Killing Mary to Save Jodie: Conjoined Twins and Individual Rights

David Wasserman

In September, 2000, British physicians separated month-old conjoined twins, Jodie and Mary, after a failed legal appeal by their parents. Joined at the abdomen, with partially fused spines and a shared bladder, the twins were kept alive by a single working heart and pair of lungs, both on Jodie's side, and presumably both controlled by Jodie's brain. The heart and lungs on Mary's side did not function, but the aorta on Jodie's side fed directly into the aorta on Mary's side, supplying Mary with oxygenated blood. Physicians estimated that if they remained conjoined, both would be likely to die in six months to a year from the strain on the single working heart. Separated, Mary was likely to die immediately, which she did, while Jodie was estimated to have "a 95-percent chance of leading a normal life."

I will argue that the decision to separate the twins was deeply troubling, despite the fact that without the surgery, neither might be alive by the time of this writing. The Court of Appeal upheld the surgery as the only way to defend Jodie against Mary's lethal parasitism. But the claim that Mary was a deadly threat to Jodie, rather than the fellow victim of an embodiment inadequate to sustain them both, cannot be made out from the biological facts alone. The justification for killing Mary rested more heavily than the Court was willing to acknowledge on judgments about their comparative life prospects, judgments that the recourse to self-defense could not avoid or circumvent.

The Legal Case

The twins' parents had come to England to assure better medical care for their children. The hospital in which the twins were born wanted to separate them, to give one a reasonable chance for prolonged life. The parents sought judicial intervention to stop a procedure which they regarded as murdering one child to save another. Both courts that heard the case declared that the twins were persons, with lives of equal intrinsic value. But both ruled against the parents, on different grounds.

The trial judge allowed the surgery on the ground that it would be in the interests of Mary as well as Jodie, or at least not against Mary's interests, since, if she was not separated, her few remaining months would "be simply worth nothing to her, they would be hurtful." He also found that the separation would not be a "positive act," but an omission akin to the withdrawal of life support that British courts had already upheld.

The Court of Appeal rejected both rationales offered by the trial judge, the first on the ground that Mary had an interest in her continued life, however brief and limited. As Lord Justice Ward concluded, "It cannot be in Mary's best interests to undergo surgery." Moreover, the separation could not be treated as a mere withdrawal of life-support: "Surgery would amount to a positive act of invasion of [Mary's] bodily integrity with no medical or other benefits flowing from it."

Lord Justice Ward, then, agreed with the parents that the surgery would "save Jodie but murder Mary." And while he maintained that it was legitimate to take account of the "actual quality of life that each child enjoys and may be able to enjoy," he sought to avoid "a balancing of the Quality of Life in the sense that I value the potential of one human life more than another." He concluded that he could uphold the surgery without such balancing, because Mary could exercise her equal right to life only by violating Jodie's:

> She is alive, because and only because, to put it bluntly but nonetheless accurately, she sucks the lifeblood of Jodie and she sucks the lifeblood out of Jodie. . . . Mary's parasitic living will surely be the cause of Jodie's ceasing to live.

Jodie had a right to defend herself even though Mary's threat was obviously innocent, and not even unlawful:

> The six-year-old boy indiscriminately shooting all and sundry in the school playground is not acting unlawfully because he is too young for his acts to be so classified. . . . [K]illing that six year old boy in self-defence would be fully justified and the killing would not be unlawful. I can see no difference in essence between that resort to legitimate self-defence and the doctors coming to Jodie's defence and removing the threat of fatal harm to her presented by Mary's draining her life blood.

If Lord Justice Ward saw Mary as a deadly parasite, others saw her as a sacrificial victim. One commentator declared that "because of her disabilities, Mary was deemed unfit to live, a medical freak now only useful to cannibalize for her sister's benefit." Another held that the surgery denied Mary "life and dignity" and reduced her to a "quarry for raw materials." Bioethicist Alice Dreger has argued that such a sacrifice would never have been permitted if the twins had "not been born with a strange conformation":

> The logic that it is better to save one patient than to lose two is not applied elsewhere. Imagine, for example, that Jodie and Mary had been born separate, conscious, identical twins, and that one had a bad heart while the other had a bad liver. Imagine also that no appropriate brain-dead organ donors were readily available, and one or both twins would die shortly without replacement organs. Would we decide that it was acceptable to kill one of the girls to harvest an organ and save the other in that case? No.

