The Conjoined Twins: The Conflict between Parents and the Courts over the Medical Treatment of Children

Heather Tierney
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I. INTRODUCTION

The anomaly of conjoined twins fascinates and amazes people around the world. Conjoined twins are the subject of television documentaries and a source of curiosity and amazement. With advances in medical treatment more conjoined twins survive birth. Parents of conjoined twins immediately face life and death decisions concerning their new babies. The most difficult of these decisions is whether or not to separate the twins. Medically, legally, and ethically the occurrence and survival of conjoined twins is an interesting and controversial topic. As Nancy Segal, an expert on twins and twinning, stated “public debates on the physical and psychological treatment of conjoined twins have engaged physicians, families and reporters in triadic tangles over pregnancy termination, surgical separation, and postoperative management.”

In August of 2000, the first legal case involving the surgical separation of

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1. Conjoined twins were once known as Siamese twins. See Conjoined Twins, at www.twinstuff.com/conjoined.htm (last visited Apr. 26, 2001). The most famous set of conjoined twins, Eng and Chang Bunker, were born on May 10, 1811 and died within hours of each other on January 17, 1864 at age 62. See id. The brothers were successful businessmen in North Carolina and fathered at least twenty-one children between them. See id. The twins married sisters and traveled around the world with Barnum’s circus to earn money. See id. After their death doctors determined that the twins could have been successfully separated because they were attached by only a five-inch ligament near their breastbones. See id. See also KAY HUNTER, DUET FOR A LIFETIME (1964). See also DARIN STRAUSS, CHANG AND ENG (2001).

2. “At one end of the spectrum is the case of two fully grown, fully equipped bodies with a minor connection which is easy to remove, leaving two complete individuals who could survive into old age. At the other end is one complete body with a number of extra parts which could be removed to leave just one complete individual. Between these two extremes are a range of gradations including two fairly complete bodies, which are so heavily fused that they cannot be separated but at a substantial risk; and two, which can be separated with the inevitable consequence that one of them will die.” Sally Sheldon & Stephen Wilkinson, Conjoined Twins: The Legality and Ethics Of Sacrifice, 2 Med. L. Rev. 149, 150 (1997).

conjoined twins arrived in a British courtroom.\(^4\) The case involved a fundamental dispute about medical care and the separation of conjoined twins which divided the scientific, legal and religious sectors of society.\(^5\) The doctors believed the twins should be separated giving the stronger, viable twin an opportunity to live. The devoutly religious parents believed that the decision regarding whether the children lived or died should be left in God’s hands. In their view no one should intentionally cause the death of another person.\(^6\)

This comment explores how the courts in the United States might review a conjoined twins case such as the one of Jodie and Mary. As a starting point, this comment closely examines the facts and the judicial treatment by the Appeals Court in Britain of Jodie and Mary’s case. This analysis examines the opinions of each Justice on the Court of Appeals as well as the Court’s decision. The second part analyzes how courts in the United States treat medical cases where children either receive extraordinary medical treatment over the advice of their doctor. This comment explores the well known case of Baby K, a baby born without brain function in October, 1992.\(^7\) This includes the judicial treatment by the trial court, as well as the court of appeals. Lastly, this comment address cases where parents refuse medical treatment for their minor children because of their religious beliefs.

This comment analyzes both the differences and the similarities in cases where medical treatment is sought to save life and cases in which parents refuse medical treatment on religious grounds. In addition to the case analysis, this comment contemplates the effect of parent’s constitutional rights under the free exercise clause, the rights of children in terms of child abuse and neglect, the parent’s rights in terms of child abuse and neglect, as well as the state’s right to intervene.

II. JODIE AND MARY - BACKGROUND

Jodie and Mary were born on August 8, 2000.\(^8\) The children were born to

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\(^8\) These are fictional names given by the court. The girls’ real names are Gracie and Rose. See Law Decreed Fate of Jodie and Mary, THE GUARDIAN, Feb. 5, 2002. George J. Annas, Conjoined Twins-The Limits of Law at the Limits of Life, 344 N. Eng. J. Med. 1104 (2001). The parents are Kosovar refugees who now live on Gozo. See Conjoined Twins Case, supra note 4, at 727. The mother discovered at four months that she was carrying conjoined twins. Id. (quoting from the parents statement). In their homeland the termination of any pregnancy is illegal. See id. The doctors in Gozo recommended St. Mary’s Hospital in Manchester. Id. The government established links with the British government, which allows patients to be treated by the National Health Service and be
Michaelangelo and Rina Attard, devout Roman Catholics. Jodie and Mary were ischiopagus tetrapus conjoined twins. Thus, each had their own arms and legs, although they were joined at the pelvis and shared a linked spine. The girls had their own internal organs, except for a shared bladder. Jodie's heart and lungs performed all of the circulatory functions for both girls. A common, shared artery enabled Jodie to circulate oxygenated blood for both of them. The strain of supporting both girls would result in the death of both twins within a matter of expense. Conjoined Twins Case, supra note 6, at 208. The doctors suggested, 'Mary is drawing nutrition from Jodie, and growing at her expense.' Conjoined Twins Case, supra note 8, at 1104.

