18. Ibid. 30.
19. Ibid. 81.

CHAINED FOR LIFE: CONJOINED TWINS, IDENTITY, AND THE ETHICS OF SEPARATION SURGERY

Jamie Bronstein
New Mexico State University

Abby and Brittany Hensel are twenty-one-year old sisters, born and raised in Minnesota. Like many other twenty-one-year-olds, they can walk, swim, type on the computer, ride a bicycle and drive a car. Unlike most other sisters, the Hensels are conjoined, and must undertake each of these activities cooperatively, since each sister only has neurological control of one arm and one leg. Sharing one bladder, one rectum, and one set of reproductive organs, the Hensels embody many moral dilemmas about personal identity. One of the Hensel twins might consent to sexual activity using the pair's shared reproductive organs, but if the other twin did not consent, would the sex constitute a rape? If the Hensel twins became pregnant, would they both be the mother? What if one of the twins wanted an abortion and the other did not? If one committed a crime, could a punishment be devised that could target only the guilty party? These questions are disturbing because they reveal the extent to which conjoined twins may lack the moral autonomy that is a crucial element of personhood.

This paper will argue for the routine separation of conjoined twins in those cases where it is possible. I will show that neither biological accounts of personal identity nor feminist accounts adequately describe the complexities of conjoined twins. While conjoined twins have two streams of consciousness and thereby can be classified as two persons under psychological accounts of personal identity, they are temporarily trapped within a single organism in ways that unfortunately and crucially inhibit moral autonomy. Some conjoined twins cannot be safely surgically separated, or, like the Hensels, have grown to adulthood without having been separated in infancy or early childhood. This paper does not propose a solution in such cases. Although adult conjoined twins often say they are content, we can still recognize that each conjoined twin has less-than-optimal autonomy to carry out a life plan. Separation surgery promotes the autonomy that is crucial to the achievement of human flourishing, and should therefore be presumed to be in the best interests of conjoined infants and children when it is physically possible.

To advocate the separation of conjoined twins on the ground that they constitute two "people," it is necessary to consider the other extant viewpoints on the metaphysical status of conjoined twins. Those who propose that humans are essentially biological organisms reject the notion of "personal identity" as question-begging.[1] They focus on the notion that humans are essentially organisms, and argue that it is this that unites humans at each stage of their lives. The human animal passes from fetal development through birth, through a period of "personhood" after certain mental capacities have been attained, and then perhaps into post-personhood, if a human loses her memories or has a devastating injury to higher brain functions.

Eric Olson has set out biological criteria for human identity. We know that a human organism exists because it has certain characteristics: functional organs, a metabolism, an internal genetic plan, and organized growth and development. A single organism has only one life, and will experience only one death. Finally, an organism possesses a boundary that separates it from things that are not it.[2] Although "personhood" is a stage of human development under the biological account, the biological account does hinge on there being a 1:1 ratio between human organism and person.[3]

Conjoined twins challenge the biological criteria of human identity.[4] In some cases the boundary between conjoined twins is unclear, if it in fact exists at all. For example, the Hensels' degree of conjoinment is so major that there is no "best candidate for ownership" of certain body parts.[5] Surgeons routinely "assign" various body parts to one conjoined twin or the other when they perform separation surgery.[6] A second problem is that the numerical identity of conjoined twins seems to be changeable in ways that don't hold true for other organisms. Conjoined twins (let's call them AB) who are born alive seem to satisfy the criterion for being an organism. They may share a heart and a bloodstream. They thus share a single life. Unless they are separated, AB will also experience a common death.[7] If successfully separated, the twins will become two organisms, which calls into question whether they were one organism to begin with.[8] If unsuccessfully separated, the twins may yield only one living organism, calling into question the status of the one who did not survive. Was she a twin, or, since she was unable to function on her own, was she an "extra part?" A similar uncertainty about whether two hemispheres of a single brain can be transplanted into bodies, yielding two "persons," led Olson to propose his biological account in the first place.