Dreger offered a second analogy against Lord Justice Ward's view that the separation can be justified as defending Jodie against Mary's deadly parasitism: "If I were accidentally trapped with another person in a time-lock vault that had an air supply adequate for one or the other but not both of us, it would not be right for me to intentionally kill him to try to save myself even though he was, in effect, unintentionally killing me." On Dreger's view, then, Mary's irregular embodiment subjected her to a surgical sacrifice that would otherwise be out of the question.

Two Views of the Twins' Embodiment

Dreger's view of Mary as a sacrificial victim, no less than Lord Justice Ward's view of Mary as an unintentional aggressor, reflects a contested understanding of the twins' "strange conformation." If the twins' separation can be seen as a forced organ transfer, it is only because the organs in Jodie's body are seen as belonging to Mary as well. On this understanding of their embodiment, Mary and Jodie share a single, asymmetrical body, and each has an equal interest in every part of it (except, perhaps, each other's brains, heads, and necks). The surgery is like a forced and unequal partition of jointly-owned property, that transfers Mary's half interest in the working heart and lungs to Jodie. But Mary can be seen as having that interest at the outset only because those organs are under her skin as well as Jodie's. Clearly, no one else besides Mary would have a claim to the heart and lungs that repose in Jodie's body (or less tendentiously, in the body cavity closest to Jodie's head).

On the other hand, it is only if the working organs are seen as belonging exclusively to Jodie that Mary can be seen as an aggressor. It is only by the use of those organs that Mary endangers Jodie's life; she does not threaten her in any more direct way, as if, say, she were the vector for some deadly pathogen.

If the organs are Jodie's alone, separating Mary is not like killing the other person in a time-lock vault with a limited air supply: the analogy breaks down because neither person trapped in the vault has exclusive title to the air. On this view of the twins' embodiment, Jodie is not competing with Mary for a common resource but defending her organs against Mary's wrongful appropriation. Shouldn't Jodie (like the man who finds himself attached to an ailing violinist in Judith Jarvis Thomson's hypothetical) be allowed to sever a life-threatening attachment to another being, however vital that attachment is to the other? A proponent of surgery could turn Dreger's claim of discriminatory treatment around: if the surgeons do not operate, Jodie would be denied a right to self-defense she would otherwise enjoy, just because of the "strange conformation" that places her aggressor under the same skin.

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How do we adjudicate between these conflicting understandings of the twins' embodiment? How can the configuration of their bodies (or body) determine their ownership of the vital organs, let alone determine whether the surgery constitutes a forced organ transfer or a defense against lethal aggression?

Different aspects of the twins' embodiment could be adduced to support opposing conclusions about their title to the vital organs in Jodie's body cavity. The fact that those organs were located on Jodie's side made them look like they belonged exclusively to her, an impression strengthened by the fact that Mary had her "own" set of organs, however inert. On the other hand, the fact that Mary and Jodie came into the world with a shared bladder, fused spines, and an extensive network of vascular attachments, particularly a direct connection from one aorta to the other, suggested that they were structured or conformed to share their vital organs.

Our intuitive judgments about the ownership of the twins' organs are strongly affected by the details of their embodiment: by how extensively they are conjoined and by how they came to depend on the same set of vital organs. If the two had been connected only by an umbilical cord, or if it turned out that the organs on Mary's side had become dysfunctional as the result of trauma that occurred sometime after twinning, it would be harder to see Mary as sharing, or having an interest in, the organs in Jodie's body cavity. In contrast, it would have been much harder to treat the organs as Jodie's alone if the twins had been more symmetrically embodied, with one centrally located heart and pair of lungs.

To some, maybe most, observers, the twins' actual embodiment falls closer to the former cases than the latter, leaving little ambiguity about the ownership of their organs. The Court of Appeal described each twin as having her own set of organs, and critics often adopted its usage even as they disputed its conclusions. It does seem natural to speak of the working organs as "Jodie's," and labored to speak of them as "the organs in Jodie's body cavity." But conceding this does not eliminate the moral ambiguity about Mary's claim to the continued use of those organs. The fact that we are inclined to speak of the organs as Jodie's hardly compels us to treat her as having the same rights in those organs against Mary that a normally embodied child would have in her organs against the rest of the world.

Even if they were clear, consistent, and uncontested, our social practices regarding privacy and bodily integrity would be difficult to extend to cases of conjoined embodiment.

