrestling with third party payers and has little confidence in their effectiveness, whether they are HMOs or the government.

Thus saving half a million dollars in lieu of one infant might well appear to be the wrong course to take, and while there were incentives for performing the procedure, there were none for foregoing it. Nevertheless, an increase in heroic medical procedures on newborn infants will lead to an increase in medical expenditure, which in turn will prompt further rationing of health care by those very authorities whom the medical community distrusts. Thus these cases illustrate the need for some form of constraint to ensure that medical procedures using public funds are not undertaken without consideration of the cost effectiveness of the procedure.

We find it troubling that the decision to separate the Massachusetts twins could have been made without any constraints or any need to justify the expenditure. More controversially, we question whether that it is always imperative to save the life of a newborn infant, especially if there are doubts from the outset about the child's prospects of living a full and healthy life. We suggest that life be seen as a journey, and that when the prospects under which the journey begins are seriously clouded, it may be better for the journey not to begin, but to await another time, when the outlook is better.[8] Parents will grieve when a newborn child dies, just as when a pregnancy miscarries at a late stage, but in most cases they will be able to have another child, and if that child's prospects are better, both they and "their child" will be better off in the long run.

Paradoxically, while on the one hand the separation surgery suggests a very high value for the life of a newborn infant, it indicates at the same time that a newborn infant does not have the same right to life as an older human and can in fact be used as a means for saving her twin sister. "Since the acardiac twin would not survive," reported the surgeons in the Massachusetts case, "the incision for separation was performed far toward her side of the fusion plane so that her tissue could be used to achieve complete closure of the ventral defect in the surviving twin."[9] If both twins had been older, capable of discussing with us their hopes and dreams for the future, it would have been much more difficult and more controversial for the doctors and parents to make the decision to sacrifice one so that the other could live. Instead, it seems probable that everything possible would have been done to prolong both lives as long as possible.

There are good reasons for saying that the physician should not also be the person who decides which forms of health care are sufficiently cost-effective to be offered to her or his patient. Leaving this decision to the physician may clash too violently with the principle that physicians should further the best interests of their patients. But in a world of limited public medical resources, some medical procedures are so costly, and their benefits so doubtful, that it should not be within the power of physicians to offer them to their patients. If doctors cannot ration, then another decisionmaking authority must be involved in these cases, so that physicians can offer their patients the best health care *available*, but not the best irrespective of cost.

1. E.J. Norwitz et al., "Separation of Conjoined Twins with the Twin Reversed-Arterial-Perfusion Sequence after Prenatal Planning with Three-Dimensional Modeling," *NEJM* 343 (2000): 399-402.

2. D. Grady, "2 Babies, 1 Heart, 90 Minutes for a Miracle," *The New York Times*, 10 August 2000.

3. See A. London, "A Separate Peace," *Hastings Center Report* 31, no. 1 (2001): 49-50; and L. Knowles, "Hubris in the Court," *Hastings Center Report* 31, no. 1 (2001): 50-52.

4. See ref. 2. Grady, "2 Babies, 1 Heart."

5. News.findlaw.com/cnn/docs/siamesetwins/siamesetwins1.html. Last accessed 10 January 2001. R. Pear, "The R Word: Justice Souter Takes on Health Care Taboo," *The New York Times*, 18 June 2000.

6. T. Kidder, "The Good Doctor," *The New Yorker*, 10 July 2000.

7. J. Raymond and A. Belli Gesalman, "Why Do Drugs Cost So Much?" *Newsweek*, 25 September 2000.

8. P. Singer, "Life's Uncertain Voyage," in *Metaphysics and Morality: Essays in Honor of J.J.C. Smart*, ed. P. Pettit, R. Sylvan, and J. Norman (Oxford: Basil Blackwell, 1987), 154-72.

9. See ref. 1. Norwitz et al., "Separation of Conjoined Twins.