Chang and Eng Bunker, the famous nineteenth-century "Siamese" twins, provide a concrete example of the problem stated above. They had only a slight degree of conjoinment, connected by a band of skin at the chest and sharing a liver. But they shared a circulatory system, so that when Chang died, and his heart could no longer pump, the blood pooled in Chang's body. Eng, who had awakened to find his brother dead, spent a few panicky hours alive before bleeding out into Chang. Eng's inability to live without Chang suggests that Chang and Eng were one organism; Eng's psychological distress suggests they were two persons. To make things even more complicated, with modern surgical techniques, Chang and Eng Bunker could easily have been separated, at which point they would have functioned as two human organisms, each with a separate life and, ostensibly, a separate death.

Finally, if conjoined twins are at their essence one human organism, then under the biological account of human identity it is possible for that organism to yield at most

one person during its personhood phase of life. Yet symmetrical conjoined twinning is defined by the presence of two separate, functional brains. If two functional brains are not present, the resulting entity is classified as a human with a parasitic twin, a vestigial twin, or as fetus in fetu. And this second brain "matters" because it is assumed to be the seat of consciousness, not because its brainstem is driving metabolism or digestion.[9] This discussion suggests that in conjoined twins, the "persistence condition" we ought to look at, and privilege, is consciousness.

Some feminist philosophers agree that conjoined twins are an organism with two streams of consciousness, but claim that this is their metaphysical essence—that conjoinment is not a biological error. David Clark and Catherine Myser argue that it is arbitrary and restrictive to propose a 1:1 ratio between organism and person.[10] Margrit Shildrick claims that conjoined twins constitute a single organism, and that we should not be misled in this respect by their failure to conform to some arbitrary norm of what human organisms are supposed to look like. Alice Dreger argues that conjoined twins constitute a single organism but that they have a unique perspective that singletons are unable to appreciate.[11] Shildrick and Dreger both argue that, due to their physical connection, conjoined twins experience life in a similar way to mothers and infants. Babies touch their mothers so much that initially, the babies are unable to differentiate between their mothers' bodies and their own. Shildrick proposes that conjoined twins be considered to have a "dual self" constructed through touch.[12] Finally, Bratton and Chetwynd argue that conjoinment is the essence of conjoined twins, and that an embryo that fails to split completely yields a different form of life than one that fully divides. Depending on their degree of conjoinment and arrangement in space, conjoined twins may constitute a single, poorly-functioning bodily organism enclosing two minds. No matter what the configuration, however, each mind has a claim over the body's organs, all of which must be seen as shared.[13]

There are several problems with the feminist argument that conjoined twins are by their very nature a single organism with a special, shared subjectivity. If conjoinment were in some metaphysical sense the "essence" of conjoined twins, then separation surgery would always result in the death of the original conjoined twin complex and the "birth" of two entirely new entities. This notion seems to rebel against our intuitions, since there are so many points of biological and psychological continuity between conjoined twins and separated twins. If the Hensel twins were successfully separated, Abby would continue to control and receive sensory impressions through her right hand and foot, and Brittany through her left hand and foot (neither can feel the hand and foot on the other side). Abby would continue to remember her own thoughts, and Brittany would continue to remember her own thoughts. Each twin's brainstem would continue to regulate bodily functions, and each twin's DNA to map out future growth.

As for the idea that conjoined twins share a special subjective experience, this is true only in a trivial way (they experience the unique reactions of others). Conjoined twins do not always share common perceptions; there are some, like Lori and George Schappell, who have faced in different directions for their entire lives. If the Schappell twins were separated, then each twin would have perceptual continuity and memories of what she had seen, but these would be very different from those of her sister.[14] Fi-

nally, by positing that conjoinment is a special subjective state, the feminist account of conjoined identity elides the ethical dilemmas noted in the opening paragraph of the paper. If Abby and Brittany Hensel disagreed about a sexual encounter, for example, their disagreement would be tantamount to an internal monologue, rather than being something that the law, or other people, should see as a transgression of someone's rights.