As Jeffrey Reiman has observed, we have developed, under the rubric of privacy, a complex set of social norms that ground the rights a normally embodied person has in "his" body. Those practices are informed, but not dictated, by the facts of normal embodiment— by the special control and access that individuals have to particular bodies. There are a variety of ways that a society could acknowledge that special control and access, and even within our own society there is controversy about how we should do so. There is protracted disagreement, for example, about how extensive a right people should have to destroy their bodies, dispose of their remains, or profit from the commercial development of their cell lines. Moreover, the autonomy that our social practices accord to individuals over their bodies is limited by the threat of adverse consequences. If we no longer believe, with Oliver Wendell Holmes, that a person's freedom to procreate may be curtailed to prevent the transmission of a genetic defect, we still believe that a person's freedom of movement may be curtailed to prevent the spread of an infectious disease.

Even if they were clear, consistent, and uncontested, our social practices regarding privacy and bodily integrity would be difficult to extend to cases of conjoined embodiment. The autonomy a discretely-embodied person enjoys over her own body rests to some degree on the recognition of a domain of self-regarding activity, where the risks and benefits of a course of action redound far more directly to that individual than to anyone else. The more extensive and intimate causal nexus between conjoined twins would make it far more difficult to delineate such a domain for each twin with respect to the other. We might well recognize limits on what each twin could do with, or to, her own body, based on the interests of the other twin, limits that we would reject, or that would have no counterpart, for physically-discrete people. Thus, Kenneth Himma suggests that we would prohibit suicide by one adult conjoined twin if it would cause the other to die, even if we normally permitted adults to kill themselves. But we can only speculate about the extent and kind of limits we would recognize. In some cases, we might be deeply uncertain or divided. How, for example, would we respond to the demands of a 22-year-old Jodie to be separated from her barely-sentient sister, when both would otherwise die within a year, and their separation would prolong Jodie's life by at least a decade while causing Mary's immediate death? If we are uncertain how to resolve the conflicting claims of conjoined adults, we can hardly expect a clear resolution of the conflicting claims raised on behalf of conjoined infants. Thus, even if the organs in Jodie's body cavity can be said to be hers, the kind of property she has in those organs, and her right to exclude Mary from their use, are by no means clear.

If we did not regard the twins' embodiment as morally ambiguous, the resolution of the case would be straightforward, however wrenching and painful. For those, like Lord Justice Ward, who see Mary as having had no more claim than a normal twin to Jodie's vital organs, the state had a compelling interest in enforcing Jodie's right against a lethal imposition, even if the parents favored it. For those, like Dreger, who see Mary as having had as much of a claim to the organs as Jodie, the state would have had a compelling interest in preventing their separation even if the parents had favored it. The resolution of the case is far more difficult if neither twin can be said to have an overriding right which the state is obliged to enforce.

Responses to Indeterminacy

We have two powerful impulses in the face of such indeterminacy, impulses which in the case of Jodie and Mary pull us in opposite directions. The first is to let the parents decide, not as surrogates for the twins, a role for which they have no special insight or expertise, but because they have to live, intimately, with the consequences of the choice. The second is to decide on the basis of the expected outcome—to compare the duration and quality of the lives the twins would likely have if they were separated or allowed to remain conjoined — their expected life spans, and their potential levels of consciousness, social interaction, and independence. Both options are problematic. Typically, parents are granted authority over decisions concerning their children when that authority is necessary for them to maintain their supervisory roles over their children's upbringing, when they have special insight into their children's interests, preferences, and values, or when the stakes are too low to require outside intervention. Clearly, none of these conditions apply to the case of Jodie and Mary.

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Perhaps the strongest reason for the recourse to parental autonomy is also the most troublesome: to avoid the alternative of deciding the twins' fates on the basis of public judgments about the comparative quality of their lives. Jodie was not only more "viable" than Mary, but more aware, alert, and responsive, capable of becoming, with surgical assistance, a more or less normal adult. Despite the courts' insistence that they regarded Jodie and Mary as moral and legal equals, it appeared to many observers that Mary was sacrificed not—or not only—as a threat to Jodie, but as an inferior being, whose interest in continued life was accorded far less weight. That conviction found support in the language that Lord Justice Ward used in upholding the twins' separation. Mary was condemned for her "parasitic living;" for "sucking the lifeblood out of Jodie." A parasite is not merely a threat; it is a lower organism.

