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Conjoined Twins and Catholic Moral Analysis: Extraordinary Means and Casuistical Consistency

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Conjoined Twins and Catholic Moral Analysis: Extraordinary Means and Casuistical Consistency

ABSTRACT. This article draws upon the Roman Catholic distinction between “ordinary” and “extraordinary” means of medical treatment to analyze the case of “Jodie” and “Mary,” the Maltese conjoined twins whose surgical separation was ordered by the English courts over the objection of their Roman Catholic parents and Cormac Murphy-O’Connor, the Roman Catholic Cardinal Archbishop of Westminster. It attempts to shed light on the use of that distinction by surrogate decision makers with respect to incompetent patients. In addition, it critically analyzes various components of the distinction by comparing the reasoning used by Catholic moralists in this case with the reasoning used in other cases that raise similar issues, including women facing crisis pregnancies who prefer abortion to adoption and the Indiana “Baby Doe” case.

A PAIR OF CONJOINED TWINS, known by the pseudonyms of “Jodie” and “Mary,” were born in a Manchester, England, hospital in August 2000. Mary’s heart and lungs were essentially non- functioning; she was entirely dependent upon her connection with her stronger sister for survival. But Jodie’s cardiovascular system could not continue to do the work necessary to support both babies indefinitely. Physicians predicted that without an operation to separate the twins, both babies soon would die, probably before their first birthday. Unfortunately, however, the surgical separation would be able to save only Jodie. Although likely to need several reconstructive operations, she was predicted to live a long and virtually normal life once her body was liberated from the burden of providing life support to her sister. Mary’s fate would be very different; she was predicted to die in the course of the procedure (Re A (children) (conjoined twins) (Ward LJ) [2000] 4 All ER 961).¹

Deep disagreement arose between the babies' physicians and their parents about whether to perform the operation, which ultimately was played out not only in the English court system, but also in the glare of the international media. The parents, who had journeyed from their native Malta to Manchester for more sophisticated medical care once they discovered that the pregnancy involved conjoined twins, objected to the operation on a number of grounds, some of them explicitly religious. Devout Catholics, they judged the operation morally impermissible, in part because they believed it entailed killing Mary to save Jodie. They were supported in their opposition to the procedure by Cormac Murphy-O'Connor (2000), the Cardinal Archbishop of Westminster, who submitted a statement to the Court of Appeal raising a number of objections both to the procedure itself and to any order to proceed with it over the strong objections of the babies' parents. Nonetheless, the three judges of the Court unanimously decided to authorize the operation, which was performed on 6 November 2000 (Dyer 2000). As expected, Mary died in the 20-hour operation. As hoped, a healthy Jodie returned home to Malta with her parents less than eight months later (Peachey 2001).

The saga of Jodie and Mary has captured our hearts because we cannot ignore the plight of two helpless babies born in the most tragic circumstances imaginable. It also has captured our minds, because coming to a judgment about the babies' fate requires us to face a host of difficult and interlocking moral and legal issues. First, was the operation *morally permissible*, or was the harm it did to Mary morally objectionable in some respect? Second, assuming that there are no grounds to say that the operation was morally impermissible because of its lethal implications for Mary, can one take the further step of concluding that it was *morally required* because it would save Jodie's life? Third, should the physicians have been given *judicial authorization* to proceed with the operation over the strong objections of the parents?

In this essay, I focus on the issues surrounding the second question, in conversation with those working within the framework of Roman Catholic tradition of medical-moral reasoning. Catholic moralists are divided about whether the operation was impermissible because it counted as the intentional killing or mutilation of Mary or because it was unfair to her in some other respect. For those who conclude that the operation was not morally precluded on those grounds, the second question arises: Was the operation merely morally permissible, or was it morally required because of its potential benefits to Jodie? In addressing this question, a significant

number of Catholic moralists have maintained that it was permissible but not required, drawing upon the tradition's distinction between "ordinary" and "extraordinary" means of preserving life or health. As I shall contend in more detail below, some of the arguments that have been used—or at least endorsed—in reaching this conclusion stand in significant tension with the way that many of these same moralists would be likely to approach closely related issues involving life or death for the unborn or newly born infants. Placing these closely related issues in juxtaposition enables one to reflect critically upon the tacit assumptions that guide discussions of these matters.

