Joining in Life and Death: On Separating the Lakeberg Twins

by Charles J. Dougherty

The birth of conjoined twins in 1993 garnered extensive media coverage when the girls were separated, resulting in the death of one twin immediately and the other's nine months later. The cost and experimental nature of the surgery focused attention on ethical issues in neonatalogy and caused society to weigh the fairness of expensive treatments with little probable benefit. By utilizing the principle of double-effect, the author assesses the ethical ramifications of this controversial case.

On June 29, 1993, Reitha Lakeberg gave birth to conjoined twins, Amy and Angela, at Loyola University Medical Center in Chicago. The twins were joined at the chest and shared one six-chambered heart. The parents, Reitha and Kenneth Lakeberg, wanted the twins surgically separated. After assessing the medical and ethical issues at stake, Loyola physicians refused to attempt surgery. Given the nature of their union, only one twin could survive the operation and the odds for that twin surviving beyond infancy were projected to be small. No child had ever survived this operation beyond a few months. The Lakebergs insisted, nonetheless, and the twins were transferred to the Children's Hospital of Philadelphia where surgeons agreed to operate.

The surgery, performed in August, involved removing the shared heart from Amy Lakeberg and reconstructing it for Angela. Amy died, a known consequence of the operation. Angela survived the operation, but died in June, 1994, less than a year after her birth. She was buried next to Amy (Caro 1994).

Angela spent the nine months after the operation in the intensive care unit at Children's Hospital, most of the time on a ventilator; she was seldom with her family. She had lived seven months longer than any other conjoined twin to undergo such an operation. The total cost of her care is estimated to exceed $1.2 million (Brandon 1994).

Numerous ethical issues are raised by this case. Three central ones will be considered here. First, was the operation to separate the twins, a procedure whose effect included the death of one twin, ethically acceptable? Second, was it just to spend so much money for such a small possibility of success? Third, if, as will be argued, it was ethically unacceptable to perform the separation and unjust to spend so much for such a small chance of success, how could the Lakebergs have been told no?

Killing Amy to Save Angela

The Lakeburgs were informed that the twins would die unless they were separated. If they were separated, one twin would be sacrificed in the operation to construct the heart needed by the other. The remaining twin would have a greater chance for survival after separation, but even then, the prognosis was bleak; the only similar "success" involved a twin who survived only several months. The dilemma the family faced was no chance for either child without separation, or death for one child at separation, and a very small probability of any significant length of life for the surviving child. Faced with these prospects, the Lakebergs chose to proceed with the separation.

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The doctors and nurses at Loyola, however, expressed moral reservations. Their first concern was that separation offered a dangerous, expensive, and painful course with very little hope for a reasonably enduring success. Yet the surgery represented the parents' only hope. It was separation or lose both twins in the relatively short term. Their reasoning can be reconstructed as a lesser-of-two-evils analysis. One course of action results in both children's deaths with certainty. The alternative results in one death with certainty and a small probability of continued life for the other. Their tragic situation was similar to that in the movie, *Sophie's Choice,* and like the fictional account, those outside the context may be shocked or terrified, but they also understand. How could a parent not do everything possible to save at least one child when inaction inevitably means the death of both?

But the other moral objection raised by members of the health care team at Loyola challenges the lesser-of-two-evils framework and questions whether this dilemma was structurally like *Sophie's Choice.* The separation that the Lakebergs authorized and that health professionals performed caused Amy Lakeberg's death so that her sister, Angela, would have a greater chance of surviving. It is not inaccurate to say that Amy Lakeberg was killed by surgery. The portion of the heart that the twins shared was removed from her chest and reconstructed in Angela.

From this perspective the dilemma was not simply choosing between two deaths and a small chance at life for one. The issue of *how* deaths occur is an essential moral ingredient in describing such situations. The dilemma is more properly expressed this way: Without separation there are two deaths, both resulting from the twins' anomalous though natural condition that they were born with. With separation, one child has a small chance at life, but the other's death comes at the hands of the surgical team. Without separation two deaths are allowed to occur; they are accepted. With separation one death is avoided in the short run but one death is caused. It was this moral fact, that they would have been agents in causing Amy's death, that gave pause to health care professionals at Loyola. Their concern was rooted in the venerable, though presently controversial, Hippocratic tradition that doctors and nurses should not kill patients.