Proponents of surgery might respond that the decision to separate the twins did not require any judgment about the comparative quality of their lives, let alone the denigration of Mary's; they might insist that the choice was simply between saving one twin or losing both. This response would be plausible if both

twins would have died almost immediately without surgery. Unlike Dreger, I would not find it objectionable to apply "the logic that it is better to save one patient than two" in such circumstances, even if saving the one meant killing the other. (Indeed, if both would have died almost immediately, it could be argued, even without recourse to self-defense, that Jodie's right to be rescued, rather than any calculation of the comparative benefits of saving her, justified the surgery. If one of the men in Dreger's time-lock vault would die almost immediately no matter what was done, while the other could survive alone, it might be justifiable to cut the air supply of the first, briefly accelerating his death.)

But the actual choice in the case of Jodie and Mary was not between the almost-immediate death of both twins and Jodie's survival. Even proponents of surgery conceded that it was likely to deprive Mary of six months or a year of sentient existence, a life during which she might well experience not only pleasure and pain, but some rudimentary forms of bonding and attachment. The choice was not between saving one child and letting both die, but between consigning two children to short, limited lives and ending one of those lives abruptly to greatly prolong the other. I suspect that the inclination of the proponents to treat the latter choice as no different than the former reflects the assumption that several months of minimally sentient existence would have so little value for Mary that she could not be said to have an interest—at least a morally cognizable or legally enforceable interest—in their preservation.

It may be possible to recognize Mary's interest in continued life while concluding that sufficiently large disparities in the length and quality of life *should* be decisive in a case like this. But it is important to appreciate the extent to which our judgments depend on the disparity in the quality, as well as the length, of the twins' lives. What if Mary, though lacking central nervous system control of the functioning heart and lungs in Jodie's body cavity, had a normally developing brain, and Jodie, though having control of the heart and lungs, was barely sentient? Mary would be no more or less of an innocent threat than she was in the actual case, although she might look less like a parasite; the only difference would be in the twins' cognitive capacities and potential. I suspect that many people who favored separation in the actual case would at least hesitate to approve it in these circumstances, where it would bring immediate death to the more conscious child, depriving her of six months or a year of life, and indefinitely prolong the life of the less conscious child. (Or, perhaps less fancifully, consider a case where twins with vast disparities in cognitive potential were more symmetrically embodied, in such a way that surgery could indefinitely prolong the life of either one, while immediately killing the other. Many of us, I suspect, would be inclined to save the more conscious child, rather than choose randomly or let both die within a year. But we could hardly justify that choice as a response to lethal aggression.)

Even if we think that some disparities in the twins' cognitive capacity and potential should make a difference in resolving such conflicts, we may be reluctant to have our courts or other public agencies decide how much of a disparity should matter. In part, our reluctance reflects the fact that line-drawing would be a contentious, divisive, and painful exercise. In a society with a plurality of reasonable conceptions of the good, there is likely to be substantial disagreement about the comparative quality of different lives. Leaving the decision to the parents would prevent such contentious judgments from becoming legal precedent or public policy. But our reluctance to impose our judgment on the parents also reflects the fact that we have reason to distrust our judgment, to fear that we will give too much weight to perceived differences in quality, and confuse quality with biological normality.

The excessive sway of quality-of-life judgments is suggested by variations where Mary does not pose an imminent threat to Jodie's life, but merely threatens her longevity, mobility, or quality of life. I find myself all too willing to kill Mary to increase Jodie's life expectancy from 30 or 35 years to 60 or 70 years, or to spare Jodie the burden of dragging Mary around the rest of their lives. In these circumstances, it would be hard to justify separation even if the self-defense analogy was apt—we should hesitate to kill innocent aggressors who threaten only reduced life expectancy or chronic impairment.

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The medical response to other conjoined twins gives us further reason to distrust our quality-of-life judgments about such cases. Dreger suggests that the grim prognosis often given for such twins may reflect a dread of, rather than doubts about, their conjoined survival. Doctors may consciously or unconsciously exaggerate the likelihood of their death because they regard their conjoined survival as no better, or worse, than death. She may well be right, based on anecdotal evidence of other conjoined twins who far exceeded the life expectancies announced by the doctors who wanted to separate them, and on the way the doctors describe the

prospects of their survival. As one surgeon declared, "It is appropriate to separate even in situations where one won't survive. Going through life conjoined is just not an appealing option." Even the lawyer for the parents of Jodie and Mary described the twins' survival as a "horrible spectre." When we consider the rewarding lives that some conjoined twins have led, despite severe physical challenges and morbid public scrutiny, it becomes apparent that this view of conjoined survival is distorted by ignorance and prejudice.