ORDINARY AND EXTRAORDINARY MEANS

The Roman Catholic medical-moral tradition has long distinguished between "ordinary" (sometimes called "proportionate") and "extraordinary" (sometimes called "disproportionate") means of preserving one's life or health; the former are morally required, while the latter are optional. Ordinary means are those that "offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community" (NCCB 2001, no. 56). Extraordinary means are those that "do not offer a reasonable hope of benefit or entail an excessive burden or impose excessive expense on the family or the community" (NCCB 2001, no. 57).

The test of whether a particular means of preserving life is ordinary or extraordinary is what lawyers would call a "facts and circumstances test," which takes into account a wide array of benefits and burdens. With respect to benefits, the focus generally is broad; the question is how effective the treatment would be in the context of the whole condition of the patient, not how effective it would be in ameliorating the very specific ailment at which it is targeted. For example, one is not obliged to undergo open heart surgery, even if the procedure would be effective in clearing an arterial blockage, if one also has terminal cancer. With respect to burdens, the approach is similarly broad-minded. In some cases, the means themselves can be burdensome, either in a concrete physical sense—e.g., the procedure in question is very painful—or in a more holistic sense that is sensitive to the patient's values—e.g., some eighteenth-century casuists argued that a consecrated virgin need not preserve her life if so doing required her to be treated by a male physician. The tradition also recognizes that a particular means can impose a wide variety of other burdens, ranging from excessive expense, to the emotional repugnance

many people experience at the thought of physical mutilation, to prolonged separation from familiar places and people (Wildes 1996). Significantly, the range of morally cognizable burdens include not only those that fall on the patient, but also those that fall on the family and the community.

What is the purpose of the distinction between ordinary and extraordinary means, and the way in which the lines between them tend to be drawn? In my view, the distinction gains full intelligibility only when placed against the backdrop of the theologically informed anthropology tacitly assumed by Catholic casuists. Two principles in particular seem to be of overriding importance. First, a human being's ultimate worth lies not in the transient instrumental value of her mental or physical attributes, but in her fundamental nature as a being created in the image and likeness of God and called to eternal fellowship with God. Consequently, all human beings have a transcendent value that makes them fundamentally equal in dignity. Second, precisely because human beings have an eternal destiny, mortal life and health are goods, but not absolute goods. Against this backdrop, a patient's decision to forgo ordinary means of preserving life raises concerns that she is attempting to kill herself by deliberate omission—e.g., a lovelorn diabetic who decides to commit suicide by forgoing insulin. At the very least, it generates worries that she does not sufficiently value her life as a precious gift from God. In contrast, a decision to omit extraordinary means suggests not that a patient has failed to appreciate the real goodness of this mortal existence, but rather that she has understood that its value is not absolute.

The *Ethical and Religious Directives for Catholic Health Care Services* state that patients in Catholic health care facilities, provided they are competent, are to make the decision regarding whether a particular means is ordinary or extraordinary (NCCB 2001, nos. 56 & 57).² What about incompetent patients? Who decides for them and according to what criteria? This question has been debated vigorously in a way that starkly reveals the potential tension between the two anthropological principles discussed in the foregoing paragraph. It is one thing to decide to accept death for oneself because the burdens of treatment outweigh its expected benefits; it is another thing entirely to make that decision with respect to an incompetent patient who has been placed in one's care. As the heated debate about such issues as artificial nutrition and hydration for PVS patients demonstrates, making quality of life judgments that determine whether another person will live or die can sometimes be perceived to be

in tension with one's commitment to the importance of affirming the sanctity of life. Nevertheless, someone must make quality of life judgments on behalf of incompetent patients; otherwise they are condemned to the potential cruelties of preserving their lives by any medical means available at any cost—even to their own well-being.

How, then, does one distinguish morally appropriate and morally inappropriate quality of life judgments in the case of incompetent patients? In my view, three basic concerns underlie the reservations about surrogates making quality of life judgments for incompetent patients. First, there is the fear that, in assessing benefits and burdens to the patient, surrogate decision makers will inappropriately import their own feelings about the patient's situation. For example, while a mentally handicapped patient might be quite content with her life, a decision maker might inappropriately attribute to that patient her own expected sense of loss of self-worth were she suddenly to find herself mentally handicapped (and know the difference). A second worry is that surrogate decision makers—many of whom are family members of the patient—will inappropriately privilege their own interests and desires relative to the interests of the patient. Although both of these worries suggest real dangers, they are fundamentally pragmatic in nature, pointing to specific instantiations of drawbacks that are always associated with the use of decision makers who may be self-interested or even broadly self-centered.