This perspective becomes clearer if the circumstances of the case are changed imaginatively (Dougherty 1993). Suppose that Amy and Angela had been born twins but born separately and each with a lethal heart defect. Doctors predict that both will die if nothing is done. However, there is a small chance for Angela if Amy's genetically matched heart can be removed and used to reconstruct Angela's heart. Most health care professionals and lay people—even most parents—would find this suggestion morally outrageous. Of course, were Amy to die even moments before Angela's expected death, surely she could be a heart donor for her sister. The moral point, however, is that Amy's death would have preceded the removal of her heart. In this respect, she would have been a normal heart donor. The removal of her heart would not have been the cause of her death; she would have died already. However, in the operation, Amy died not before her heart (or her portion of it) was taken but immediately afterwards, and, arguably, as a direct result of it.

The question of whether or not Amy's death was the direct result of the separation operation is an important one since health care professionals frequently do things that contribute to death or to the hastening of death. Such acts can be considered indirect forms of killing. Though sometimes controversial themselves, these acts are generally not considered violations of the Hippocratic tradition's ban on killing patients. For example, increasing the levels of sedation for a dying patient even to the point where his or her life is shortened by days or even weeks, is generally morally acceptable if the goal of the sedation is to ease the terminally ill patient's pain. Life support systems are withheld or withdrawn from terminally ill patients in hospitals across the nation in ways that may be said to contribute to their deaths indirectly. The ethical question in the Lakeberg case is not whether the removal of Amy's heart contributed

to her death—it plainly did. The ethical question is whether this form of killing is direct and therefore morally unacceptable or indirect and therefore morally acceptable.

One framework for elaborating the distinction between direct and unacceptable versus indirect and acceptable killing is one that would have been (and perhaps was) congenial to health care professionals at Loyola: double-effect analysis, long a staple of Catholic medical ethics. According to this analytic framework, an act of killing is indirect and thus morally acceptable only if it meets all four of the following conditions (Beauchamp and Childress 1994). First, the act itself, considered independent of its effects, must be morally good or neutral. Put another way, the act itself cannot be wrong. Second, only the good effect or effects of the act can be intended directly. The bad effect or effects can be foreseen and tolerated but cannot be intended. Third, the bad effect of the act cannot be the means for achieving the good effect. Finally, the good effect or effects must outweigh the bad effect or effects. (The last condition is the lesser-of-two-evils standard, but it is used only in conjunction with the other three conditions that forbid doing directly any act that is morally wrong.)

The bad effect of hastening death is not itself the cause of the good effect of relieving pain.

The usefulness of this framework is clear in cases of sedating terminally-ill patients. Administering morphine in a medical setting is a good or neutral act. The intended good effect is relief of pain. The bad effect that is foreseen and tolerated is shortening the patient's life. But this shortening is not directly intended. (In acts of euthanasia or doctor-assisted suicide where a deliberately lethal overdose is employed, patient death is directly intended. These acts cannot be justified by double-effect analysis.) The bad effect of hastening death is not itself the cause of the good effect of relieving pain. Finally, in the context of an inevitable and proximate death, relief of pain generally outweighs whatever benefits are lost due to a small shortening of life.

Is such an analysis applicable to the killing of Amy Lakeberg? Was the killing of Amy indirect and therefore morally acceptable? One notorious problem with double-effect analysis lies in articulating an appropriate description of the act itself; was it morally good or neutral? If, for example, the act is described merely as heart surgery, then it is plainly good or neutral since heart surgery is done routinely to save lives. On the other hand, if the act is described as removing that portion of a beating heart that motors Amy's circulatory system—as seems more accurate—it is hard to characterize it as a good or neutral act. Are there other cases in which removing a beating heart from a living patient is a good or neutral act? The Lakebergs' separation may therefore fail the double-effect test on the very first condition.