10. Conjoined Twins Case, supra note 4, at 728. Ischiopagus twins are joined at the ischium and tetrapus twins have four lower limbs. See id. The girls bodies are merged, with their legs emerging at right angles from each side and their heads at opposite ends. See Judges Rule Conjoined Twins Can Be Separated, Sept. 22, 2000 at http://www.cnn.com/2000/WORLD/europe/UK/09/22/britain.twins.03 (last visited Apr. 26, 2001) [hereinafter Judges Rule]. Ischiopagus twins account for only 6% of all conjoined twins. See Conjoined Twins at www.twinstuff.com/conjoined.htm (last visited Apr. 26, 2001) (describing the occurrence of conjoined twins and the different types of conjoined twins, as well as a history on the most famous sets of conjoined twins). The most common form of conjoined twins are thoraopagus which account for 35-40% of all cases. Id. Thorapagus twins share part of the chest wall and sometimes share a heart. Id. Conjoined twins are extremely rare and are always identical, same-sex twins, 70% being female. Id. See also Types of Conjoined Twins, http://zygote.swathmore.edu/cleave4a.html (last modified Apr. 5, 1996). There are no documented cases of conjoined triplets or quadruplets. See id. See also Conjoined Twins, infra note 10. However, there are cases of conjoined twins in triplet and quadruplet sets. See SEGAL, supra note 3, at 296. Furthermore, conjoined twins are less likely to occur in the United States or China than in India or Africa. See How Are Conjoined Twins Formed? at http://www.conjoined-twins.i-p.com/how.html (last visited Apr. 26, 2001); See also SEGAL, supra note 3, at 301 (reviewing a study regarding the occurrence of conjoined twins in different parts of the world. The study also investigates the effect of the environment). Conjoined twins occur as often as once in every 40,000 births but only once in every 200,000 live births. See How Are Conjoined Twins Formed, infra note 10. Seventy-five percent of conjoined twins are still born or die within 24 hours. Id. They are the product of a single egg that, for some unknown reason, failed to divide fully into separate twins during the first three weeks of gestation. See Claudia Wallis, The Most Intimate Bond: Conjoined for Life, the Hensel Twins are a Medical Mystery and a Lesson in Cooperation For Us All, TIME MAG., Mar. 25, 1996, available at http://www.time.com/time/magazine/archive/1996/don/960325/medicine.html (last visited Aug. 10, 2001). The mother of Jodie and Mary went into spontaneous labor at 42 weeks. See Judges Rule, infra note 10. The parents wanted little intervention during delivery so the doctor delivered the children at the last possible moment by Caesarean section. See id.

11. Annas, supra note 8, at 1104. See also Christopher Kaczor, The Tragic Case of Jodie and Mary: Questions about Separating Conjoined Twins, http://bellarmine.imu.edu/faculty/ckaczor/articles/twins.html (last visited Aug. 10, 2001). Justice Ward described the twins from photographs. "Jodie's head seems normal but Mary's is obviously enlarged, for she has a swelling at the back of the head and neck, she is facially dysmorphic and blue because she is centrally cyanosed." Conjoined Twins Case, supra note 4, at 729.

12. See Hewitt, supra note 6, at 208.

13. Kaczor, supra note 11. Mary grew at a normal rate while Jodie did not grow. See Hewitt, supra note 6, at 208. The doctors suggested, "Mary is drawing nutrition from Jodie, and growing at her expense." Conjoined Twins Case, supra note 4, at 732.

14. See Conjoined Twins Case, supra note 4 at 726 (describing Mary's and Jodie's situation). The separation of the twins would involve severing this artery, which would result in Mary's death. See id. If the girls are not separated they could live as long as six months and perhaps longer. See id. Jodie's heart will eventually fail leading to the death of both girls. See id.
weeks. As the stronger twin, Jodie could survive on her own if separated from Mary but Mary would certainly die.

The parents believed that God, not doctors, should decide whether their daughters lived or died. The parents declined St. Mary's Hospital's offer to perform the operation to separate the girls. In their eyes, the twins were equal in the eyes of their parents, so they would not sacrifice one to save the other. As a result, the twins' doctors turned to the court to order the surgery over the objections of the parents.

III. IN RE A (CHILDREN) – THE DECISION OF THE BRITISH APPEALS PANEL

In British courts, Lord Justices on an appeals panel customarily issue separate opinions. The Lord Justices agreed with the trial court judge's decision to separate the girls. The appeals panel justices did not agree with the Family Division's justices legal reasoning, as well as each other's legal reasoning as to the legality of the operation to separate the girls. Interestingly, the Lord Justices quoted Justice Scalia in *Cruzan v. Missouri Department of Health* where the doctors predicted this result).

See also Daniel P. Sulmasy, *Heart and Soul: The Case of Conjoined Twins*, http://www.americapress.org/articles/sulmasy.htm (last visited Aug. 10, 2001) (stating that the doctors decision to separate the twins as the only medically proper decision was hasty). The fact that the doctors do not have thousands of cases in which to compare this case means they were not speaking from experience. Id. The author questions the assumptions by doctors that both girls would die without the surgery. Id. Furthermore, the doctors also questioned the probability of success of the surgery to separate the girls at 80%. Id. Also questioned is the decision not to try a heart and lung transplant for Mary, although the author recognized that there is not enough medical knowledge to determine if this was possible. Id.

Approximately 200 surgical separations of conjoined twins were attempted, approximately 90% of these after 1950. See SEGAL, supra note 3, at 306-307. Since 1950 three quarters of the surgeries have resulted in one or both of the twins surviving. Id.