The third concern, however, is different in nature. Perhaps the decision makers will count as “benefits” or “burdens” certain consequences of the decision which should not objectively be placed in such a category, although they may well be experienced as such subjectively by those affected by the decision. In the case of defective newborns, for example, the debate about burdens clusters around two sets of questions. Is it always morally acceptable to take into account the distinct difficulties to parents and society that caring for a seriously handicapped child will entail? Or is it the case that promoting and protecting the overriding values of unconditional parental love and societal acceptance of all persons as equal in fundamental worth morally require us to refrain from treating at least some of these difficulties as “burdens” that justify a decision not to proceed with life-saving medical treatment, no matter how sincerely they are experienced as such? Second, is it morally acceptable to take into account the stigma and discrimination that a patient and her family will unavoidably experience as a result of her being handicapped in a society that values conformity and competence, or should we expect them courageously

to face down such adverse perceptions as a cost associated with their contribution to building a more just society? As I argue below, these considerations become acutely important in considering whether the surgical separation of Mary and Jodie constituted an ordinary or extraordinary means of preserving Jodie's life.

SAVING JODIE'S LIFE: ORDINARY OR EXTRAORDINARY MEANS?

What light does the distinction between ordinary and extraordinary means shed upon the question of whether the surgical separation of Jodie and Mary was morally required or merely morally permissible? It is important to remember that discussion of this question within the Catholic medical-moral tradition requires that the lexically prior question about the operation's moral acceptability has already been answered in the affirmative. More specifically, the legitimacy of the discussion depends upon the prior conclusion that (1) the operation did not constitute the intentional killing of Mary; and that (2) the operation was not otherwise unjust or unfair to Mary. In my view, that two-pronged conclusion is correct. The intent or purpose of the operation was to separate the babies; Mary's death figured neither as an end nor as a means in the surgical team's actions; it was a foreseen and unintended side effect. In addition, going forward with the operation was not unfair to Mary. I have argued elsewhere that our conception of what is fair in this situation depends in part upon whether we draw upon a view of embodiment that stresses bodily distinctness or one that affirms the value of bodily relatedness as a type of personal relatedness (Kaveny 2001). Although the two views would not necessarily yield the same conclusion in a different case, in this situation they converge to support the operation. The former view would give great weight to Jodie's right to be free of a physical connection to Mary that not only impinges upon her bodily integrity, but also saps her very lifeblood. The latter view, although less negative about permanent physical connection and even dependence between conjoined twins, would justify the operation in this case on the grounds that both babies soon would be dead without it.

Given that the operation was morally permissible, was it also morally required? The benefits of the operation to Jodie were simple, straightforward, and considerable. Without it, she soon would die; with it, she likely would lead a normal or virtually normal life. The burdens of the operation require a more nuanced assessment, however. Direct burdens include the difficulties associated with the surgery itself. Clearly falling in this

category are the grueling nature of the procedure—it took 20 hours to perform—and the inevitable uncertainty associated with major, and by no means routine, surgery. Ancillary burdens include the expense of the procedure, for society if not for the family (although social expense may have been offset by the knowledge gained during the procedure), as well as the long and difficult separation from family and homeland required of the twins’ parents in order to be with their surviving daughter through the ordeal of her recovery. The prospective need for further medical treatment down the road raises the possibility of additional burdens on the child, family, and society.

Finally, is it morally legitimate to allow certain quality of life considerations to enter into the equation? In keeping with the three concerns identified in the preceding section, one must ask whether the parents, as surrogate decision makers, gave too much weight to their own interests and well-being, as well as whether they overestimated the social difficulties that Jodie’s unique status as the surviving member of a pair of conjoined twins would pose for her. In addition, is it morally acceptable to count as “burdens” two factors that the parents clearly considered to be such. In other words: (1) What weight, if any, should be given to the parental suffering that would have ensued if they had been required permanently to relinquish custody of Jodie to an English family in order for her obtain the medical treatment she needed? And (2) what weight, if any, should be given to the possible social stigma that Jodie might have encountered growing up as a handicapped child in Malta? It is to these two questions that I turn in the remainder of the paper.

THE BURDEN OF FAMILIAL SEPARATION

In addition to worries about Mary’s fate, the parents offered several considerations pertaining to Jodie’s post-operative situation as reasons against proceeding with the surgical separation. One consideration was the worry that they would be forced by circumstances to leave her permanently in England so that she could receive proper treatment while they returned to Malta.