With respect to the second condition—intending only good effects—the good effect of preserving a chance for life for Angela Lakeberg was the direct intent of all involved. The bad effect of causing Amy's death was foreseen and tolerated. The morally critical question remains: Was Amy's death directly intended? Again, there seems to be two ways of construing the matter. No one intended Amy's death in the way that a murderer or an executioner intends death. Psychologically, therefore, there was no intent to kill Amy. On the other hand, if the action is described as the removing of her heart (or the portion of a heart on which she depends), it is hard to avoid the implication that the intent of Amy's death was contained directly in the act itself; it is objectively in the act, so to speak. It would be hard to conceive of circumstances in which it makes sense to say that an agent intends to remove a patient's beating heart but does not intend that he or she should die. In fact, such a claim would be dismissed as an obvious deception (or self-deception), like a murderer's defense that he only meant to pull the trigger but not to fire the gun, or intended only

that a bullet should pass through the victim's heart but not that she should die. In a double-effect analysis, separation may therefore fail to meet the second condition as well.

The third condition—that the bad effect cannot be the means for achieving the good— also is problematic. The good effect of giving Angela a chance at life could only be accomplished by removing the portion of the heart upon which Amy depended, thus causing her death. Amy's death was a necessary condition—the means—for extending Angela's life. Therefore, it appears that the separation failed the third condition as well. Amy's death—the bad effect—was the means for Angela's chance at survival.

How can life, mortality, quality of life, advancement of science, and money be weighed on the same scale?

The fourth condition of double-effect analysis—that the good effect must outweigh the bad—requires comparing the good and bad effects of the separation. The good effects include extending Angela's life by a number of months. (She lived nearly a year, but it is unclear when both twins would have died without the separation.) Surgical techniques and methods of postoperative care were probably improved; that is, there were research benefits. The Lakeberg family and many of the health care team have the satisfaction of knowing that everything possible was done to save Angela's life. No doubt, there were also many intangible goods that occur whenever efforts are expended to care for a vulnerable human being. The bad effects include shortening Amy's life (compounded by the moral wrong of direct killing, if that was the case), the relatively brief life Angela lived, the pain that she experienced during her postoperative months in the NICU, and the massive amount of time, effort, and money expended to achieve this meager result.

Difficulties that stand in the path of definitive weighing of such good and bad results are legend. First is the problem of incommensurability. How can life, mortality, quality of life, advancement of science, and money be weighed on the same scale? Second is the problem of uncertainty. With benefit of hindsight, the brevity of Angela's survival makes the decision to separate the twins appear less defensible. But in the context of the decision, this outcome could not be known (even though there was every reason to believe it). Had Angela survived and thrived—had she become a healthy and happy child, teen, and woman—separation would have appeared a very good bargain. Last is the problem of assessing the importance of research and advancment in medical care. How, for example, should one assess the benefits gained by coping with the unique challenges of Angela's postoperative period? Suppose more was learned about providing ventilator support for other infants with breathing problems. Theoretically, this new knowledge now would be at the service of all infants who need respiratory support, an indefinitely long list of potential beneficiaries. The ability to benefit an indefinite future shows why the imperative of medical research is both strong, yet also seductive. How should potentially endless but speculative benefits be weighed against Angela's real but inarticulated experience?

Even after admitting these difficulties in applying the fourth condition, we must make a judgment. Knowing what we now know about the brevity of Angela's life, the most reasonable view is that the bad effects outweighed the good. Moreover, when the choice was made, the likelihood was that the bad effects would outweigh the good.

It seems fair to conclude that the separation of the Lakeberg twins cannot be justified within the double-effect framework. The act of removing Amy's heart was not good or neutral. Her death was intended directly in the act of separation. Her death was the means by which her sister was given a chance to live. The good produced probably does not outweigh the bad. Amy Lakeberg's killing cannot be considered indirect. It was a direct killing incompatible with the main thrust of the Hippocratic ethic: First, do no harm.