Choosing to save Jodie at the cost of Mary's life would be ending a life, directly conflicting with the parents' religious views. See *The Separating of Conjoined Twins: A Human Life has the Greatest Value, but its Loss May be Justified*, http://www.bmj.com/cgi/content/fuIll/321/7264/782 (last visited Aug. 10, 2001) [hereinafter *The Separation of Conjoined Twins*].

As devout Roman Catholics, they believe, "that it is God's will that their children are afflicted as they are and they must be left in God's hands." Id.

20. See Hewitt, supra note 6, at 210. The parents entered an "originating summons" with the High Court. Id.

21. See Annas, supra note 8, at 1104.

22. Id. at 1104. The Justices commented on the personal difficulties each had in reaching a decision. See *The Separation of Conjoined Twins*, supra note 17. The Justices made comments about experiencing many sleepless nights agonizing over their decision. Id.

23. Id.

24. 497 U.S. 261 (1990). The court determined that it does not violate the Constitution to implement the wishes of the appointed surrogate even if there is not clear and convincing evidence of a patient's wish to have medical care withdrawn. Id. at 292. The predecessor to this case is the Quinlan case. In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976). In the Quinlan case, Karen Quinlan suffered from severe brain damage causing a permanent vegetative state. Her parents wanted her respirator
United States (U.S.) Supreme Court Determined the legality of a parent’s decision to end life sustaining treatment for their daughter.\(^{25}\)

According to the “welfare principle” the British court had the right to override the decision of the parents if it is in the best interests of the child to do so.\(^{26}\) This principle puts the child’s welfare above parental interest.\(^{27}\) The judges decide if it is in the child’s best interest to have “an independent and objective judgment.”\(^{28}\) This differs from the U.S., where the only way to override a decision by the parents is to convince a judge that it was a case of abuse or neglect.\(^{29}\) The issue in this case was whether the parents could refuse medical treatment for their daughters. The Family Division court determined that the parents could refuse medical treatment, but the doctor’s request to operate on the girls was in their best interest, therefore overriding the decision of the parents.\(^{30}\)

The Family Division judge concluded “that separation was not a case of killing Mary but one of passive euthanasia in which her food and hydration would be withdrawn (by clamping off her blood supply from Jodie).”\(^{31}\) The parents and the official solicitor, appointed to represent Mary’s interest, appealed the judgment of the Family Division Court\(^{32}\)

A. Lord Justice Alan Ward

British Appeals Court Justice Ward addressed the court’s ability to hear the case.\(^{33}\) The parents are entitled to consent or reject medical treatment on behalf of a minor child if it is in the child’s best interest.\(^{34}\) The hospital has the right to ask the court to overturn the parent’s decision and give consent to the operation.\(^{35}\)

The fundamental principal of medical law allows people the opportunity to decide for themselves whether or not to receive medical treatment.\(^{36}\) This principal

\(^{25}\) "The point at which life becomes ‘worthless’ and the point at which the means necessary to preserve it become extraordinary or inappropriate are neither set forth in the constitution not known to the nine Justices of this Court any better then they are known to nine people picked at random from the Kansas City phone directory.” 497 U.S. 261, 293 (1990).

\(^{26}\) See The Separating of Conjoined Twins, supra note 17.

\(^{27}\) Id.


\(^{29}\) Id.

\(^{30}\) See Conjoined Twins Case supra note 4, at 747.

\(^{31}\) See Annas, supra note 8, at 1104. See Conjoined Twins Case, supra note 4, at 748.

\(^{32}\) Conjoined Twins Case, supra note 4, at 736.

\(^{33}\) See Annas, supra note 8, at 1104.

\(^{34}\) See Conjoined Twins Case, supra note 4, at 751-752.

\(^{35}\) Id.

\(^{36}\) Id. at 748.
is enforced regardless of the unreasonableness of the decision. In the case of minor children, a safeguard exists allowing the court to override the parents’ decision if it is in the child’s best interest. The parents have a right and duty to determine whether to consent or withhold medical treatment.

Family law dictated the test to determine whether the parents refusal can be overridden. The Courts paramount consideration is the welfare of the child. Lord Justice Ward addressed Jodie’s best interest first and agreed with Justice Johnson in the Family Court that it was in Jodie’s best interest to have the operation. The operation would allow Jodie to have a normal life expectancy with little risk of brain damage of death. He stated...”it seems to me impossible to say that this operation does not offer infinitely greater benefit to Jodie than is offered to her by letting her die if the operation is not performed.”

Determining Mary’s best interest was more difficult for Lord Justice Ward. The critical distinction was whether the operation was viewed as a prolongation of Mary’s life or a termination of her life. The important consideration in respect to Mary was that her condition would never improve. There was no determination as to whether or not she was in pain and that prolonging her life would be to her disadvantage.

In determining Mary’s best interest, Lord Justice Ward recognized that there was no best health interest. He determined that, “the operation is not capable of enduring any other improvement in her condition or preventing any deterioration in her present state of health.” He concluded that Mary’s life has value even if she did not have the capacity to enjoy it. The Court used best interests and welfare interchangeably.