[W]e have also had to give very careful consideration to leaving Jodie in England, should she survive, to be looked after by other people. . . . It would be an extremely difficult if not impossible decision for us to reach, but again we have to be strong and realistic about matters and understand that certainly Jodie would receive far better care and importantly the required medical treatment should she continue to reside in England. We do

not know if it is possible or feasible for Jodie to remain in England as opposed to her being taken home. We do not know if it is possible or feasible for her to be fostered by another family so that we can have an involvement in her upkeep or whether she would have to be adopted and we could have no contact with her at all. That would break our hearts. (Re A (children) (conjoined twins) (Ward LJ) [2000] 4 All ER 961, 986)

The parent's articulation of this burden seems to have passed with nary a critical word from most, if not all, of the Catholic moralists who considered the case. Although Cardinal Murphy-O'Connor's belief that the surgical separation was unjust to Mary constituted the primary source of his opposition, his submission to the Court of Appeal also clearly reflects the judgment that the operation would be an "extraordinary" means that should not be imposed upon the family.³ Other Catholic moralists pass over this aspect of the parents' objection to the procedure without comment or even uncritically incorporate it into their own analysis (see, e.g., Gormally 2001; Lysaught 2000; May 2001; Sulmasy 2000).⁴

This omission of critical scrutiny is surprising, because the parents' arguments on this point bear a striking resemblance to arguments put forward by women facing crisis pregnancies who choose to have an abortion rather than to give up their babies for adoption. In *Rachel Weeping*, James T. Burtchaell (1984) quotes extensively from women who express this perspective. Taken together, the quoted passages reflect the strong sense that putting a child up for adoption is unfair not only to the woman, but also to the child.

No, I don't approve of that! Not at all. I have very strong feelings about that. I think you have no right to do that to another human being. I don't think you have any right at all to create a human being and *give it away*. (Burtchaell 1984, p. 25)

Statistics suggest that about half of all unintended pregnancies end in abortion. Approximately 2 percent of such pregnancies result in a live birth followed by an adoption; the vast majority of women who decide to carry their pregnancies to term choose to raise their children themselves (Chandra et al. 1999; Alan Guttmacher Institute 2001, 1999; Hsu 1996).

What can be learned from the juxtaposition of the reasoning of the parents of the conjoined twins and that of the women who stated their moral preference for abortion over adoption? Two important insights can be gleaned. First, I think that the medical-moral tradition on "extraordinary" means can help one to appreciate more sympathetically the moral

repugnance that many women feel at the prospect of permanently relinquishing their children through adoption. By recognizing that a treatment that can take one permanently away from one's family is an "extraordinary" means, the Catholic medical-moral tradition itself acknowledges that separation from one's closest relatives can work great hardship upon persons. No one suggests, for example, that all parents in developing countries have a moral obligation to send their critically ill children permanently to the United States or the United Kingdom in order to obtain life-saving treatment for them, even if it were practicable for them to do so. Tacitly underlying the judgment that it would be wrong to impose such a requirement upon parents is the sense that the shape of one's life can be at least as crucial as its length. A baby who is born, lives a short while, and dies within the bosom of her family and village lives a good life, even if not the best one. A baby who is sent to a far-away land for medical treatment may live a longer life, but not necessarily a better one, if all ties to her family and culture are permanently severed as a result.

One might object, however, that death, no less than permanent separation, breaks a family apart. Why should not there be an automatic preference for the option that allows the child to live? This is not an easy question to answer. Indeed, both the twins' case and the case of abortion present the strongest imaginable claim for the preferability of permanent familial separation; in both cases, the parents' relationship with the baby in question has not had as much time to develop as in other cases of separation, and in both cases there is a stark difference in outcome for the babies: death versus a long and relatively normal life in an adoptive family. Furthermore, in both the case of the twins' parents and the case of women who choose abortion over adoption, some all-too-human but less-than-praiseworthy desire to make the problem "disappear" through the death of the child may be exerting its influence. In both cases, therefore, there is reason to worry about self-interested decision makers inappropriately preferring their own interests over those of their children—a legitimate worry in "quality-of-life" decision making with respect to incompetent patients, as noted above.