Neither the biological nor the feminist accounts of personal identity convincingly describes conjoined twins. A psychological account of personal identity better describes the metaphysical status of such twins, since it is able to account for continuity in case of separation surgery. A psychological continuity criterion of identity is predicated on the notion that only we have first-person access to our mental states. Even twins as closely conjoined as the Hensels think in the first person.[15] Although they share many experiences, conjoined twins will have different memories, mental states, and perceptions. Conjoined twins who survive past infancy develop different character traits, personal interests, aesthetic preferences, and tastes for food.

While it clarifies the metaphysical status of conjoined twins to consider each a separate psychological entity that continues over time, this fact alone does not clarify the ethical dilemmas described in the first paragraph. Through the exigencies of moral luck, people born conjoined are forced to live in a way which is unacceptably morally constrained.[16] Conjoined twins may understand and form the intention to abide by moral rules, but like prisoners chained together on a chain gang, each is partly in the thrall of the other. Physical punishment of a body part that seems to belong to one twin calls on the resources for healing of the other; confinement of one twin confines the other. If one of a pair of conjoined twins becomes ill or is disabled, the other is constrained. Lori Schappell can walk, while George Schappell, who has spina bifida, cannot; Lori must alternately carry her sister and wheel her around on a barstool. Neither will ever have the opportunity for respite from this caretaker relationship.

Conjoined twins lack the moral freedom to choose and carry out a life course, since actions some consider to be self-regarding are automatically other-regarding in conjoined twins. As David Wasserman notes, Chang Bunker's alcoholism, which accelerated his death, directly harmed his brother.[17] Every action and every movement may require consulting the interest of a peer with the same interest in decision-making. Even consenting to medical procedures is complicated. As Kenneth Himma notes, in order to enter into a contractual obligation with regard to the use of your body, it is necessary to have complete ownership of your body: conjoined twins lack that ownership.[18] Depending on the power dynamics between conjoined twins, a life lived conjoined might encompass everything from complete control in the case of a healthy and dominant twin, to true cooperation, to a life of near-slavery.

The Ethics of Separation Surgery

The metaphysical interpretation of conjoined twins has direct relevance to the ethics of separation surgery. Those writing in the feminist tradition see "conjoined twins" as a natural kind, with its own benefits and definition of flourishing, so that to perform separation surgery is to deform someone(s) rather than to repair them. Their arguments,

however, are drawn from a very small number of retrospective cases: they look back from the perspective of the few conjoined twins who have lived to adulthood, rather than forward from the perspective of conjoined infants who might have a range of different choices. The most tendentious part of their line of reasoning is the portrayal of conjoinment as beneficial.

Margaret Shildrick applauds the Hensels' parents for refusing to consider separation surgery, despite the pressures they must have faced from the medical establishment. The twins have been very successful as a unit: they graduated from high school and attend college; they have friends and a large degree of social acceptance in their small town; they have mutually agreed to pursue a career as teachers. The Hensel twins' parents privileged some aspects of human flourishing over others; had the twins been separated, each would only have had one arm and one leg, making walking and athletic activities difficult (although not impossible). But Shildrick does not acknowledge that the choice that the Hensels' parents made in their infancy was a choice to sacrifice something; the parents traded the prospect of a common physical disability against the prospect of a very uncommon moral disability.

Alice Dreger also argues against separation surgery on the ground that conjoinment is a positive trait. She notes that, far from lacking agency or being objects of pity, conjoined twins used to be able to command a good living by exhibiting themselves in sideshows.[19] Dreger also maintains that conjoined twins play an essential social role, since they raise metaphysical questions; separating conjoined twins would "eliminate their accidental and profound questioning of the very concept of human individuality."[20] But to relegate a person to a single, offensive occupational choice from birth is not in any way superior to the range of choices that most people contemplate. And conjoined twins owe society no duty to *embody* profound questions; that is why we have thought experiments. To draw an analogy: if intellectual disabilities caused by a particular syndrome could be cured by giving an infant medicine, it would not be morally acceptable to withhold the medicine from a particular child on the grounds that interacting with intellectually disabled children helps other people to appreciate human diversity.

