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Who Should Deicide? The Conflicting Legal, Ethical, and Moral Dilemmas Surrounding the Separation of Conjoined Twins

Introduction and Roadmap

Parents and medical professionals involved with the lives of conjoined twins are often faced with challenging decisions regarding the treatment, quality of life, and survival of both babies. But perhaps the most emotionally intricate of these decisions is whether or not to surgically separate the twins. Due to advancements in medical knowledge over the last half century, doctors are performing separation procedures previously not thought possible. Nonetheless, cases where conjoined twins share vital organs or have severe abnormalities still pose a number of moral, ethical, and legal implications for all of the parties involved.

This paper will argue that applying an exclusively legal analysis to cases involving the separation of conjoined twins is inadequate and unsuitable to confront the complex dilemmas posed by these cases. A court's role in conjoined twin separation cases should be limited to simply advising physicians on the legality of the procedure in question. The decision-making authority should be left to the family and the physicians to strike a balance between each twin's interest in life, the opinions of the involved medical professionals, and the parents' moral beliefs and values. Although physicians do not have the same interest in life and interest in caring for one's child as the twins and their parents, doctors have an interest in providing treatment that aligns with permissible medical judgment and the standard of care in their field. Thus, an

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¹ Colleen Davis, *Separating Conjoined Twins: A Medical and Criminal Law Dilemma*, 17 J. L. & MED. 594, 594 (2010).

 $^{^{2}}$ Id.

intersectional approach that factors in relevant legal, medical, ethical, and moral inquiries better serves the interests of the parties involved.

Part I of this paper will briefly overview the history of conjoined twins, as well as the social awareness towards the condition. Part II will lay out three prominent conjoined twin separation cases disseminated in the news: from New England in 2017, Philadelphia in 1977, and England in 2001. Each of these cases raised similar issues, but they all had unique resolutions due to the objections of the parties involved. Unlike the U.S. examples from Philadelphia and New England, the British case resulted in a judicial opinion from three appellate judges on England's Court of Appeals. Part III will examine the difficulties raised by these cases from a medical and ethical perspective, highlighting relevant bioethical theories that support or challenge the separation of conjoined twins. Lastly, Part IV will examine the substantive law that the Lord Justices applied in the English case of *Re A (Children)* and the consequences from the decision.

I. Conjoined twins from a historical perspective

Largely due to deep-rooted superstition and the rarity of the condition itself, conjoined twins were rarely depicted in the vast artistic representations of the human body that date back over 15,000 years.³ Nonetheless, excavations of Tlatilco, a small Mexican village that existed 3,000 years ago, have discovered extremely accurate clay sculptures depicting babies with facial and cranial duplications.⁴ The Tlatilco sculptures are the first recorded instance of developmentally and proportionately correct representations of conjoined twins, and not just fictitious hybrids like centaurs.⁵ At its roots, classical religious theory attempted to explain

³ G.E. Kennedy, The 3,000-Year History of Conjoined Twins, 175 W. J. MED. 176, 76 (2001).

 $^{^4}$ Id

⁵ *Id*.

medical abnormalities as warnings from God and reminders of man's imperfections and original sin.⁶ Unfortunately, conjoined twins were not exempt from this classification and "were long thought to be omens of the future or God's punishment for man's wickedness." Anecdotal writings of viable conjoined twins date back more than 1,000 years in European medical history.

The first well-known case of conjoined twins was not documented until 1811, when twin boys Chang and Eng were born in Siam, or modern-day Thailand. Chang and Eng, connected by a band of abdominal tissue, amassed wealth and rose to fame in P.T. Barnum's traveling circus where they were labeled as the "Siamese twins." While traveling in the circus, the twins consulted several influential physicians who concluded that a separation procedure would be fatal to both boys. Throughout their lives, Chang and Eng married sisters, had 21 children between them, and became successful farmers and businessmen. Ultimately, the twins died within hours of each other at the age of 62. An autopsy revealed that Chang and Eng shared no organs, explaining their longer than normal lifespan. Even with their success, the deep-rooted stigma and misconception surrounding conjoined twins followed Chang and Eng to death, where one of the autopsy examiners referred to them as "monsters."

⁶ Arif Kokcu, Mehmet B. Cetinkaya, Oguz Aydin & Migraci Tosun, *Conjoined Twins: Historical Perspective and Report of a Case*, 20 J. MATERNAL-FETAL & NEONATAL MED. 349, 49 (2007). (St. Augustine's explanation for "gross anomalies").

⁷ J. Raffensperger, *A Philosophical Approach to Conjoined Twins*, 12 PEDIATRIC SURGERY INT'L 249, 49 (1997).
⁸ Kennedy at 176.

⁹ *Id*.

¹⁰ Kokcu, et al. at 350.

¹¹ Id

¹² See Kennedy at 176; See also Raffensperger at 249.

¹³ Kennedy at 176.

¹⁴ *Id*.

¹⁵ See Raffensperger at 249. See also Julian Savulescu, Conjoined Twins: Philosophical Problems and Ethical Challenges, 41 J. MED. PHIL. 41-55, 43 (2016) (quoting a 1928 article from the Lancet, a well-respected medical journal, which commented on a conjoined twin case. The article stated, "[t]he monster here described was born at full term and survived four and a half days; its two components behaved as two separate individuals and died within a few minutes of each other").

By the middle of the twentieth century, separation attempts slowly became more prevalent. In the 1950s, there were 16 reports of separation procedures, with 13 known operative survivors. Today, a conjoined birth is still an extremely rare medical phenomenon, occurring only once in every 200,000 live births. The overall survival rate of conjoined twins is between 5% to 25%, with about 75% of surgical separations resulting in at least one twin surviving.

Understandably, the individual facts of each case are the driving force in determining the projected survival rate and whether separation is recommended.¹⁹ For the purposes of this article, the subsequent case discussion and analysis will focus on scenarios where separation is highly recommended by physicians because the twins share vital organs, with the more dependent twin often draining the resources from physically stronger twin.