In cases considering the best interest of two children, the court must first balance the matter relevant to each child. The

37. *See* Conjoined Twins Case, *supra* note 4, at 749.
38. *Id.* at 751. The parents did not contest the court’s ability to review their decision. *Id.*
39. *Id.* at 752.
40. *Id.* The Court used best interests and welfare interchangeably.
41. *Id.* at 755.
42. *Id.* at 756.
43. *Id.*
44. *Id.*
45. *Id.*
46. *Id.* at 757.
47. *Id.* at 756.
48. *Id.* This was part of Justice Johnson’s decision.
49. *Id.* at 757.
50. *Id.*
51. *Id.* at 761. Lord Justice Ward disagreed with Justice Johnson that Mary’s life was worth nothing to her. *Id.*
52. *Id.* at 764.
53. *Id.*
54. *Id.*
wishes of the parents are considered in finding this balance.55

The important distinction addressed by Lord Justice Ward is the withdrawal of care or treatment versus the ending of a patient’s life by lethal injection.56 He quoted Lord Goff, stating:

The distinction appears, therefore, to be useful in the present context in that it can be invoked to explain how the discontinuance of life support can be differentiated from ending a patient’s life by lethal injection. But in that end the reason for that difference is that, whereas law considers that discontinuance of life support may be consistent with the doctor’s duty to care for his patient, it does not, for reasons of policy, consider that it forms any part of his duty to give his patient a lethal injection to put him out of his agony.57

B. Lord Justice Brooke

Lord Justice Brooke agreed with Lord Justice Ward’s determination that when balancing the girls’ interests against each other, Mary’s interests should not outweigh the interests of Jodie.58 He determined that the issues involving criminal law were the most difficult. The most important question was whether or not the operation to separate the girls was lawful.59 He looked at the legal definition of murder, as well as the exceptions.60 The Lord Justice focused on the words and phrases important to this case: “unlawfully,” “kills,” “any reasonable creature,” and “with intent to kill.”61

Lord Justice Brooke analyzed the meaning of the word “kills.”62 He used the case of Airedale NHS Trust v. Bland63 where the House of Lords made an important distinction between a doctor’s decision not to prolong a life through treatment and a doctor’s decision to end a life by administering a lethal drug.64 Withholding medical treatment is lawful in situations where the patient gave consent and in some circumstances where the patient did not give consent.65 Conversely, the doctor may not administer a drug to bring about death, even in circumstances of extreme suffering.66 A positive act can be categorized as

55. See Conjoined Twins Case, supra note 4, at 765.
56. Id. at 763.
57. Id at 762.
58. Id. at 779. Lord Justice Brooke agree with Lord Justice Ward’s analysis in terms of family law. Id. Lord Justice Brooke adopts Lord Justice Ward’s description of the facts as well but considered the literature before the court valuable in deciding the issues of the case.
59. Id. at 784.
60. Id. Lord Justice Brooke concluded that the exceptions were irrelevant in this case. Id.
61. Id. at 786.
62. Id. at 788.
64. Conjoined Twins Case, supra note 4, at 788-89. This is the decision the House of Lords faced in the Airedale case.
65. Id. at 789 (discussing the Airedale case).
66. Id. The House of Lords called this form of killing euthanasia. Euthanasia is unlawful at common law.
murder.  

Lord Justice Ward discussed the defense of necessity and attempted to draw an analogy to when "murder" may be necessary. He relied on Sir James Stephen's requirements for the application of the doctrine of necessity. First, the act is needed to avoid inevitable and irreparable evil. Second, the lawful killing should be no more than is reasonably necessary for the purpose to be achieved. Third, the evil inflicted must not be disproportionate to the evil avoided.

In weighing the factors, Lord Justice Brooke turned to the case of Regina v. Dudley & Stephens to demonstrate the doctrine of necessity. In Dudley, a four member crew escaped their sinking yacht with only two tins of turnips. After eight days without food, Dudley and Stephens killed the youngest and weakest crew member. The rest of the crew ate him to survive and four days later the crew members were rescued. At their trial for murder, Dudley and Stephens argued that they killed the other crew member out of necessity. The Court's opinion questions the doctrine of necessity and the Court determined that the crew's actions were murder and that their actions could not be justified by necessity. Most importantly when applying the doctrine of necessity, "[b]y what measure is the comparative value of lives to be measured."

Lord Justice Brooke determined that even though Mary's death would constitute murder, Sir James Stephen's requirements for the application of the doctrine of necessity justified the surgery. Lord Justice Brooke concluded that Jodie's interest in life must outweigh Mary's conflicting interest.

67. See Conjoined Twins Case, supra note 4, at 789. In the Airedale case the House of Lords determined that cutting off life prolonging treatment was not a positive act and therefore did not fall under the law of murder.
68. Id. at 794.
69. Id. at 816.
70. Id.
71. Id.
72. Id.
73. The Queen v. Dudley and Stephens, 14 Q.B.D. 273 (1884).
74. Id.
75. Id. Dudley and Stephens did not inform the other crew member, Brooks, of their plans. Id. Dudley and Stephens choose the boy because they both had families. Id.
76. Id.
77. Id.
78. Id. at 287. Lord Coleridge states, "Though law and morality are not the same, and many things may be immoral which are not necessarily illegal, yet the absolute divorce of law from morality would be of fatal consequence; and such divorce would follow if the temptation to murder in this case were to be held by law an absolute defense of it." Id. He determined that it is not always necessary to preserve life. Id. For example, lives are sacrificed in war. Id.
79. Id.
80. Conjoined Twins Case, supra, note 4, at 815.
81. Id. at 816. He also argued in the doctrine of sanctity of life and that the operation to separate the girls would give the girl's bodies the integrity denied to them by nature. Id.
C. Lord Justice Robert Walker

Lord Justice Robert Walker recognized two central questions in this case. First, are these conjoined twins two persons or one in the eyes of the law? Second, if they are two persons, was Mary born alive? This second question was important because there is no criminal liability if she was not born alive. Lord Justice Walker believed they should be regarded as two separate people. Mary did not fall within the definition of a still-born child as defined by the Births and Deaths Registration Act of 1965. The Lord Justice points out that the Children Act requires the Court to consider the best interests of each child. In cases where the Court looks at the well being of two siblings, it must balance the interests of the children and achieve the "situation of least detriment."