Like Dreger and Shildrick, Bratton and Chetwynd criticize separation surgery. They note that the "entangled singletons" model "automatically favours physical separation as good in itself, and therefore tends to lead to decisions for surgical separation which play down its disadvantages and ignore the benefits of remaining conjoined." Like other opponents of separation surgery, Bratton and Chetwynd fail to set out convincingly what these benefits of conjunction might be. They recognize that continued conjoinment creates a host of problems for the conjoined, but then suggest that such twins "should perhaps be treated as a challenge to the rest of us to rethink" our understanding of the legal issues that such conjoinment raises.[21] But it is possible to rethink these issues without relegating conjoined twins to serve as salutary object lessons.

Y. Michael Barilan proposes that conjoinment "is actually a distortion of a unique inter-human world"—and that there are benefits to being part of a conjoined entity.[22] Barilan and Dreger both note that the few pairs of conjoined twins who have lived to adulthood have professed satisfaction with their lives and denied wanting to be separated. But a better question to ask such twins might have been: if you could have been

born as separate identical twins, would you have preferred to have been? This question separates out what it is about conjoinment that twins say they like (always having a companion, for example) without the confounding variables of physical conjoinment, the unknowns of surgery, or the prospect of never having existed at all.

Conjoined twins experience problems medically, legally, and politically. Violet Hilton, joined to her sister Daisy at the hip, wished to marry, but she and her fiancé were refused a marriage license in 21 different states because the notion of a threesome offended morality.[23] Lori and George Schappell, currently one of the oldest sets of conjoined twins at age 50, spent the first 24 years of their lives in an institution for the mentally retarded (they are of normal intelligence) when it was determined that their parents could not take care of them at home. Ladan and Laleh Bijani, conjoined twins from Iran, were so intent on pursuing separate careers, and, reportedly, so exasperated with living constrained by each other's wishes, that they chose to be separated at the age of 29 despite the extreme level of risk inherent in having separation surgery so late in life. Both twins died.[24]

The final argument against the benefits of continued conjunction involves the medical statistics. As an anomalous result of a natural process, conjoined twinning is biologically taxing. It is estimated that 40-60 percent of conjoined twins carried to term are stillborn, and that another 35 percent die within a day after birth. Thus, only between 5 and 25 percent of conjoined twins survive for more than a day. These statistics do not include the number of conjoined twin fetuses subject to therapeutic abortion.[25]

While the argument against separation surgery based on some benefit of conjunction fails, there may be other arguments to consider. Many conjoined twins have a poor joint prognosis, because they share hearts and lungs and have insufficient cardiac power and blood circulation for two. In such cases, doctors quickly determine—sometimes even in utero—that separation surgery is possible, but that only one twin can be saved. In 2000, British judges considered whether or not to order separation surgery for Gracie and Rosie Attard (referred to as "Jodie" and "Mary" in the press and legal records to protect privacy). Born in Malta, the twins had been brought to Britain under a reciprocal agreement to provide advanced medical care. Gracie and Rosie shared a common circulatory system. Doctors predicted that they would live for only a few more months if not separated; but that if they were separated, one twin would die. The twins' parents opposed separation surgery, arguing that Gracie and Rosie constituted two infants and that it was never justified for Catholics to take the life of one infant to save another.