II. Background facts from three prominent examples

This section will discuss three prominent conjoined twin separation cases that demonstrate the medical, ethical, and legal issues that will be highlighted throughout this article. Although each of these cases raised similar issues, they all concluded in different ways based on the objections from the parties involved. The first case from New England in 2017 demonstrates the difficulties for medical professionals, even when the doctors and parents agree on the need for treatment and surgical separation. Although the stakes were still high from a medical and ethical standpoint, the legal and parental interests were much lower because the parents consented. The second case from Philadelphia in 1977 depicts an instance where all of the parties raised unique hesitations with separation. In this case, the parties turned to religious leaders and

¹⁶ Raffensperger at 249.

¹⁷ Jen Christensen, *Parents Make Difficult Decision to Keep Conjoined Twins Together*, CNN, Apr. 25, 2014, https://www.cnn.com/2014/04/24/health/conjoined-twins-will-stay-together/index.html.

¹⁹ I.e., twins with several shared organs have a much lower survival rate compared to twins with no shared organs, like Chang and Eng above.

the courts for acceptance and authorization before conducting the surgery. Third, the 2001 case from Britain shows the inadequacy of attempting to apply legal principles to a case where the parents of the twins deeply disagreed with the hospital's recommendation of performing a separation procedure. These cases will serve as the backdrop for the subsequent sections on the medical, ethical, and legal concerns that arise and overlap in these life-and-death scenarios.

A. 2017 New England case of "Twin A and Twin B"

In late 2017, a New England hospital was confronted with a rare dilemma. Twenty-two-month-old conjoined twins connected by the abdomen and pelvis came to the U.S. to seek treatment or possible separation.²⁰ The twins, hereafter Twin A and Twin B, were born with a long list of medical abnormalities that made their case difficult for doctors to analyze and treat: the twins had three legs, one of which was separated; they shared a single liver; each had one complete kidney, which drained into a single bladder, and one undersized kidney; finally, their gastrointestinal tracts were fused together with a shared anus and one vagina. ²¹

At the outset, Twin B was clearly larger than the other; she was alert; and she often interacted with caregivers. ²² Twin A, on the other hand, was physically smaller, was less active, and was not able to engage with the caregivers to the extent of her sister. After undergoing medical evaluation at the New England hospital, it became clear that Twin A was dying and was slowly killing her sister. Doctors believed that "Twin B is normal and living relatively healthy and we know that she can live without her sister, whereas Twin A relies completely on her sister.

²⁰ Ashley Welch, *Doctors Face Heartbreaking Decision, Can Only Save One Twin*, CBS NEWS, Oct. 26, 2017, https://www.cbsnews.com/news/doctors-heartbreaking-decision-conjoined-twins/.

²² *Id.*; *See also* CBC Radio, *Conjoined Twins and a Doctor's Dilemma: Is It Ever Morally Acceptable to Sacrifice One Child for Another?*, CBC RADIO, Mar. 8, 2018, https://www.cbc.ca/radio/thecurrent/the-current-for-march-8-2018-1.4567264/conjoined-twins-and-a-doctor-s-dilemma-is-it-ever-morally-acceptable-to-sacrifice-one-child-for-another-1.4567966.

Her sister is her life support." (Emphasis added).²³ Twin A became progressively sicker, with several episodes of respiratory troubles that required admission into the ICU. At this point, the doctors agreed that Twin A would not survive a surgical separation from her sister. Twin A's declining health status also meant that she would most likely die if she remained conjoined with her sister. If Twin A died while still attached to her sister, it would result in the inevitable death of both twins because of the stress that it would place on Twin B's system and body.²⁴

Faced with this situation, the hospital assembled a "pediatric ethics committee" to analyze the case and weigh their options.²⁵ Committee discussions led to the conclusion that "while each twin should be regarded as a distinct individual, there was little to no chance of saving the smaller twin; yet not attempting the separation surgery would risk her sister's life, as well."²⁶ After discussions with the team of doctors and support from a religious leader, the parents made the decision to proceed with the surgery. Ultimately, the 14-hour surgery went as originally predicted: After separation of the twins' pelvic structure, the surgeons divided the arterial connection and Twin A's blood pressure and oxygen levels dropped, resulting in her death.²⁷

²³ *Id*.

 $^{^{24}}$ Id

²⁵ Ideally, pediatrics ethics committees should be made up of individuals from various disciplines including medicine, nursing, law, clergy, social work, behavioral sciences, and ethics/philosophy that aid physicians and/or parents in resolving disputes or when facing difficult ethical decisions. The role of an ethics committee is to help those making these difficult decisions understand the ethical issues that may be involved, to facilitate discussion, and to often make specific recommendations to the parties. A committee generally does not carry direct decision-making authority, but rather serves solely in an advisory role. Although physicians and parents are typically informed that they are under no obligations to follow the recommendations of the committee, the opinions of the committee often carry significant influence or "moral authority." It is important to note that ethics committees should not serve as, or replace, the role of legal counsel. A sharp line should be drawn between the distinct questions, "is it legal?" and "is it ethically permissible?" M.R. Mercurio, *The Role of a Pediatric Ethics Committee in the Newborn Intensive Care Unit*, 31 J. PERINATOLOGY 1-9 (2011).

²⁷ *Id*.

The 2017 case at the New England hospital involving "Twin A and B" demonstrates the weighty moral dilemmas that attach to the medical decisions in deciding whether or not to separate conjoined twins. Although not addressed directly, the case also raises several questions regarding the potential legal ramifications of separating conjoined twins. The doctor that performed the separation procedure said that she left the operating room "crying" and that "it was not easy," but ultimately, she did not regret it because there was a life saved and the parents were thrilled. Arthur Caplan, Ph.D., the head of the Division of Medical Ethics at NYU School of Medicine said that "when it comes to the decision about whether to perform separation surgery on conjoined twins, 'there's no one-size-fits-all answer'... the issue is how are the twins conjoined." The decisional significance at the forefront of conjoined twins cases often rests on asking if it is acceptable to "remove" one twin as a means to save the other.