But more laudatory motives may be admixed as well. A parent may not wish the death of the child *per se*, but may privilege familial loyalty in a way that makes abandonment a fate worse than death. This kind of loyalty is embedded in our tacit conception of the role-related obligations of family members. We do not want our loved ones to give up on us too

soon, we do not want to encourage an “out of sight, out of mind” conception of how relatives should perceive their bonds to one another, particularly in an era where family members are dispersed all over the country and even the globe. Nor do we want a conception of family loyalty to depend upon similarities in education, values, and lifestyles, particularly in a highly socially mobile society such as our own. The strength of familial bonds and the importance of familial devotedness—particularly of parents to children—are things that we hope will transcend separation and differences of this sort. Yet these are precisely the sorts of separation and difference that are likely to be at issue between birth parents and a child they relinquish to be raised by adoptive parents.

In short, on a coherent role-related understanding of the meaning of familial loyalty, one might hold that the duties of family members to one another are completely extinguished only by death. According to such a view, both the twins’ parents and the women facing crisis pregnancies who are morally repelled by the prospect of adoption express a similar sense of role-related obligations. They all believe that the maternal obligations of a woman who has died are extinguished in a way that those of a woman who has permanently separated herself from her child are not. The first in some sense has “fulfilled” her role; the second in some sense has “abandoned” it.

One might object that a legal adoption proceeding terminates a parental relationship just as absolutely as death does. The response is that while law may have the power instantaneously to create and extinguish relationships *de jure*, *de facto* relationships are not quite so malleable to legal commands. More specifically, death is widely perceived to end—or at least to transform—the role-related obligations of family members in a way that mere termination of rights in a legal proceeding does not. Women who consider abortion to be a morally and psychologically better option than adoption may be expressing something of this sense as they reflect upon their options for dealing with a crisis pregnancy.

My second point is that there seems to be some dissonance in the way that Catholic moral thought has responded to the twins’ parents, on the one hand, and to women facing crisis pregnancies, on the other, with respect to the prospect of permanent separation from their living children. Although criticism of the twins’ parents on this point has been extremely muted if not entirely absent, pregnant women who express greater abhorrence of adoption than of abortion or raising the child on their own have not infrequently been criticized as selfish or unduly emotional in

their decision-making procedures. Burtchaell's own moral assessment of the stories he recounts offers a good example of the kind of judgment I have in mind:

But what of this vehemently negative view regarding adoption, this moral outrage that so many of the women express. The women who reject adoption as either hurtful to their offspring or hurtful to themselves reveal in their remarks this tendency to consider children as proprietary objects. They are desired or annulled as the mother wishes, very much to suit her plans or needs. (Burtchaell 1984, p. 26)

What accounts for the difference in treatment? In asking this question, I do not mean to deny, of course, that abortion and forgoing life-saving treatment are not morally different in many respects. In many cases (but not all), abortion involves intentional killing; in many cases (but not all), a decision to forgo life-saving treatment involves accepting the child's death as a foreseen but unintended side effect of an action whose primary purpose is legitimate. At this point in his argument, however, Burtchaell's focus is not on the other morally salient aspects of abortion, but upon the fact that in choosing abortion rather than adoption, so many women appear to prefer the death of their children to permanent separation from them.

Why, then, do we seem inclined to accept so uncritically the claim of the twins' parents that permanent separation would be worse than death while dismissing similar claims of women with crisis pregnancies? Perhaps we are operating with a conception of parenthood—particularly of motherhood—that is too morally simplistic and that fails to account for the admixture of self-gift and self-interest that exists in all human hearts—even in the hearts of mothers. From the perspective of basic Catholic teaching on marriage and the family, the credentials of the twins' mother as a “good mother” were unimpeachable. She followed the appropriate course of behavior for responsible parenthood; she got married, she and her husband built a life together, she became pregnant, and she monitored the pregnancy in joyful anticipation of the birth—until she discovered she was carrying conjoined twins.

In contrast, many women who find themselves facing crisis pregnancies do not follow the course of action prescribed by Catholic teaching. They engage in premarital or extramarital sex; their pregnancies are not only unanticipated, but also are undesired; and they contemplate abortion as a way out of a difficult situation. Because their actions do not

comport with the ideal of marriage and family life, it may be tempting to assume that such women have no morally worthy maternal instincts at all. By immediately dismissing as “selfish” the deep moral repugnance that such women express regarding the permanent separation involved in adoption, we in effect deny that they have become “mothers”—that they have or could ever develop any true maternal feelings for the unborn children they carry.