Lord Justice Walker considered the parents' opinion about the future of their children. Their sincere religious beliefs though controversial, are unlike Jehovah’s Witnesses objections to blood transfusions because they are not contrary to society’s generally accepted views. In addition, their views are supported by the society in which they live. Lord Justice Walker understood the doctor’s assertion that the surgery was the best way to save Jodie and that this must be respected, even though the Justices or Court of Appeals could not determine the legality of the operation.

Lord Justice Walker agreed with the determination of Lord Justice Brooks that the doctrine of necessity was important in this case, but found no helpful parallel case. Ultimately, Lord Justice Walker found that the doctor's testimony that the operation was in the best interest of both twins persuasive and agreed with the decision to allow the surgery. The parents choose not to appeal the court’s decision.

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82. Conjoined Twins Case, supra note 4, at 817.
83. Id. at 818.
84. Id.
85. Id. This was more than parasitic attachment. Id. The girls each had a brain and almost complete bodies. Id.
86. Id. A child which has issued forth from its mother after the twenty-fourth week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any signs of life. Id. Mary struggled to breathe. Id.
87. Children’s Act, 1989, sec. 3 (Eng.).
88. Conjoined Twins Case, supra note 4, at 819.
89. Id. See In Re H 1 FLR 883 (1993). Cases that have involved the balancing of interests have not been decisions as a matter of life or death. Conjoined Twins Case, supra note 4, at 819.
90. Conjoined Twins Case, supra note 4, at 821.
91. Id.
92. Id.
93. Id. at 835.
94. Id. at 836.
95. Id.
D. Holding

Six weeks after the Court of Appeal's dismissal of the parents appeal the hospital performed the operation separating Jodie and Mary. 96 As expected, Mary died during surgery. 97 Jodie needs extensive surgery in the next few years, but could recover fully. 98 She returned to Gozo with her parents. 99

IV. THE UNITED STATES: THE CASE OF BABY K

The case of Baby K presented a situation where the wishes of the doctors and parents collided. 100 As in the case of Jodie and Mary, the parents and doctors disagreed about what should be done with their babies. On October 13, 1992, Baby K was born by cesarean section in Falls Church, Virginia. 101 Baby K was diagnosed as anencephalic. 102

Immediately after birth, Baby K was put on ventilation. The doctors urged the mother to discontinue respiratory methods because there was no chance of long-term survival for Baby K. 103 The physician treating Baby K sought advice from the hospital ethics committee, as well as a subcommittee composed of a family practitioner, a psychiatrist, and a minister. 104 The subcommittee decided that a legal remedy would be sought if the impasse continued between the doctors

96. Annas, supra note 8 at 1106. The surgery took twenty hours. See Sulmasy, supra note 15.
97. Annas, supra note 8, at 1106.
98. Id.
99. Id.
101. See George J. Annas, Asking the Courts to Set the Standard of Emergency Care-The Case of Baby K, 330 NEW ENG. J. MED. 1542 (1994) [hereinafter Asking the Courts].
102. Anencephaly is "the congenital absence of major portions of the brain, skull, and scalp characterized by a large opening in the skull accompanied by the absence or severe disruption of the cerebral hemispheres." See The Medical Task Force on Anencephaly, The Infant With Anencephaly, 322 NEW ENG. J. MED. 669 (1990). The infants are permanently unconscious and have some responses to stimuli. See id. A low percentage of infants born with anencephaly survive more than a week after birth. See id. Each year approximately 1,000 infants are born with this condition. See Carol J. Castaneda, Baby K Now Stephanie Turns 2, USA TODAY, Oct. 13, 1994. She had a brain stem, which functioned allowing her to have respiratory reflexes, minimal feeling reflexes and reflexive responses to noxious stimuli. See Hylton Rushton, supra note 100, at 367. Baby K was diagnosed parentally, but her mother would not agree to terminate the pregnancy despite the advice of her doctors. See Asking the Courts, supra note 101, at 1542. She declined to have an abortion because of her devout Christian beliefs. See Karen R. Long, Whose Life is it Anyway? Debate Rages on Baby K Kept Alive for Two Years, Child Cannot See, Hear, Think or Feel, THE PLAIN DEALER, Oct. 9, 1994. The father of the baby sided with the hospital and believed that care should be discontinued. See id. The parents were unmarried and the father was less involved in the case. See id.
103. See Resuscitation Required, Court Says, BALTIMORE SUN, Oct. 4, 1994. The baby did not interact with her environment and was permanently unconscious. See Hylton Rushton, supra note 100, at 367. She did not see, feel, hear, talk, think or feel pain. Id.
104. Asking the Courts, supra note 101, at 1562. The mother had a strong religious belief that all life has value and should be preserved." See Life and Law in the Case of Baby K, THE VIRGINIAN-PILOT AND THE LEDGER-STAR, Oct. 6, 1994.
and the mother. On November 30th, 1992 the hospital transferred Baby K to a nursing home, but agreed that if respiratory difficulties reoccurred she would be immediately returned to the hospital. Baby K returned to the hospital in January and two additional times after that. Fairfax hospital took the case of Baby K to federal court. The hospital requested the court to determine whether it could discontinue life sustaining treatment in the event that Baby K arrived at the emergency department in emergency distress.