B. 1977 case at the Children's Hospital in Philadelphia, Pennsylvania

In October of 1977, the first prominent case highlighting the issues surrounding the separation of conjoined twins took place at the Children's Hospital in Philadelphia,

Pennsylvania.³⁰ Dr. C. Everett Koop performed a unique separation of what was then known as,

"Siamese" twins at the Children's Hospital in Philadelphia.³¹ Although Dr. Koop performed successful separation surgeries before, this was different because the twins shared a single

²⁸ *Id*.

²⁹ Id

³⁰ Francis X. Meehan, *The Siamese Twin Operation and Contemporary Catholic Medical Ethics*, 45 LINACRE Q. 157, 157 (1978).

³¹ The reference to the twins as "Siamese twins" highlights the strong influence that the case of Chang and Eng had on popular culture and society. While the name has maintained cultural significance for the better part of two centuries, the classification still broadly stereotypes many conjoined twins. (*See* Part I of this paper for a more detailed explanation of Chang and Eng's story).

heart.³² The physicians had advised the parents that they had to "sacrifice" one twin so that the other could live. If the twins remain conjoined, they would both die.³³

The parents in this case were deeply devout practitioners of Judaism and objected to the thought of "sacrificing" one child as a means to save the other.³⁴ Both parents made it clear they would not consent to the separation without rabbinical support.³⁵ As a response, rabbinic scholars used two analogies to justify the separation. The first analogy concerned two men who jumped form a burning airplane. One man's parachute failed to open and while free falling he grasped the leg of the other whose chute could not sustain the weight of both. The thrust of the scholars' question was whether both men in the analogy must die or if one of the men can kick away the second man to save himself.³⁶ The rabbis replied that it was acceptable for the first man (with the working parachute) to "free himself" since the second man was already destined for death. The second analogy that the rabbis set forth involved a caravan surrounded by bandits who demanded a specified individual be turned over for execution as a condition for letting the others go. As in the first example, the rabbis determined the since the targeted individual was already "destined for death," there was no moral issue in turning the individual over to the bandits.³⁷

In addition to the objections from the parents of the twins, the Catholic nurses at the hospital refused to participate in the surgery without assurance from the archdiocese of

³² *Id.* at 157-64.

 $^{^{33}}$ *Id*.

³⁴ J.J. Paris & A.C. Elias-Jones, *Do We Murder Mary to Save Jodie? An Ethical Analysis of the Separation of the Manchester Conjoined Twins*, 77 POSTGRAD MED. J. 593, 94 (2001).

³⁶ George J. Annas, At Law: Siamese Twins: Killing One to Save the Other, 17 HASTINGS CENTER REP. 27, 27

³⁷ J.J. Paris & A.C. Elias-Jones, *Do We Murder Mary to Save Jodie? An Ethical Analysis of the Separation of the Manchester Conjoined Twins*, 77 POSTGRAD MED. J. 593, 94 (2001).

Philadelphia regarding the moral acceptability of "killing" one twin to save the other.³⁸ In approving the operation, the Catholic authorities in Philadelphia based their position on the doctrine of "double effect." The principle of double effect is a theory first formulated by Thomas Aquinas in the 13th century as a justification for self-defense. It holds that while "one may never directly intend an evil act (such as killing an innocent person), the evil effect (the death) may be permitted if the effect is not intended in itself but is an indirect consequence, justified by a commensurate reason."³⁹

Lastly, the pediatric surgeon, Dr. Koop, refused to perform the surgery without judicial approval and legal immunity from potential charges of homicide. A judge in the Philadelphia Family Court insisted that a three-judge panel hear Dr. Koop's petition. The panel quickly rejected the first argument from the hospital that "because the twins only had one heart, there was only one person and thus no 'killing' would occur if the twins were separated." The lawyers' second argument before the panel was similar to the rabbis' two analogies above. The hospital's lawyers provided the panel with an example of two mountain climbers who were attached to each other by a rope. One climber slipped and was caught dangling at the end of the rope. The other partner was unable to pull the climber to safety no matter how hard he tried. If the rope remained uncut, the secure climber would soon tire, and both would subsequently fall and die. Similar to the justification that the rabbis gave the parents, the hospital's lawyers argued that it was legitimate for the secure climber to cut the rope to save himself. Confronted with these dilemmas, the panel in the Family Court deliberated only for a few minutes before

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³⁸ *Id*.

³⁹ *Id*.

⁴⁰ *Id*.

⁴¹ *Id*.

⁴² *Id*.

authorizing the surgery.⁴³ The surgical procedure itself was successful, but the surviving twin died three months after the separation.⁴⁴

C. 2001 British case of "Jodie and Mary"

In August of 2000, the first legal case involving the separation of conjoined twins took place in a British courtroom.⁴⁵ The *Re A (Children)* case centered around a fundamental dispute regarding the "separation of conjoined twins which divided the scientific, legal and religious sectors of society."⁴⁶

Conjoined twins, Jodie and Mary, were born on August 8, 2000 to Maltese parents

Michelangelo and Rina Attard, who were devout Roman Catholics. Teach twin had her own

arms and legs but shared a linked spine. Besides a shared bladder, the girls had their own internal

organs. A hospital in Manchester, England agreed to assume care of the twins and decide

whether a separation surgery was medically feasible. Issues quickly arose because Jodie's heart

operated the circulatory functions for both girls. Doctors believed that the excessive stress on

Jodie's heart would result in their untimely death within a matter of weeks. As the more

independent twin, doctors predicted that Jodie could survive on her own if separated from Mary.

However, this prediction meant that Mary would certainly die during the procedure.

⁴³ *Id*.

⁴⁴ Id

⁴⁵ Re A (Children) (Conjoined Twins: Medical Treatment) No. 1, [2000] H.R.L.R. 721 (C.A.Civ.); In re A (Children)(Conjoined Twins: Surgical Separation), [2001] Fam. 147 (C.A. Civ.); Re A (Children) (Conjoined Twins: Surgical Separation) [2000] 4 All E.R. 961 (C.A. Civ.).

⁴⁶ Heather Tierney, Conjoined Twins: The Conflict Between Parents and the Courts Over the Medical Treatment of Children, 30 DENV. J. INT'L L. & POL'Y 458, 459 (2002).