In my view, the moral reality in both cases is probably more ambiguous. Blinded by the fact that the twins’ mother’s dilemma was generated by no “wrongful act” on her part, we may brush too quickly over the possibility that denial, fear, and grief for her nonexistent ideal babies might lead her—as it might lead many of us—to look for the easier way out, the way to make the entire situation “go away.” At the same time, we may too easily use the fact that the plight of women facing crisis pregnancies is in part of their own making to dismiss the concerns of the many of them who find adoption more morally repugnant than abortion—who find separation worse than death. Instead, drawing upon the analogy with end-of-life decision making, we might just as well see it as confirmation that some form of the “maternal instinct” can arise—by nature—even in circumstances where the role of mother is not voluntarily chosen or immediately welcomed by the woman in question.

We might begin to question also the easy assumption that childbirth followed by adoption is the “best” solution for the unborn child and her mother. In effect, by too quickly assuming that the best way to handle a crisis pregnancy is adoption, we make the assumption that a woman *can* choose not to be a mother after she has conceived—provided the choice is made after birth. We also confer on positive law a power to break and remake families that is not commonly recognized by the natural law tradition of jurisprudence associated with Roman Catholic thought. More specifically, we assume that the power of positive law is not limited by natural ties of blood and affection; we believe, naively, that it can step in and redefine familial relationships—with no cost, loss, or remainder. We give priority to restoring a certain appearance of order, by assuming that it is possible easily to take apart and recombine the components of “childless couple” and “single mother and her baby” so that we are left with the morally more gratifying categories of “loving family” and “single woman.”

The dismal statistics on adoption rates suggest that such recombinations are not often desired by women facing crisis pregnancies. Perhaps more consideration should be given to the possibility that the recombined

categories do not accord with the underlying realities of the relationships at stake. An understanding of pregnancy as a time when a woman develops a deep bond with the child she carries, along with an appreciation of the role-related obligations of family members, particularly parents, may give us some sense of why this may be the case, and why it may not be entirely bad. Perhaps, then, those who would like to reduce the number of abortions in this country would do well to develop and encourage ways to transfer child-rearing responsibilities that do not pressure birth mothers to “give up” all contact with the children they bear. In addition, instead of viewing the abhorrence that a woman facing a crisis pregnancy may feel at the prospect of relinquishing her baby after birth as confirmation of her “selfishness,” perhaps it could be viewed as a morally beneficial instinct that provides a contact point, a bit of common ground from which to begin to explore other ways of handling the situation. Upon reflection, adopting much the same approach might have proven beneficial with the mother of Jodie and Mary—affirming her desire not to be permanently separated from her only living daughter, but also exploring whether allowing Jodie to die is really the only alternative to such separation, or the alternative that is most consistent with her love for her child in this situation. In my view, the answers to these questions in the end must be “no.”

THE “BURDEN” OF DISCRIMINATION

The parents of Jodie and Mary offered another reason why the surgical separation should not be performed: If she survived, Jodie’s quality of life on Malta would not be very good. In addition to not receiving first-rate medical care, she would face a lifetime of discrimination because of the circumstances of her birth and any remaining postoperative disabilities she suffered (Allen 2001). The first concern, addressed in the preceding section, raised the question of whether it would be fair to expect the family to relinquish custody of Jodie so that she could remain in England. The second concern, addressed here, pertains to the potential burden of future discrimination against Jodie.

In an interview given at the time when Jodie was allowed to return home to Malta, about seven months after the operation, her mother spoke of the difficulties she faced at first in accepting her new daughters. “At the beginning it was so hard for us to see them like that. I didn’t want to touch them. I was afraid of them. It took days before I could” (Allen 2001). Slowly, the parents said, they got used to their daughters; they

began to love them. Nonetheless, one factor in the decision about whether to authorize the surgical separation was the treatment that Jodie would receive if she returned to her native land. “Nobody likes handicapped people on Malta. They are hidden away. In the old days, it was seen as a sign that you had done something to deserve this” (Allen 2001).