In the case of several conjoined twins, separation was attempted even when the odds of one or both twins surviving conjoined were conceded to be higher than in the case of Jodie and Mary, or when the odds of one or both twins surviving their separation was lower. The 1993 case of the Lakeberg, Minnesota twins is an example of the latter: closely conjoined twins with a single heart and liver and with little chance of surviving together were separated by an operation that was virtually certain to kill one of them immediately and unlikely to significantly prolong the life of the other; the one died during surgery, the other ten months later. To be sure, the decision in cases like Lakeberg are explained in part by a desire to increase the odds, however slightly, of *someone* surviving, but that desire appears to have greater sway when the advertised benefits would result from anatomical normalization.

It would be naive to think that the parents of conjoined twins would not make equally questionable judgments about the comparative quality or value of their children's lives if the decision were left to them—after all, it was the Lakeberg parents who insisted on the risky separation of their twins. Even parents who, like the parents of Jodie and Mary, initially saw their twins' fates as bound together by God or Nature, would face powerful social and economic pressure to take a more utilitarian view. But they would make their decisions privately, without creating destructive precedent. If we take the decision away from parents, particularly parents fervently opposed to intervention, we may take a small but significant step towards establishing the priority of anatomically and cognitively normal lives in our health care policy, and perhaps towards state-sponsored eugenics. We should be terribly wary of ordering the death of a child, even a sickly, oddly-formed, and barely sentient child, because we see her as a parasite on a child with greater health, vigor, and cognitive potential.

On the other hand, our experience with the "privatization" of reproductive decision-making has made it clear that the absence of direct state coercion does not mean the absence of coercive social pressure or distorting social bias. There is something to be said for a critical public examination of the kind of judgments that many parents will privately make, or will feel compelled by social or economic pressure to conform to. What is clear is that quality-of-life judgments will play some role in the terribly difficult decisions that often have to be made about conjoined twins. Whether or not it is better to assign those decisions to parents or the state, it is important to have a public debate about the role that quality-of-life judgments should play.

David Wasserman
Institute for Philosophy and Public Policy
School of Public Affairs
University of Maryland
dw79@umail.umd.edu

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Sources and useful readings: Court of Appeal (Civil Division) Case No: B1/2000/2969, September 22, 2000; Katie Grant, "On a Calculated Taking of Life, " *The Scotsman* (November 12, 2000); Daniel Johnson, Comment, *Daily Telegraph* (November 7, 2000); Alice Dreger, "Why Change the Rules for Twins Like Them?" *Washington Post* (*Outlook*, September 24, 2000); Judith Jarvis Thomson, "A Defense of Abortion," *Philosophy & Public Affairs,* vol. 1 (1971); Jeffrey H. Reiman, "Privacy, Intimacy, and Personhood" in *Philosophical Dimensions of Privacy*, edited by Ferdinand Schoeman, (Cambridge, 1984); Alex John London and Lori P. Knowles "The Maltese Conjoined Twins: Two Views of Their Separation," *Hastings Center Report* (January-February, 2001); David Thomasma, "The Ethics of Caring for Conjoined Twins: The Lakeberg Twins," *Hastings Center Report* (July-August, 1996); George Annas, "Siamese Twins: Killing One to Save the Other," *Hastings Center Report,* (April, 1987); Kenneth Himma, "Thomson's Violinist and Conjoined Twins," *Cambridge Quarterly of Healthcare Ethics,* vol. 8 (1999); John K. Davis, "Commentary on Himma," *Cambridge Quarterly of Healthcare Ethics,* vol. 8 (1999); Kenneth Himma, "Reply to Davis," *Cambridge Quarterly of Healthcare Ethics,* vol. 9 (2000); Natalie Angier, "A Life Less Ordinary," *The Scotsman* (September 30, 2000); Darin Strauss, *Chang and Eng* (Dutton, 2000); Nancy L. Segal and Thomas J. Bouchard, *Entwined Lives: Twins and What They Tell Us About Human Behavior* (E.P. Dutton, 1999).