⁴⁷ The names "Jodi and Mary" were fictional names given to the twins by the British court. The girls' real names were Gracie and Rose. *See* George J. Annas, *Conjoined Twins—The Limits of Law at the Limits of Life*, 344 N. ENGL. J. MED. 1104 (2001).

⁴⁸ Tierney at 459-60.

⁴⁹ *Id.*; *Re A (Children)*, 4 All E.R. 961 (C.A. Civ.).

⁵⁰ *Id*.

Jodie and Mary's parents raised both religious, financial, and quality of life objections to the hospital's offer to perform the separation procedure.⁵¹ As devout Catholics, Jodie and Mary's parents believed that God, not doctors, should decide whether their daughters lived or died.⁵² The parents also raised the argument that if Jodie survived, she would be left with severe disabilities.⁵³ They noted that there were few, if any, facilities on their remote home island to care for a disabled child. Essentially, there was no chance for the child "to have any sort of life at all."⁵⁴ Furthermore, the parents did not have the financial resources to provide Jodie's medical treatment at home.⁵⁵ Without the financial means and medical resources to care for their child, Jodie would have to stay in England to receive treatment. These factors all weighed heavily in the parents' ultimate decision to reject the hospital's offer to perform the separation.⁵⁶

Following the parents' objections, the physicians turned the case over to the British court to receive authorization (over the parents' wishes) for the separation procedure.⁵⁷ In the United States, the decision of the parents is typically final unless the physicians or the state demonstrates abuse or neglect.⁵⁸ However, unlike their U.S. counterparts, British law leaves the decision to a judge to decide "what the welfare or best interests of the child require by exercising 'an independent and objective judgement." At the trial level, the judge concluded that the separation would be in the "best interest" of both children and this was not a case of "killing one

⁵¹ J.J. Paris & A.C. Elias-Jones, *Do We Murder Mary to Save Jodie? An Ethical Analysis of the Separation of the Manchester Conjoined Twins*, 77 POSTGRAD MED. J. 593, 95 (2001).

⁵² See Re A Children (Conjoined Twins Case), note 4, at 726. As devout Roman Catholics, the parent believed that the lives of their children "must be left in God's hands."

⁵³ Paris & Elias-Jones at 595.

⁵⁴ *Id*.

⁵⁵ *Id*.

⁵⁶ *Id*.

¹¹⁴ 57 x 1

⁵⁸ George J. Annas, *Conjoined Twins—The Limits of Law at the Limits of Life*, 344 N. ENGL. J. MED. 1104, 04 (2001).

⁵⁹ Id.; See also Re A (Children) 4 All E.R. 961 (C.A. Civ.).

to save the other," but rather one of passive euthanasia.⁶⁰ The parents and the official solicitor (chosen to represent Mary) ultimately appealed the decision of the lower Family Court.⁶¹

At the appellate level, each of the three judges on the panel issued a separate opinion. All three judges agreed with the trial court's conclusion that the separation should be performed, but "none of the three judges on the appeals panel fully agreed with one another's legal reasoning." This disagreement demonstrates the difficulty with attempting to apply exclusively legal principals to issues that intersect the law, morality, and medical ethics.

Lord Justice Alan Ward started his opinion by pronouncing that it is a fundamental principle of medical law to allow people the opportunity to decide for themselves whether or not to receive medical treatment.⁶³ In the case of a minor, British parents typically have a right and duty to determine whether to consent or withhold medical treatment for their children. British jurisprudence provides a safeguard for the courts to override the parents' decision if it is in the child's "best interest." LJ Ward proclaimed that the paramount consideration is determining the best interest and the welfare of the children. In coming to his conclusion, LJ Ward agreed with the lower court that it was in Jodie's best interest to have the operation but disagreed that the surgery can be considered a passive "omission" of treatment. Quite simply, he viewed the procedure as an active surgical procedure that would effectively end Mary's life. Ward did not attempt to justify the affirmative "killing" of Mary as being in her "best interest." Rather, he focused his analysis on choosing between the lesser of two evils.

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⁶⁰ Re A (Children) 4 All E.R. 961 (C.A. Civ.).

⁶¹ Id

⁶² Annas at 1104.

⁶³ Tierney at 459-60; *Re A (Children)* 4 All E.R. 961 (C.A. Civ.).

⁶⁴ Id

⁶⁵ Annas at 1104.

⁶⁶ *Id*.

⁶⁷ *Id*.

Attempting to ground his decision in legal precedent, LJ Ward stated that Mary was, in essence, "killing" her sister. Thus, the act of killing Mary through surgical separation was a case of "quasi self-defense." LJ Ward believed that "Mary may have a right to life, but she has little right to be alive. She is [only] alive because...she [parasitically] sucks the lifeblood out of Jodie. If Jodie could speak, she would surely protest, 'Stop it, Mary, you're killing me." 69

Lord Justice Robert Brooke agreed with LJ Ward regarding the ultimate decision to separate Mary and Jodie. But for LJ Brooke, the issues relating to criminal law required a more in-depth analysis to rationalize the separation procedure in the law. ⁷⁰ LJ Brooke began his analysis by questioning whether the operation to separate the girls was in-fact lawful. In answering this question, LJ Brooke looked at the legal definition of murder and its relevant exceptions. LJ Brooke concluded that although the surgery itself would constitute murder under the law, the exception for the defense of "necessity" justified the procedure. ⁷¹

The third judge on the Court of Appeals panel, Lord Justice Robert Walker, noted that the religious objections of the parents, although controversial, were "not obviously contrary to any view generally accepted in our society." With that being said, LJ Walker paid a great deal of deference to the opinions of the medical professionals who testified at the trial. U Walker believed the doctors' assertion that the separation surgery was the best way to "save" Jodie, regardless of whether the court could determine the legality of the operation. Although Walker agreed that necessity was an important factor in analyzing the case, he found no analogous cases

⁶⁸ *Id.* at 1105 (citing to *Re A (Children)* 4 All E.R. 961 (C.A. Civ.))

⁶⁹ Id

⁷⁰ *Id.*; *See also* Tierney at 464-65.