Considering whether or not each of a pair of conjoined twins has the potential for personhood helps to clarify this issue, by picking out the entity within the conjoinment that ought to be given greater moral weight. The court found that since Rosie did not have a full set of organs or a developed brain, the conjoined twins only had the potential to yield one person: Gracie. The case then became one of considering separation surgery to be Gracie's self-defense against a parasitic twin who was literally draining her blood. In a case in which a woman's life is in danger from a pregnancy, the fact that the woman is a person, while the fetus only has the potential to become a person, helps to guide doctors' decision-making. If it were also the case that the fetus had a syn-

drome incompatible with life outside the womb, the disparity in moral considerability between the two entities would be even clearer. Similarly, conjoined fetuses in a triplet pregnancy are routinely selectively reduced, since the fact that the two are conjoined threatens the singleton, who has the best chance of personhood.[26] In the Attard case, surgery was accomplished over the parents' protests, and, as expected, Rosie died.[27] But by 2003 the beneficial consequences of the surgery had become clear, and even the surviving twin's parents expressed joy that their decision not to separate the twins had been overruled by the court. Gracie was flourishing, and her parents had another baby, whom they called Rosie after the deceased twin.[28]

Ethical guidelines developed by the hospitals that deal with the greatest number of conjoinment reflect the notion that separation surgery is a positive good. For example, the Great Ormond Street Children's Hospital in London recommends routine separation in all cases in which it is feasible and has a good chance of success, even if only one of two involved twins can be saved. In other cases, supportive care should be provided. Such a stance acknowledges the importance of autonomy to human flourishing.

Separation surgery is sometimes risky. It is least risky, however, when conjoined twins are still infants or toddlers. When it is successful, separation surgery increases moral autonomy in symmetrical conjoined-twin pairs. It provides the opportunity for continued life and for the attainment of personhood in cases of asymmetry. And it resolves the many ethical and legal concerns that may inhere in conjoined-twin relationships. It may be the case that conjoined twins who have reached adulthood say that they enjoy being conjoined, but it should be emphasized that separation surgery itself does not deny anyone the choice of a life spent together. If the main benefit of conjoinment is social intimacy, then there is no reason why formerly conjoined twins may not still choose to do everything together. Separation surgery does not remove cooperation or closeness; what it removes is the involuntary aspect of that cooperation and closeness and to enable those born with extraordinary bodies the opportunities that many of us take for granted.

Notes

1. Eric Olson, *The Human Animal: Personal Identity without Psychology* (New York: Oxford University Press, 1997), 24.
2. Olson, 137-8.
3. David Shoemaker, "Personal Identity and Ethics," *The Stanford Encyclopedia of Philosophy (Fall 2008 Edition)*, Edward N. Zalta (ed). <http://plato.stanford.edu/archives/fall2008/entries/identity-ethics>, last accessed December 14, 2011.
4. Rose Koch, "Conjoined Twins and the Biological Account of Personal Identity," *The Monist* 89 (2006), 351-70.
5. David Hershenov, "Countering the Appeal of the Psychological Approach to Personal Identity," *Philosophy* 79 (2004), 447-473.
6. See, for example, H. Rode et als., "Four decades of conjoined twins at Red Cross Children's Hospital—Lessons Learned," *South African Medical Journal* 96 (2006), 1-10.
7. Although he is usually identified with a psychological account of personal identity, John Locke did also address the question of the identity of an organism, for which a common

life was his criterion: an organism was a functional unit made up of connected vital parts. John Locke, *An Essay Concerning Human Understanding* (London: A. Bettesworth, 1735).

8. Eric Olson acknowledges an analogue of this problem when he discusses whether or not an embryo that divides is numerically identical with each of the cells into which it divides, or whether it disappears. See Olson, 92.

9. Here I agree with Lynn Rudder Baker on the metaphysical significance of consciousness. See "Response to Eric Olson," *Abstracta* special issue 1 (2008), 43-45.

10. David L. Clark and Catherine Myser, "Being Humaned: Medical Documentaries and the Hyperrealization of Conjoined Twins," in Rosemarie Garland Thompson, ed., *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: NYU Press, 1996), 338-355.