So Much for So Little

Attempting to balance the good and bad consequences of the Lakeberg separation inevitably raises questions of justice. Can the amount of time, effort, and money expended on Angela Lakeberg be justified? Was it a just choice, when everyone admitted that the chances of success were exceptionally small and the costs high?

In order to set a framework for pursuing the justice issue, recall the inadequacies of the American health care system. About forty million Americans have no health insurance whatsoever. A number at least that large have inadequate health insurance. The health care infrastructure in America's cities and rural areas is fragile and crumbling. There is no primary health care network. The long-term care "system" is inadequate, stressing families, and rapidly bankrupting the Medicaid program.

While these access problems remain unsolved, the United States spends more than any other nation on health care, both in absolute dollars and as a percentage of the gross domestic product. Presently, more than one of every seven dollars in the overall economy goes to health care; by the turn of the century health care may well consume one of every five dollars.

Against this backdrop the Lakeberg surgery and postoperative care appear to be excessive in a system that combines serious deficiencies in access with uncontrolled spending. It is a paradigmatic example of the system's tendency to favor expensive, high-tech, aggressive interventions over prevention, primary care, and public health efforts. Would the health care system have found a way to get the uninsured Lakebergs routine pediatric care for their children had the twins not been conjoined?

We must take care in exploring the justice issue so that we do not devalue the life of Angela Lakeberg. Our moral and religious traditions support the view that regardless of the brevity of her life and its compromised quality, Angela Lakeberg was a person with dignity, and her life was literally priceless. Problems of justice in health care often turn on this dilemma: while every human life is priceless, no health care intervention is. Excess spending on a small chance for one individual is not only incompatible with service to the common good of the health care system in general; it also uses money that could assist and save the lives of other priceless human beings. Considering only money spent in this case—in excess of $1.2 million—how many infant deaths might have been avoided had that money been spent on prenatal care and educational programs for high-risk pregnant teenagers in Philadelphia?

Another difficulty regarding issues of justice is the conflict between commutative or person-to-person standards of justice constitutive of the Hippocratic ethic, and distributive or community-based standards of social justice. From the former point of view, individuals should get what is due to them from other individuals. Promises must be fulfilled, for example, and debts repaid. The commutative obligation of a physician to a patient is to put the patient's interests first, and to do everything reasonable for that patient, regardless of cost or impact on others. From the point of view of Angela's caregivers, justice meant doing everything possible for Angela. It did not mean limiting care for Angela so that some other social agenda could be fulfilled, regardless of how worthy that social agenda might be.

However, from the social justice perspective fairness is distributive. It lies in seeking to achieve equity in the community as a whole. Angela's first-rate neonatal intensive care unit is in a city with poor and underserved populations, a fact typical of all larger American cities. In addition to unmet human needs, there are specific deficits in the health care delivery system in the immediate vicinity of Angela's exorbitantly expensive care: lack of insurance, financial and cultural barriers to care, misused and stressed emergency rooms, and so on. These facts raise pressing questions of distributive justice. Angela's doctors may not have had an immediate obligation to correct social imbalances, but surely someone does.

Correcting these large patterns of social injustice, however, is not something that can be done

on a retail basis. The system as a whole must be corrected. This further complicates an assessment of the justice of the investment in Angela's care. To see this point, consider the multiple sources of payment for Angela's surgery and postoperative care. The Medicaid program of Indiana (the Lakeberg's home state) paid for some of it. Private donations helped. Perhaps there were funds at Children's Hospital of Philadelphia to support research and innovative surgeries. Some of the cost will be written off as bad debt or collected from insured patients through cost shifting. In other cases where large amounts of money are spent for small chances, private health insurers or Medicare may be payers.