⁷¹ *Id.*; *See also* Tierney at 464-65.

⁷² J.J. Paris & A.C. Elias-Jones, *Do We Murder Mary to Save Jodie? An Ethical Analysis of the Separation of the Manchester Conjoined Twins*, 77 POSTGRAD MED. J. 593, 97 (2001).

⁷³ Heather Tierney, *Conjoined Twins: The Conflict Between Parents and the Courts Over the Medical Treatment of Children*, 30 DENV. J. INT'L L. & POL'Y 458, 467 (2002)
⁷⁴ *Id*.

that supported using the defense in conjoined twin separation cases.⁷⁵ In sum, Walker found that "there is no helpful analogy or parallel to…this case."⁷⁶ The distinct circumstance in this, and other conjoined twin cases, led walker to rely heavily on the opinion of the "highly skilled and conscientious doctors [who] believe that the best course, in the interest of both twins, is to undertake elective surgery in order to separate them and save Jodie."⁷⁷

In sum, England's Court of Appeals dismissed the parents' appeal and gave the hospital authorization to perform the surgery.⁷⁸ The surgery was performed just six weeks after the Court of Appeal's decision. As predicted, Mary died during the procedure, but Jodie survived and returned home with her parents.⁷⁹

III. Issues from a medical and ethical perspective

The practice of "medicine" is often defined as the "science or practice of the diagnosis, treatment, and prevention of disease" or "the science and the art dealing with the maintenance of health and the prevention, alleviation, or cure of disease." These definitions depict the practice of medicine as a field or occupation primary concerned with the preservation of life. Cases regarding the separation of conjoined twins, much like other termination of life cases, clearly diverge from these traditional medical principles.

In the three cases discussed above, the doctors owed conflicting duties to each of the twins: "saving" the stronger twin meant "killing" the more dependent twin; "prolonging" the life of the more dependent twin meant "shortening" the life of the stronger twin. Faced with this dilemma, medical professionals must consider the distinct and personalized circumstances of

 $^{^{75}}$ Id

⁷⁶ Annas at 1106; *Re A (Children)* at 1066-67.

⁷⁷ Id

⁷⁸ Tierney at 467.

⁷⁹ Id.

⁸⁰ Noun; definition from Google and noun; definition from Webster's online dictionary, respectively.

each case that comes before them, prior to recommending a separation surgery to parents or seeking court intervention. Often, ethic committees in hospitals are assembled to address these concerns prior to recommending treatment or conducting surgical procedures.⁸¹ Among other medical inquires, these ethics committees often decide if each twin should be regarded as a distinct individual and if there are any chances, however small, to save the weaker, dependent twin.⁸²

An initial issue that confronts medical professionals when confronted with conjoined twin cases is whether the twins are considered one or two individuals. There appears to be no definitive answer to this question within the medical field. Although doctors typically view a fetus with one head and duplicative arms or legs as a single human being, some doctors are split as to whether a fetus with two independent heads (or a shared body) can be classified as the same. Additionally, both parents and doctors typically agree that a "functional and independent brain is the essence of existence." Thus, a conservative definition of a conjoined twin is an individual with a separate (or, almost separate) brain, who has the independent ability to communicate. Dobiously, following this definition has drastic implications in the separation decision-making process. On one hand, a conjoined twin without its own head would not be seen as an independent human being. Rather, they are viewed ethically as a "tissue parasite or teratoma conjoined to a single human being." On the other hand, if two human beings are believed to be present, then ethical considerations come into play that seek the protection of both

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⁸¹ Ashley Welch, *Doctors Face Heartbreaking Decision, Can Only Save One Twin*, CBS NEWS, Oct. 26, 2017, https://www.cbsnews.com/news/doctors-heartbreaking-decision-conjoined-twins/.

⁸² **I**d

⁸³ Prof. John Pearn, M.D., *Bioethical Issues in Caring for Conjoined Twins and Their Parents*, 357 LANCET 1968, 68 (2001).

⁸⁴ *Id*.

⁸⁵ Id

⁸⁶ *Id.*; *See also* Dr. Enas Qutieshat, *The Legal Personality of Conjoined Twins*, 9 Euro. J. Bus. & MGMT. 88, 94 (2017).

lives, weighing the risks and benefits to each twin as a result of a separation procedure (i.e., bodily integrity and the principle of double effect), and the principles of parental autonomy concerning conjoined twins.⁸⁷

In the medical field, the distinction between two individual persons typically hinges on the physical nature of the attachment. Some ethical scholars differ and propose that all conjoined twins are two individuals, psychologically separate but, by degrees, with a shared body. 88 Under this view, a conjoined twin's body is not something they are in competition over, rather the body is something that they both have an interest in and neither has exclusive rights to it. 89 Although factoring in this argument may often lead to the conclusion that separation is still necessary in difficult cases like that of Mary and Jodie, this approach would not involve "having to think of one twin as somehow preying and being a problem for the other" or presupposing that separation is automatically in the twins' "best interest." In viewing conjoined twins as two separate individuals with pitting interests, the medical field and several Lord Justices on the British Court of Appeals overlook the actual reality of the condition itself: conjoined twins are not separate and never have been. 91

The impact on a twin's bodily integrity is another fundamental ethical consideration that parents, doctors, and courts must evaluate in determining whether a separation procedure is proper or lawful.⁹² In short, bodily integrity refers to "the right not to have your body touched or your body interfered with without your consent.⁹³ In cases involving the separation of a stronger

⁸⁷ Id

⁸⁸ M.Q. Bratton & S.B. Chetwynd, *One Into Two Will Not Go: Conceptualizing Conjoined Twins*, 30 J. MED. ETHICS 279, 80-81 (2004).

⁸⁹ *Id*.

⁹⁰ *Id.* at 285.

⁹¹ *Id*.

⁹² Jonathan Herring & Jesse Wall, *The Nature and Significance of the Right to Bodily Integrity*, 76 CAMBRIDGE L.J. 566, 68 (2017).