11. Alice Dreger, *One of Us: Conjoined Twins and the Future of Normal* (Cambridge: Harvard University Press, 2004), 19.

12. Margrit Shildrick, "Some Speculations on Matters of Touch," *Journal of Medical Philosophy* 26 (2001), 387-404.

13. M.Q. Bratton and S.B. Chetwynd, "One into Two Will not Go: Conceptualising Conjoined Twins," *Journal of Medical Ethics* 30 (2004), 279-285.

14. Here I adopt the same position as Richard Hull and Stephen Wilkinson, in "Separating Conjoined Twins: Disability, Ontology, and Moral Status," in David Benatar, ed., *Cutting to the Core: Exploring the Ethics of Contested Surgeries* (New York: Rowman and Littlefield, 2006), 113-126.

15. This paper does not address the issue of the Hogan twins, who, it is thought, may share a mind because they possess a unique thalamic bridge. So far, they are unique in the literature. Susan Dominus, "Could Conjoined Twins Share a Mind?" *New York Times,* May 25, 2011, <http://www.nytimes.com/2011/05/29/magazine/could-conjoined-twins-share-a-mind.html?pagewanted=all>, last accessed December 14, 2011.

16. Thomas Nagel, "Moral Luck," in *Mortal Questions* (Cambridge: Cambridge University Press, 1979), 24–38.

17. David Wasserman, "Conjunction and Separation: Viable Relationships, Equitable Partings," in David Benatar, ed., *Cutting to the Core: Exploring the Ethics of Contested Surgeries* (New York: Rowman and Littlefield, 2006), 113-126.

18. Kenneth E. Himma, "Thomson's Violinist and Conjoined Twins," *Cambridge Quarterly of Healthcare Ethics* 8 (1999), 428-435.

19. Scholars disagree over the extent to which past sideshow performers had "agency" or meaningful choices to do anything different. See David A. Gerber, "The 'Careers' of People Exhibited in Freak Shows: The Problem of Volition and Valorization," in Rosemarie Garland Thompson, ed., *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: NYU Press, 1996), 38-54.

20. Dreger, quoted in Bratton and Chetwynd, 283.

21. Bratton and Chetwynd, 284.

22. Y. Michael Barilan, "One or Two: An Examination of the Recent Case of the Conjoined Twins from Malta," *Journal of Medical Philosophy* 2 (2003), 27-44.

23. Allison Pingree, "The 'Exceptions that Prove the Rule': Daisy and Violet Hilton, the 'New Woman,' and the Bonds of Marriage," in Rosemarie Garland Thompson, ed., *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: NYU Press, 1996), 173-184.

24. Marjorie Wallace, "The Tragedy of a Double Life," *Guardian,* July 12, 2003, <http://www.guardian.co.uk/society/2003/jul/13/health.lifeandhealth>, last accessed December 14, 2011.

25. Dreger, 31. I have not found statistics on the rate of therapeutic abortion of conjoined twin fetuses.

26. John Harris argues that neither Rosie nor Gracie was a person at the time of surgery,

and that the court on this basis should have ruled separation of the twins to be "lawful but not mandatory." "Human Beings, Persons, and Conjoined Twins: An Ethical Analysis of the Judgment in *In Re A*," *Medical Law Review* 9 (2001), 221-236.

27. Pierre Mallia, "The case of the Maltese Siamese Twins—when moral arguments balance out should parental rights come into play," *Medicine, Health Care and Philosophy* 5 (2002), 205-209.

28. Paul Harris, "Amazing Grace, Three Years On," *Daily Mail Online, <http://www.dailymail.co.uk/health/article-187689/Amazing-Grace-years-on.html>*, last accessed August 20, 2011. J. Raffensperger provides several case studies of successful separation surgeries in "A Philosophical Approach to Conjoined Twins," *Pediatric Surgery International* 12 (1997), 249-255. Soren Holm and Charles A. Erin reject consequentialist reasons for separation surgery in "Deciding on Life: An Ethical Analysis of the Manchester Conjoined Twins Case," *Jahrbuch fur Wissenschaft und Ethik* 6 (2001), 67-87.