With this picture in mind, imagine that someone at the time of the decision to separate the twins confronted the Lakebergs and insisted that it would be unjust to spend so large an amount of money on so small a chance. The Lakebergs could have responded rightfully that it is far from clear that the system would be more just if the Indiana Medicaid program spent less that year, less by the amount saved on Angela Lakeberg; or that voluntary contributions would better be spent on any number of things (including frivolous things) had donors not provided those dollars for Angela. The Lakebergs might also have retorted that it would not be unjust to take a chance on life for Angela at the price of the small impact the cost of her care would have upon the cost shifting done in virtually every hospital in the nation. There simply is no link conceptually or practically between denying care to the Lakebergs and providing it to other individuals with unmet health care needs.

The real choice faced was not one between an expensive operation for Angela Lakeberg or prenatal care for Philadelphia teenagers. Philadelphia teenagers would have gone without prenatal care whether or not Angela had the operation. The problem of social justice in the health care system is that the cumulative impact of cases like the Lakeberg's contributes to the injustice of the overall system. Yet denying care in one such case—even an extraordinarily expensive case—contributes little to achieving greater justice and perhaps contributes nothing at all. It is not at all clear, for example, that justice is served by denying conjoined twins expensive interventions if the only consequence is greater profits for private health insurers. The fragmented character of the American health care system simply does not allow for morally clean trade-offs in individual cases. It does not give us the confidence we need to deny Angela Lakeberg what her parents desire *because* the money saved would be spent for something morally better.

The social justice question, therefore, cannot profitably be asked on a cased by case basis, but must be asked. One way to focus the question more usefully is to ask whether an expensive intervention like Angela Lakeberg's should be included in a basic benefit package that all should have as a matter of right. If the health care system could be reformed to guarantee that all Americans have a decent minimum of care, would a million dollar price tag for a one percent chance to survive past infancy be a covered benefit? To put the question this way is to provide an obvious answer. A reformed health care system with a clear overall rationale, that is, a system with a reasonably utilitarian approach to maximizing the benefits of its own resources, could not commit itself to such exorbitant spending for such a small chance for such a small number of individuals. It would simply be unfair.

Health care deals most intimately with the great equalities of human experience—body, mind, and death.

A reformed system would likely allow significant investment in research including innovative surgical techniques. A case might be made that the Lakeberg operation, if considered a research project, could draw funding from that account in a national health care scheme. While this may be true, justice in the disbursement of research fund-

ing would also have to take the common good into account. Based on the small numbers of conjoined twins who could benefit from what might be learned in the Lakeberg case, it is likely that funding for such surgeries would be given a very low priority. The potential benefit to society even from a dramatic breakthrough in this area would be negligible. As the case turned out, so was the real benefit to Angela Lakeberg.

Would justice forbid the Lakebergs themselves from raising sufficient funds to pay for the operation from donations or to pay for it directly were they wealthy enough to do so? For several reasons, a health care system is more equitable and more likely to be politically successful if it has one basic benefit package and one standard of care for all. The value of equality is more pertinent to the health care arena than to other areas of the economy. Health care deals most intimately with the great equalities of human experience—body, mind, and death. Moreover, the public is likely to support a program politically if everyone relies on it for care, as opposed, for example to a program that serves only the poor. However, American traditions of liberty are so important and so deeply instinctive in the national consciousness that even were there a successful health care reform that guaranteed care to all, two tiers of health care would be inevitable: one tier for those using the basic benefit package and another for those who buy above. Therefore, while it offends some aspects of justice, it would not be wrong morally and certainly would not be unacceptable politically for patients with independent means to buy procedures not covered by a basic benefit package—including the separation of conjoined twins.

The justice issue at stake is complex, yet some lessons can be drawn. Although there is much to be admired in the Hippocratic ethic that motivates health care professionals and others to move heaven and earth for single patients, the Lakeberg case represents a serious, perhaps the most serious, dysfunction in the American health care system. Not only does it express the system's disposition toward high tech, expensive, acute care interventions, but it also represents America's collective unwillingness to set health care priorities that serve individuals while also honoring a commitment to the common good. The Lakeberg case is a reminder that despite recent setbacks, health care reform remains an insistent moral imperative. A new system must set priorities designed to achieve a more just distribution of health care and health.