The hospital sought a declaration that the refusal to provide life-supporting medical care to Baby K would not transgress the Emergency Medical Treatment and Active Labor Act (EMTALA), the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990 (ADA), the Child Abuse Amendments of 1984, and the Virginia Medical Malpractice Act. The Court refused to make any legal rulings concerning the rights or obligations of the hospital under the Child Abuse Amendments of 1984 and under the Virginia Medical Malpractice Act.

Under EMTALA, the hospital wanted an exemption from the requirements of the statute when the treatment is deemed by hospital physicians to be “futile” or “inhumane.” According to the court, the exceptions the hospital sought under EMTALA did not apply in the case of Baby K. The federal court determined that the treatment of acute symptoms of respiratory difficulty by the use of a mechanical ventilator is not “futile” or “inhumane.” The court reasoned that this was similar to refusing an AIDS or cancer patient medical treatment after an accident on the grounds that because they will die anyway the care would be “futile.”

“The Rehabilitation Act prohibits discrimination against an ‘otherwise qualified’ handicapped individual, solely by reason of his or her handicap, under

105. Life and Law in the Case of Baby K, supra note 104. The father of Baby K was only distantly involved.
106. Id.
107. Id.
108. See In the Matter of Baby “K,” supra note 7, at 1022. See also Hylton Rushton, supra note 100, at 367. See also Asking the Courts, supra note 101, at 1542.
113. Virginia Medical Malpractice Act, Va. CODE § 8.01-581.1 et seq.
115. Id. at 1027.
116. Id.
117. Id.
118. Id.
any program or activity receiving federal financial assistance." The court then turned to the ADA. The ADA "prohibits discrimination against disabled individuals by 'public accommodations,'" Under the ADA. Anencephaly is a disability and public accommodations include health care providers. It differs from the Rehabilitation Act in that, "the ADA does not require an individual to be 'otherwise qualified' to receive benefits." The Court determined that "the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would be otherwise be provided to a baby without disabilities at the parent's request." In addition to these statutes, the court looked last at the constitutional and common law issues surrounding the case. Various issues arose because Baby K’s father and guardian ad litem opposed the continuation of medical treatment and wanted to override the wishes of the baby’s mother. The Fourteenth Amendment due process clause protects a parent’s constitutional right to "bring up children." In addition, decisions made for children based on a parent’s free exercise of religion are guaranteed by the First Amendment of the United States Constitution. Furthering parental rights, parents retain the medical authority to seek medical care for minor children (even if it impinges on the child’s liberty interest) absent a finding of abuse or neglect. The court recognized a presumption that the parents act in the best interests of their child because the "natural bonds of affection lead parents to act in the best interests of their children." The court pointed to the hospital’s failure to provide clear and convincing evidence that the mother’s decision should not be respected because it constituted severe abuse and neglect. Accordingly, the court denied the hospital's request for a declaratory judgment that they would not violate the EMTALA, the Rehabilitation Act, and the ADA. In addition, according to EMTALA and the Rehabilitation Act, the hospital was required to provide ventilator treatment to

120. Id.
121. Id. at 1028.
122. Id.
123. Id.
124. Id.
125. Id. at 1029.
126. Id. at 1030. The guardian ad litem was appointed on the hospital's motion. Id. at 1026.
127. Id. See also Meyer v. Nebraska, 262 U.S. 390, 399 (1923).
129. Id. See also Parham v. J.R., 442 U.S. 584, 603-04.
130. See Parham, supra note 129, at 602.
131. In the Matter of Baby “K,” supra note 7, at 1031. The clear and convincing standard was upheld by the United States Supreme Court in Cruzan. Cruzan, supra note 24, at 284.
132. See In the Matter of Baby “K,” supra note 7, at 1026.
Baby K.\textsuperscript{133}

The Fourth Circuit Court of Appeals affirmed the judgment of the District Court and noted that EMTALA, "gives rise to a duty on the part of the hospital to provide respiratory support to Baby K when she is presented at the Hospital in respiratory distress and treatment is requested for her."\textsuperscript{134} The court refused to address the hospital's obligations under the other federal statutes and the laws of Virginia because there was a duty to render treatment under EMTALA.\textsuperscript{135} Furthermore, the Court determined "[i]t is beyond the limits of our judicial function to address the moral and ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants."\textsuperscript{136}

The Court of Appeals specifically addressed the hospital’s four arguments, agreeing with the District Court's analysis of the applicable statutes.\textsuperscript{137} First, the hospital argued that EMTALA required that the hospital provide Baby K the care that other anencephalic infants received.\textsuperscript{138} The court disagreed and determined that the Act required the hospital to provide stabilizing treatment regardless of the condition of the patient.\textsuperscript{139} Second, the hospital argued that the Act did not require medical treatment outside the prevailing standard of care.\textsuperscript{140} The Court disagreed and determined that the hospital was required to stabilize the child.\textsuperscript{141} Third, the Court disagreed with the hospital that it was not required to administer "inappropriate" care.\textsuperscript{142} Lastly, the hospital argued that EMTALA only applied to patients who were transferred from the hospital in an unstable condition.\textsuperscript{143} The court refused to address the moral and ethical treatment of anencephalic infants.\textsuperscript{144} On October 3, 1994, the Supreme Court declined to hear the case.\textsuperscript{145}