⁹³ *Id*. at 568.

and weaker conjoined twin, there appears to be a clear violation of this right to bodily integrity, no matter if the twins are conjoined or surgically separated. In a conjoined state, the nature of the medical condition itself physically deprives a twin from enjoying their own, independent, bodily function and integrity. ⁹⁴ In the alternative, undergoing a separation surgery clearly deprives the more susceptible twin of bodily integrity because "she will be dead before she can enjoy her independence."

Furthermore, ethical considerations in cases concerning the separation of conjoined twins often invoke the doctrine of double effect. ⁹⁶ St. Thomas Aquinas first formulated the principle in the 13th century as a justification for self-defense. ⁹⁷ The principle of "double effect can be used as a justification of a harmful effect if 'the harmful effect is seen as an indirect or merely foreseen effect, not the direct and intended effect of the actions." ⁹⁸ More simply, this principle allows for death to be foreseen, but not intended. ⁹⁹ They are four main conditions for the application of the principle of double effect to apply: (1) The action in itself must be good or at least morally indifferent; (2) The agent must intend only the good effect and no the evil effect. The evil effect is foreseen, not intended; (3) The evil effect cannot be a means to the good effect; and (4) there must be a proportionality between the good and evil effect of the action. ¹⁰⁰ The principle of "double effect" is often used as a means to weigh the risks and benefits to each twin if they were to undergo a separation procedure.

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⁹⁴ *Id.* at 573-74

⁹⁵ *Id.* (citing Ward L.J.'s opinion in *Re A (Children)*)

⁹⁶ David H. Wenkel, *Separation of Conjoined Twins and the Principle of Double Effect*, 12 CHRISTIAN BIOETHICS 291, 91 (2006) (A critique of Pearn's article cited above).

⁹⁷ Paris & Elias-Jones at 594 (citing Thomas Aquinas, *Summa Theologiae*, 2-2, q 64, a7).

⁹⁸ *Id.* at 292.

⁹⁹ Id.

¹⁰⁰ *Id.*; *See* Joseph Boyle, Jr., *Toward Understanding the Principle of Double Effect*, 90 ETHICS 527-38 (1980) reprinted in Woodward (ed.), 7-20.

Since Aquinas' conception of the principle of "double effect," subsequent ethical and theological scholars believed that the four aforementioned conditions must always be satisfied for the principle to apply. But, "not all of these criteria are always met in [cases involving] the separation of conjoined twins." Taking the four elements of the principle literally, some ethical scholars believe that double effect will "never apply to a separation surgery that requires the killing or euthanization of one of the twins. 103

Issues surrounding parental autonomy and consent for separation surgeries is also at the heart of the ethical analysis. ¹⁰⁴ While parents feel violated if their consent is removed, society has a significant interest in preventing active "euthanasia" of infants. ¹⁰⁵ Ethical scholar John Pearn argues that "if surgery were to be undertaken against parents' wishes, it should be done only after all attempts to reach an agreement between the parents and society have failed." ¹⁰⁶ It seems that there is a fine line between giving parents the right to choose what *they* think is best for their children and *society* protecting the safety of children who have the ability to receive potentially lifesaving treatment. (Emphasis added).

The three cases discussed above each involved conjoined twins classified by doctors as two independent human beings. Therefore, in all three cases presented, the ethical considerations previously listed must be analyzed. In the 2017 case in New England, the twins were connected by the abdomen and pelvis. Further, there was also evidence in the case that both twins interacted with their caregivers (although the one twin interacted more regularly) and thus had the

¹⁰¹ Prof. John Pearn, M.D., *Bioethical Issues in Caring for Conjoined Twins and Their Parents*, 357 LANCET 1968, 69 (2001).

 $^{^{102}}$ *Id*.

¹⁰³ Wenkel at 298. "According to the first criteria, the nature of the act is killing a person and is thus a wrong. According to the second and third criteria, the killing of a person is being used in a way to benefit another and is thus wrong. According to the fourth criteria, the killing of a person entails disproportionate effects." ¹⁰⁴ Pearn at 1969.

¹⁰⁵ *Id*.

¹⁰⁶ *Id*.

independent ability to communicate. ¹⁰⁷ Similarly, in the 1977 Philadelphia case, the issue revolved around the fact that the twins shared a single heart. Lastly, there is no question that Jodie and Mary were considered two independent individuals by their parents, the medical professionals, and the lord justices on the Court of Appeals. More specially, the three lord justices found this question compelling in their opinions and they each came to the conclusion (albeit through different legal avenues) that Mary (the weaker twin) was a separate individual from her sister, capable of being killed. ¹⁰⁸

The issue of bodily integrity was also at the forefront of LJ Ward's analysis in determining whether a surgical separation would bring Mary any benefit in *Re A (Children)*. ¹⁰⁹ LJ Ward persisted that, although there was an interference with Mary's bodily integrity while conjoined with her sister, the idea that a separation surgery would give her more integrity is "wholly illusory goal because she will be dead before she can enjoy her independence." ¹¹⁰

Two out of the three aforementioned cases contain justifications grounded in the principle of double effect. First, in the 1977 Philadelphia case, the Catholic authorities who approved the operation grounded their position in the doctrine of double effect because the unintended evil effect of the separation (death of the dependent/weaker twin) was *indirect* and *justified* by a commensurate reason. Second, Lord Justice Walker's opinion regarding the case of Jodie and Mary also used the doctrine of double effect as a means to justify the surgery. LJ Walker

¹⁰⁷ Ashley Welch, *Doctors Face Heartbreaking Decision, Can Only Save One Twin*, CBS NEWS, Oct. 26, 2017, https://www.cbsnews.com/news/doctors-heartbreaking-decision-conjoined-twins/.

¹⁰⁸ J.J. Paris & A.C. Elias-Jones, *Do We Murder Mary to Save Jodie? An Ethical Analysis of the Separation of the Manchester Conjoined Twins*, 77 POSTGRAD MED. J. 593, 97 (2001).

¹⁰⁹ Jonathan Herring & Jesse Wall, The Nature and Significance of the Right to Bodily Integrity, 76 CAMBRIDGE L.J. 566, 73-74 (2017).

¹¹⁰ *Id.* (citing Ward L.J.'s opinion in Re A (Children)).