The attitude of the twins’ parents toward raising a handicapped child on Malta was explicitly identified as one of the reasons for their opposition to the operation in the lower court opinion that prompted Cardinal Murphy-O’Connor’s intervention in the case (High Court Justice-Family Division 2000, p. 5). Nonetheless, their perspective passed without criticism from virtually all the Catholic moralists who considered the case, including the Cardinal himself.⁵ Their silence is somewhat surprising, since the parents’ views on this point seem to raise the specter of invidious quality-of-life judgments far more vividly than other cases that have been widely criticized on just this point. For example, consider the famous “Baby Doe” case that transpired in Indiana in the spring of 1982. The baby boy was born with an esophageal atresia and tracheoesophageal fistula. The upper end of his esophagus was not connected to his stomach, but instead emptied into a pouch. At the same time, the lower end of the baby’s esophagus—arising from the stomach—connected directly to his windpipe. The parents were told by the obstetrician that they could save the baby’s life by performing a surgical procedure to repair his trachea and esophagus. However, it was a “rigorous” operation that was accompanied by significant pain and that might require follow-up surgery in the years to come (Lyon 1985, pp. 26–27).

Baby Doe’s parents refused to consent to the procedure. For them, the decisive factor was not the nature of the operation itself, but the state of their baby after the operation. He was born with Down’s syndrome, which no surgical procedure could repair. At the judicial hearing, the father testified that he had taught public school for more than seven years and had on occasion worked closely with children with Down’s syndrome and other handicaps. According to the court, he and his wife “felt that a minimally acceptable quality of life was never present for a child suffering from such a condition” (Indiana. Circuit Court of the County of Monroe 1986, p. 79). The court supported the parents’ decision, holding that they were making a legitimate choice between two medically recommended courses of treatment—surgery and no surgery.

The Baby Doe case set off a public firestorm regarding the selective nontreatment of handicapped newborns, which culminated in the pas-

sage of the Reagan administration's "Baby Doe" regulations. The discussion in the ethical literature regarding handicapped newborns is extensive and complicated;⁶ I do not propose to engage it here except to raise a comparative point. For many Catholic ethicists, including those who agree that nontreatment of newborns would be permissible in more extreme cases, the Indiana Baby Doe case was the paradigm of an unjustified decision not to treat; they did not consider the burdens associated with being—and raising—a child with Down's syndrome to be so significant that they warranted a decision to allow the baby's esophageal and tracheal defects to go uncorrected.

It is arguable, however, that if one focuses on comparative medical prognoses, a decision not to treat Jodie would be even more problematic than the decision not to treat Baby Doe. True, the surgical separation itself was invasive and extensive. Nonetheless, in the context of a full-blown adversarial proceeding conducted before the Court of Appeal, the testimony that the surgery was very likely to be successful was uncontradicted. The doctors fully expected Jodie to walk one day; in the worst-case scenario, she might have needed a crutch or possibly a wheelchair. They were a little more cautious about her gaining bowel control, as well as about the success of vaginal reconstructive surgery; nonetheless, their prognosis on these matters was extremely positive. In essence, they fully expected her to live a normal life (*Re A (children) (conjoined twins) (Ward LJ) [2000] 4 All ER 961, 979–82*). In contrast, Baby Doe's medical prognosis was more mixed.⁷ Without treatment, both babies were predicted to die an uncomfortable death, which could be alleviated to some degree by palliative measures (*Lyon 1985, pp. 33–35; Re A, pp. 979–80*).

Factors other than medical prognosis also suggest that a decision not to treat Jodie would be more morally problematic than the decision not to treat Baby Doe. A better case can be made that the burdens at stake for the parents of Baby Doe included a host of financial and familial difficulties that might ensue if his medical prognosis was as bad as it seemed to be to some physicians involved in the case. In contrast, it is arguable that the long-term burdens at stake for Jodie's parents if she lived were far more likely to be limited to the incremental difficulties and shame associated with having a less-than-perfect child whose circumstances of birth were extremely unusual.⁸

In short, despite the fact that the burdens associated with Jodie's continued life seem to be paradigmatic of the sort that should not be recognized as morally legitimate considerations—e.g., fear of societal preju-

dice against persons with disabilities—this aspect of the situation received virtually no attention from the Roman Catholic moralists who might most be expected to express concern about it—including the Roman Catholic Cardinal Archbishop of Westminster in his submission to the Court of Appeal. Why did this question not receive the attention it deserved?