A. Refusal of Medical Treatment

The U.S. courts differentiate between medical treatment for life-threatening and non life-threatening situations. A court ordered medical treatment for a child when the parent's religious beliefs forbade them to seek life-saving treatment.\textsuperscript{146} When the illness is not life-threatening, courts differ as to whether treatment will be ordered over the parent's objections.\textsuperscript{147} A parent's refusal of life-saving

\textsuperscript{133} See In the Matter of Baby "K," supra note 7, at 1026.
\textsuperscript{134} In the Matter of Baby "K," 16 F.3d 590, 592 (4th Cir. 1994) [hereinafter Baby "K"].
\textsuperscript{135} Id. at n.2.
\textsuperscript{136} Id. at 598.
\textsuperscript{137} Id. at 595.
\textsuperscript{138} Id.
\textsuperscript{139} Id.
\textsuperscript{140} Id. at 596.
\textsuperscript{141} Id.
\textsuperscript{142} Id. at 597.
\textsuperscript{143} Id.
\textsuperscript{144} Id. at 598.
\textsuperscript{146} See Laura M. Plastine, "In God We Trust": When Parents Refuse Medical Treatment for their Children Based Upon their Sincere Religious Beliefs, 3 SETON HALL CONST. L. 123, 141-42 (1993).
\textsuperscript{147} Id. at 145.
medical treatment for a child because of sincere religious beliefs will be overridden to ensure that a child receives medical treatment.148 In order to override the wish of the parents, the state must prove that the life-threatening condition can be addressed by available medical treatment.149 Courts generally find that the parents violated child endangerment and neglect statutes and that the state’s interest in saving the child’s life is most important.150

1. United States Supreme Court Decisions

The Supreme Court affirmed the decision of the federal district court in Jehovah’s Witnesses in Washington v. King County Hospital151 without opinion. In this case, the hospital gave the minor children of Jehovah’s Witnesses blood transfusions pursuant to court orders.152 The parents brought suit against the hospital and the doctors seeking declaratory and injunctive relief on the behalf of all Jehovah’s Witnesses residing in the state of Washington.153 The parents argued that the practice of making their children wards of the state so that they receive medical care violated their First Amendment rights under the Free Exercise Clause and their right of religious freedom of association, as well as other guaranteed Constitutional rights.154

The Court applied the holding in Prince, stating that claims of religious liberty do not outweigh public interest.155 The Court said, “[a]s stated in Prince, the right to practice religion freely does not include liberty to expose the child to ill health or death.”156 The court also stated, “[p]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”157

The Court held, In the Interest of D.L.E.158 that “where a minor suffers from a life-threatening medical condition due to a failure to comply with a program of medical treatment on religious grounds, . . . permits a finding of dependence and neglect and does not violate the constitutional provisions protecting the free exercise of religion.”159 In this case, the adoptive mother of D.L.E. belonged to the General Assembly and Church of the First Born and refused medical care for her

150. Plastine, supra note 146, at 142-44.
151. Jehovah’s Witnesses in Washington v. King County Hospital, 278 F. Supp. 488 (N.D. Wash. 1967), aff’d, 390 U.S. 598 (1968) [hereinafter Jehovah’s Witnesses].
152. Id. at 498. The court had authority pursuant to provision of the Juvenile Court Law of the State of Washington. Id. at 499.
153. Id. at 500.
154. Id.
156. Jehovah’s Witnesses, supra note 151, at 504 (quoting Prince, supra note 155, at 166).
157. Jehovah’s Witnesses, supra note 151, at 504 (quoting Prince, supra note 155, at 170).
159. Id. at 276.
son because of her belief that prayer and assistance by church elders would improve his condition. D.L.E. experienced a series of epileptic seizures as a result of brain damage at birth. Doctors ordered D.L.E. to take Dilantin which would control his seizures. The doctors determined this was a life-threatening situation because without the medication, D.L.E. was in danger of choking during a seizure.

D.L.E. and his mother challenged the finding that he was a dependent and neglected child. The Court rejected their claim of a violation of the constitutional right to Free Exercise of Religion. The Court relied on Prince to hold that a parent’s religious beliefs are not without limitations. The Court also cited Prince where the Supreme Court determined that, “[t]he right to practice religion freely does not include the right or liberty to expose the community or the child to ill health or death.”

The First Amendment to the United States Constitution states, in part “Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof.” In Prince, the Court balanced the rights of a parent under the Free Exercise Clause of the First Amendment against the interest of the state in protecting the health and welfare of its children. Not only did Prince claim a freedom of religion right, but also a claim to a parental right under the due process clause of the Fourteenth Amendment. The Court determined that neither the rights of parenthood nor the rights of religion are beyond limitation. The Court also rejected Prince’s claim of freedom of religion of her child. There still exists an interest in the welfare and well-being of a child even if she is exercising her First Amendment freedom of religion right. The state has the power to limit parental freedom and authority when it effects the welfare of the child, even if it includes a matter of religious conviction.