¹¹¹ See Paris and Elias Jones at 594; See also Francis X. Meehan, The Siamese Twin Operation and Contemporary Catholic Medical Ethics, 45 LINACRE Q. 157, 157 (1978). (Emphasis added).

¹¹² Davis at 597; Re A (Children) at 1062-63.

pointed out that since the principle essentially holds that death may be foreseen but not intended, the doctrine can be used to excuse a doctor's mere foresight of *accelerated death* from constituting intent to murder. In phrasing the issue, it is important to classify the imminent death of the dependent twin as an "accelerated," and not as an "intended" consequence of the surgery or doctor. Ultimately, whether the double effect applies to a separation surgery (where one twin will likely die) depends on the phrasing of the issue and the ability to shoehorn the facts into the requisite four elements of the ethical principle.

IV. Substantive Legal Analysis

Examining the inconsistent judicial opinions in *Re A (Children)* demonstrates the inadequacies that result from using traditional legal principals to answer a multifaceted problem that spans across medicine, ethics, religion, as well as the law. Nonetheless, it is important to analyze how the substantive legal theories relied on in the case came up short.

Arguably, the most significant shortcoming of the *Re A (Children)* decision was the inability of the judges to rest their decision regarding the legality of the separation surgery on any legal principle.¹¹⁴ The judges appeared to pick and choose different legal theories to shoehorn in the authorization of the separation procedure and defer to the doctors. As a result, the decision provides no guidance to other courts on how to rule in conjoined twin separation cases. Rather, this case awards the lord justices an extraordinary role to make substantial ethical, moral, and medical decisions that should be exclusively reserved for the parents and doctors of conjoined twins. Legal scholar George Annas maintains that "if the circumstance of [*Re A (children)*] were duplicated tomorrow ..., the physicians involved could, on the basis of the

¹¹³ *Id.* (Emphasis Added). Binding authority in England (*R v. Woolin*) held that if a doctor knew death was the certain outcome of a surgery, then they have the requisite intent for murder under British law.

¹¹⁴ George J. Annas, *Conjoined Twins—The Limits of Law at the Limits of Life*, 344 N. ENGL. J. MED. 1104, 08 (2001).

reasoning of this case (and contrary to its conclusion), decided to follow the wishes of the parents and let both twins die. Although, the court's ruling gives a great deal of deference to medical professionals in deciding what is "perfectly acceptable" under the circumstances, judges should not be the final decider in authorizing life-and-death separation surgeries.

Several of the justices attempted to apply the criminal law defense of "necessity," which laid dormant in English law until the court's decision. 117 Lord Justice Brooke based his application of necessity by distinguishing this case with the classic, 1884 case of *R v. Dudley & Stephens*. 118 In *Dudley*, a boat crew escaped a sinking ship without enough food to survive. Faced with impending starvation, the crew killed and ate the youngest and weakest surviving crew member. Just four days after killing the boy, the remaining crew members were rescued and arrested for murder. During the murder trial, the crew members justified the murder out of necessity for their own survival. The court concluded that killing "the weakest, the youngest, the most unresisting" life to save one's own life does not justify murder. Therefore, the members of the crew were charged with murder and sentenced to death. 119 Lord Justice Brooke opined that the case of "Jodie and Mary" was drastically different than the facts of *Dudley* because the "victim in that case was not already destined for death as Mary was. 120

Although the defense of necessity was rejected in *Dudley*, LJ Brooke suggested that certain circumstances allow for the defense. ¹²¹ LJ Brooke stated that three conditions had to be

¹¹⁵ Id

¹¹⁶ *Id.* (citing to LJ Ward's holding).

¹¹⁷ Laura Offer, A Court of Law or a Court of Conscience: A Critique of the Decision in Re A (Children), 4 PLYMOUTH L. & CRIM. JUST. REV. 132, 39 (2012).

¹¹⁸ Annas at 1105; R v. Dudley & Stephens, 14 QBS 273 DC (1884).

¹¹⁹ *Id.*; *R v. Dudley & Stephens*, 14 QBS 273 DC (1884).

¹²⁰ See Colleen Davis, Separating Conjoined Twins: A Medical and Criminal Law Dilemma, 17 J. L. & MED. 594, 598 (2010); see also Dr. Enas Qutieshat, The Legal Personality of Conjoined Twins, 9 Eur. J. Bus. & MGMT. 88, 90 (2017)

Annas at 1105. Re A (Children) at 1051-53. The first example is the case of a mountain climber who must cut the rope holding him to another who has fallen or else they will both die. The second is the 1987 sinking of the

met for the defense of necessity to apply: (1) the act is needed to avoid inevitable and irreparable evil; (2) no more should be done than is reasonably necessary to achieve the purpose; and (3) the evil inflicted must not be disproportionate to the evil avoided. 122 In applying these principles to Jodie and Mary's circumstances, LJ Brooke concluded that the surgery was necessary to avoid the inevitable and irreparable harm to Jodie. As a way to limit the potential for abuse of the necessity defense, Lord Justice Brooke limited his holding to conjoined twin cases where doctors can place the relevant facts before the court for pre-surgery approval. 123 Nonetheless, it was left up to the three lord justices to decide the fate of Jodie and Mary.

The first issue with LJ Brooke applying, and ultimately evolving, the defense of "necessity" to Jodie and Mary's case is that it is based solely on his opinion that Mary "designated herself for death." A more plausible explanation is that "Mary did not designate" herself for anything, she was simply born and survived."125 Outside of LJ Brooke interweaving his personal views into the holding of the case, the use of the "necessity" defense appears to be so specialized that its effect is unlikely to extend beyond the narrow context. 126 Once again, this illuminates the lord justices' inability to firmly and adequately ground their decision in principles of law. 127 As would have likely been the case in the United States, the Court in the case of Jodie and Mary should have exercised more judicial restraint before simply deferring to the decision of

passenger ferry Herald of Free Enterprise near Belgium where 200 passengers drowned. A survivor said that he and dozens of other passengers were in the water near the ladder waiting to be rescued. On the ladder was a young man who was paralyzed with fear. The corporal of the rescue team ordered the man to be pushed off the ladder so that the other could safely climb to safety. The final two examples were the same ones used by the rabbis in the 1977 Philadelphia case explained above (parachute and bandit examples).