When No Is the Right Answer

Separating the Lakeberg twins was the wrong thing to do for two reasons. The operation killed one of its patients and did so in a manner that cannot be justified on the traditional grounds of double-effect. The expenditure of so much for so little was unjust even if the overall health care system is itself unjust. Such a procedure could not be part of a reasonably fair basic benefit package in a reformed health care system. Loyola professionals recommended a course that should have been taken. The twins should have remained together. They should have been kept as comfortable as possible until their inevitable deaths.

But when Loyola said no, Children's Hospital of Philadelphia said yes. There is little consensus on the double-effect analysis provided here. Indeed, there is a growing acceptance of direct medical killing, as the annual number of elective abortions indicates and the doctor-assisted suicide movement suggests. There is no basic benefit package to appeal to and the prospects for systemic reform are bleak for the near future. Under these conditions, if no is the right answer, how can that answer be given in the present environment? Three strategies are possible.

Laws or regulations might be made that would build "no" systematically into certain situations by forbidding the killing of patients in operations, even in Lakeberg-type situations. Medicaid might refuse to fund procedures whose outcomes are as speculative as this kind of twin separation; bcause regulations take years to develop, this strategy is not likely to prove helpful in the near future.

A second strategy is to rely on the marketplace, where saying no—no to choice of doctor, no to

hospitalization, no to specialty care—is an increasing phenomenon as managed care becomes the norm in the nation. Such plans may indeed prevent the Lakeberg-type operation from occurring with any frequency. It is hard to imagine, for example, that had the Lakebergs been members of an HMO that this operation would have been authorized by their plan.

The problem with this strategy, however, is that while its results may be consistent with a moral analysis, the motive for saying no in the marketplace has little to do with morality. The main goal of managed care is not to improve access or enhance quality. It is unabashedly focused on cost containment. Thus while managed care plans may rule out some procedures based on exorbitant costs, this will not be done so that money can be shifted to higher social priorities. Nor will it be done because of the moral questions raised by killing patients. In fact, there is reason to fear that if doctor-assisted suicide becomes widespread, managed care plans will develop protocols determining when doctor-assisted suicide is recommended or expected. It will always be cheaper to kill patients than to provide additional care. Therefore, the marketplace may help in saying no under some circumstances, but not always the right circumstances and seldom for the right reasons.

The third strategy is the simplest and most difficult. Health care providers and institutions must develop the moral muscle to say no when no is the right answer. Greater willingness to say no will give patients pause and force them to a deeper level of moral reflection. This will serve to reduce the number of morally questionable cases.

Although this is a simple recommendation, it is also a very difficult one in the present moral climate. A seldom articulated but increasingly influential view among health care providers is that respect for patient autonomy entails providing each service patients want, or at least each service they want and can afford to pay for. To say no to a patient on moral grounds is, on this account, a vestigial form of paternalism.

But this view is unacceptable. It omits the fact that doctors, nurses, hospitals, and other health care professions and institutions are partners with patients. What patients want is only one-half of the moral equation. The other half involves what health care providers agree to do. Their own individual and corporate consciences are also at stake in decisions about questionable procedures. Too many doctors and hospitals, while theoretically admitting the possibility of conscientious objections to this procedure or that, in fact do many things for patients that they believe to be wrong, even contrary to the interests of the patients themselves. This represents a dangerous deprofessionalization of health care and a triumph of the view that health care is a commodity that can be served up in any manner the customer demands. Patient autonomy is indeed an important corrective to old-style medical paternalism. But the unwillingness to say no to anything patients demand is a dangerous moral relativism that undermines professional standards.

The Lakeberg case was tragic from the outset. There were no good choices. But the choice that was made was nonetheless the wrong choice. Laws and regulations may eliminate some choices like this in the future. Certainly the marketplace will make some choices like this impossible. In the final analysis, however, health care professionals and health care institutions must use their own moral reasoning and reach their own decisions before agreeing to partner with patients in such extraordinary ventures. Sometimes no is the right answer. When it is, that is the answer that health care professionals and institutions ought to give.

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