161. Id.
162. Id. at 272. Dilantin is an anti-convulsant medication.
163. Id.
164. Id. at 272.
165. Id. at 275.
166. Id. at 275-76.
167. Id. at 276 (referring to Prince, supra note 155).
168. U.S. CONST. amend. I.
169. See Prince, supra note 155. This was an appeal of a conviction for violating Massachusetts statute regarding child labor laws. Id. at 7. The defendant appealed on the grounds that she was exercising her religious convictions in accordance with the Free Exercise Clause of the First Amendment. Id. The fact of the case are that Sarah Prince, aunt and at the time of the commitment of the offenses, the custodian of the nine year old girl, are Jehovah’s Witnesses. Id. at 161. The child violated a statute which prohibited the sale by children of magazines or newspapers in any street or public place. Id. at 160-61.
170. Id. at 164. See Meyer v. Nebraska, 262 U.S. 390 (1923).
171. Prince, supra note 155, at 166.
172. Id. The Court compared this to a claim by a parent that a child will not be vaccinated on religious grounds. Id. See Jacobson v. Massachusetts, 197 U.S. 11 (1905).
173. See Prince, supra note 155.
174. Id. at 167.
2. Application to Mary and Jodie

The case of Baby K presents a case very similar to that of Mary. In both cases neither child had long term prospects for survival. As noted, Baby K was born without brain function and would likely not live to see her first birthday. Mary’s brain did not fully develop and her condition was unlikely to improve. Mary’s lungs did not function and she had an enlarged heart that did not receive any blood flow. On the other hand, the situation of Jodie is comparable to the cases in which a parent refuses medical treatment because of religious beliefs. Jodie could be saved with medical treatment. Her parents’ religious beliefs presented two problems. First, they did not believe in killing one child to save the other. Second, they wanted as little medical treatment as possible, as the girl’s fate should rest in God’s hands.

In the case of Jodie and Mary, the courts may determine that the right of the parents to religious freedom may be outweighed by the concern for the welfare of both children. In Mary’s case, the concern may be that she be allowed to die with dignity and not “cause” the death of her sister. For Jodie, it is the belief that she be allowed to live as the twin with the best chance for survival. Furthermore, Prince recognizes that when state action impinges on religious freedom it is appropriate when “shown to be necessary for or conducive to the child’s protection against some clear and present danger.” The state could argue for action because Mary and Jodie face a clear and present danger, namely death.

The Court makes one last important distinction in the Prince case: “Parents may be free to become martyrs themselves. But it does not follow they are free... to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.” Jodie and Mary are not old enough to make a decision about their medical treatment but this does not mean their parents are free to make them martyrs. It may be helpful to try to determine what Jodie and Mary may want if they could speak.

In the cases of Baby K and Jodie, the parents were asked to choose between medical treatment and their religious beliefs. For most people it is too difficult “to imagine being confronted with the choice of either complying with the law or complying with deeply held religious beliefs, with the life of a child hanging in the

175. See In the Matter of Baby “K,” supra note 7; see Conjoined Twins Case, supra note 4, at 817.
177. See Conjoined Twins Case, supra note 4, at 817.
178. See id.
179. See id. at 726.
180. See id.
181. See id.
182. Id.
183. See id.
184. Id. at 170.
185. See id.
186. See id.
balance. The cases of Baby K and Jodie and Mary can be distinguished. In the case of Baby K, the mother wanted medical treatment to be continued even though the doctor deemed it to be futile, as the baby would not recover. The mother believed that her daughter’s life had value and that if it was God’s will to perform a miracle, he would. God should decide the moment of death, not the doctors. The mother believed in medical treatment to keep her daughter alive. The parents of Jodie and Mary wanted as little medical intervention as possible because they believed that it was God’s will that their children were born conjoined. The central difference between the two concerns the use or withholding of medical treatment.

V. CONCLUSION

The medical and legal ethics of conjoined twins present an interesting and controversial debate. On one hand parents should be free to make difficult medical decisions for their minor children without question by the courts. On the other hand, if a child can be saved with medical attention, the child should have the opportunity to receive treatment. The entire situation is complicated by issues of religion, cost, uncertain outcomes and inherent differences. I fully sympathize with the parent’s difficult decisions. No parent wants to make this difficult “Sophie’s Choice” type of decision where if one child is not chosen to live then both die. The situation of Jodie and Mary differs from “Sophie’s Choice,” in that the parents had no choice for Mary. With or without medical intervention, Mary would die. Jodie would die if she was not separated from Mary. The ultimate choice here is the decision to save one child.

While these decisions are usually left to the parents, there may be situations where the court can advise doctors about the legality of other options. However, courts should not make decisions regarding medical care. This should be done by families and doctors.

One such example of parents’ actions without court intervention is the Lakeburg Twins. Amy and Angela Lakeburg were born on June 29, 1993, at Loyola University’s Chicago Medical Center. The twins shared a six-chamber heart and a liver, but had separate brains, lungs, kidneys and gastrointestinal tracts. Congestive heart failure was a major concern because one heart was supporting both bodies. Neither twin would survive conjoined, but there was a one percent chance of survival beyond infancy for one twin. The twins

188. Plastine, supra note 146, at 124.
194. Id. SEGAL, supra note 3, at 307.
195. Thomasma et. al., supra note 192, at 5.
196. See Dougherty, supra note 193, at 16. The total bill was at least $500,000. Id.
presented a major ethical dilemma. Should one twin be sacrificed for another even if there was little chance either twin would survive? The physicians recommended against the surgery because of the poor chance for survival and poor quality of life.\textsuperscript{197} The mother thought that she “could not live with herself if she did not at least try to save one life.”\textsuperscript{198} In this case, one twin was sacrificed for the other twin. The doctors choose Angela for life and Amy for death.\textsuperscript{199}

\textsuperscript{197} SEGAL, supra note 3, at 308.
\textsuperscript{198} Thomasma et. al, supra note 192, at 5.
\textsuperscript{199} Id.