¹²² Davis at 598; *Re A (Children)* at 1052.

¹²⁴ See Colleen Davis, Separating Conjoined Twins: A Medical and Criminal Law Dilemma, 17 J. L. & MED. 594, 598 (2010); see also Dr. Enas Outieshat, The Legal Personality of Conjoined Twins, 9 Eur. J. Bus. & MGMT. 88, 90 (2017).

¹²⁵ Annas at 1107.

¹²⁶ Gary T. Trotter, Necessity and Death: Lessons from Latimer and the Case of the Conjoined Twins, 40 ALBERTA L. REV. 817, 39 (2003).

¹²⁷ *Id*.

the doctors and authorizing the surgery. In the United States, the decision of the parents is typically final unless the physicians or the government demonstrates abuse or neglect.¹²⁸

On a completely different end of the spectrum, LJ Walker and LJ Ward sidestepped the necessity defense application because they found it unsupported by the context and the analogies raised in the case. Rather, LJ Walker moved away from common law exceptions for murder and attempted to use the ethical principle of "double effect" to justify the separation. While "double effect" has been invoked by the United States Supreme Court in a footnote as a justification for the administration of pain-relieving drugs to patients receiving palliative care, its foundation in the law has not extended to cases involving conjoined twins outside of the *Re A* (*Children*) context. Additionally, LJ Ward saw the lawfulness of the surgery hinging of a theory of "quasi self-defense," which he "modified to meet the quite exception circumstances nature has inflicted on the twins." On its face, it appears that all three of lord justices interlaced their own personal views into their opinions by tailoring distinct legal principals to ultimately reach the same conclusion of authorizing the separation.

In coming to their decision, the British Court of Appeals totally superseded the cultural, religious, and economic wishes of Jodie and Mary's parents. The British Court's overly paternalistic reasoning and conclusion essentially caused the parents' role to vanish from the decision-making process altogether. LJ Ward was clearly the hardest on the parents, using the analogy of a parent at the gates of a concentration camp when attempting to rationalize the situation.¹³² In his analogy, the Nazi doctor in charge of determining who dies and who can work

¹²⁸ Annas at 1104.

¹²⁹ Davis at 597.

¹³⁰ See Vacco v. Quill, 521 U.S. 793 (1997) (footnote 11).

¹³¹ Davis at 598.

¹³² Annas at 1106.

or be used in medical experiments tells the parent that both her children will be killed if she does not choose one to save. ¹³³ LJ Ward persists that, like Jodie and Mary's parents, the parent in the analogy *must* choose a child to save. ¹³⁴ (Emphasis added). The first troubling aspect of LJ Ward's analysis is his conclusion that a parent must choose which child will die when only one can be saved. ¹³⁵ Clearly, LJ Ward's oversimplification of the situation does not fully consider how difficult of a situation this is for parents of conjoined twins. The second and more unsettling component is that LJ Ward appears to apply "concentration-camp" ethics to reach his conclusion in deferring to the British physicians. ¹³⁶ Besides the inability to firmly ground the decision in operative law or common law principles, LJ Ward's decision exemplifies judicial activism and is based partly on insensitive personal opinion.

The Court in *Re A (Children)* not only answered the case according to their own personal views, but it also established weak precedent for future cases concerning conjoined twins.¹³⁷ The shoehorning of common law principles provides no clarity for future courts and litigators in deciding these complex dilemmas. The inconsistences raised by *Re A (Children)* begs the question, what should a court's role be in cases concerning the separation of conjoined twins? A more rational approach would be to withhold the courts from making the ultimate decision in separation cases. By placing courts in an advisory role, they would have the ability to comment on and determine whether a proposed procedure is legally permissible, but go no further.¹³⁸ There is a clear distinction between a court determining whether a particular course of action,

¹³³ *Id*.

 $^{^{134}}$ *Id*.

¹³⁵ *Id*.

¹³⁶ *Id.* at 1107.

¹³⁷ Offer at 151.

¹³⁸ For example, and similar to the 1977 Philadelphia case explained above, physicians should be able to seek judicial approval and legal immunity regarding the procedures they choose to undertake as a way to proactively prevent civil and criminal liability.

chosen by the parents and physicians, is legally permissible and whether a particular medical procedure is *required* by law.¹³⁹ (Emphasis added). The decision to separate should be left to the physicians and the parents of the conjoined twins, even in situations where one of the babies will likely die. If the physicians and parents cannot come to an agreement, then respecting the decision and beliefs of the parents, outside of those constituting neglect, is the most reasonable. Prior to asking a court whether a procedure is legally permissible, it is important for the parties to consult both ethics committees and legal counsel as a means to assess the potential implications. This proposed framework breaks away from the court-driven and highly personalized reasoning used throughout *Re A (Children)*, and ultimately places the decision-making authority in the hands of the parties where it belongs most: the family and the treating physicians.

Conclusion

It is clear that the law, by itself, is inadequate and inappropriate to answer the life-and-death questions raised in cases involving the separation and care of conjoined twins. Judges alone should not be elevated to the role of deciding what is medically, ethically, and morally "right" or "wrong" as the court did in *Re A (Children)*. First, there are no "right" or "wrong" answers in these cases, and second, these substantial choices should be left to the parents and the treating physicians of conjoined twins. The 2017 case of "Twin A and Twin B" in New England demonstrates what happens when the parties consider fundamental ethical principles, the independent moral beliefs of the parents, as well as the professional recommendations of doctors. Additionally, the 1977 case in demonstrates how the court should be used as a last resort to merely determine the legality of a separation procedure. The issues surrounding the separation of

¹³⁹ Annas at 1108 (Stating that "the first role seems reasonable; the second seems justified only in cases in which the failure to act (on the parent of either parent or physician) is child neglect").

conjoined twins raised in this article are in no way exhaustive. Rather, they are merely the starting point for a more holistic inquiry that intersects the fields of law, ethics, and morality.