In my view, the explanation is rooted in the way that the lower court judge chose to characterize the legal issue at stake. Needless to say, the situation was virtually without precedent both legally and morally; there was no line of clearly relevant cases for the judge to draw upon. Johnson J. therefore needed to frame the question in a way that would make sense within an already established line of English law. Focusing upon the fact that the surgical separation would deprive Mary of the life support she received from Jodie, he decided to treat the case as if it were analogous to a decision to withdraw life-sustaining treatment from an incompetent patient. On this issue, he could find precedent. In the leading English case on this question, *Airedale NHS Trust v. Bland* [1993] AC 789, the House of Lords decided that doctors may withdraw life-sustaining treatment from an incompetent patient if it is in the best interests of the patient to do so. Having framed the question in this manner, Johnson J. then proceeded to justify the operation on the grounds that it was in Mary's best interest to have the life support provided by her sister withdrawn from her.

In my view, much of the hostility that the decision to separate the twins received from Catholic quarters can be traced to the fact that it was framed as a *Bland* case by the lower court. *Bland* has come under heavy fire from leading English Catholic legal scholars and moralists (see, e.g., Finnis 1993; Keown 1997). The root of their difficulties with the case lies in the action theory it adopts. The Catholic tradition defines intention in terms of purpose, not in terms of any degree of foresight. Consequently, on the Catholic view, it is possible for a good physician to make a determination to withhold or withdraw life-preserving treatment from a patient without intending to kill that patient. Such a physician would intend simply to stop the overly burdensome or insufficiently beneficial treatment; she would not intend the patient's death but rather would foresee it as an inevitable side effect of her action. In contrast, English law collapses the distinction between intended and foreseen effects; at least in the context of voluntary homicide, an effect foreseen by the agent as a "virtually certain" consequence of her action is an intended effect (see *Reg. v. Woollin* [1999] 1 A.C. 82).

From the perspective of Catholic moralists and legal scholars such as John Finnis and John Keown, the *Bland* decision entailed two very prob-

lematic claims. First, it wrongly implied that physicians who withdraw life-preserving treatment from patients inevitably intend their deaths. Second, it dangerously claimed that it is legitimate for them to withhold treatment with that intention, provided that dying is in the best interests of the patient. The critics denied that it is ever morally permissible—or should ever be legally justified—to aim at the death of an innocent person, even if one’s act is classified legally as an “omission.” They contended that by adopting the death of another human being as the object of an intentional action, an agent inevitably sets herself over and above the other as the arbitrator of the value of the other’s life. Consequently, they feared that by giving social sanction to this description of physicians’ actions in withholding treatment, the Bland case inevitably would encourage invidious quality-of-life judgments inconsistent with a fundamental anthropological commitment to the equal dignity of all human beings.

A close examination of the Murphy-O’Connor statement reveals that these are precisely the concerns that animate his consideration of the case of the conjoined twins. More specifically, homing in on the fact that Johnson J. decided to use the Bland framework to resolve the legal issues involved in the separation, he looks for—and seemingly finds—Bland-type problems in the Johnson opinion. Seeing the situation as a Bland case, he looks for invidious quality-of-life judgments to be made with respect to the patient from whom life support is being withdrawn—i.e., Mary. Cardinal Murphy-O’Connor writes, for example, that “Johnson J.’s reasoning invites several criticisms. . . . It is seriously unreasonable to seek to justify the ending of someone’s life on the grounds that that human being’s life lacks value or worth, so that he or she would be better off dead” (Murphy-O’Connor 2000, p. 271; see also Gormally 2001, pp. 42–43).

In my view, Cardinal Murphy-O’Connor’s criticisms of Bland—and the action theory it endorses—are justified. It may not have been wise, however, to extend them so quickly to Mr. Justice Johnson’s opinion in the conjoined twins case. In so doing, one may fail to account for the limited jurisprudential options actually available to him. What would seem to many Catholic moralists to be the best option for resolving the case—a “double effect” argument that the physicians performing the operation would foresee but not intend Mary’s death—was simply not a realistic possibility, given the current state of English law.

Practically speaking, Johnson J. unfortunately was forced to choose between two unsatisfactory jurisprudential options: either he could argue

that the operation was a justified withdrawal of life support from Mary, or he could maintain that it was an intentional homicide justified by the necessity defense—which was the route eventually followed by the Court of Appeal. Arguably, by adopting the first option, Johnson J. took the route that posed the lesser harm to fundamental moral and jurisprudential values. The second approach would have required him to take the unprecedented step of straightforwardly arguing that the necessity defense can be available to justify intentional killing of the innocent, a claim that would have been unprecedented not only in Catholic moral theology, but also in English law. The first approach, for all its flaws,⁹ at least did not make new law. The worst that can be said about it is that it did not correct defects in existing law, namely *Bland*. Making that sort of correction, however, particularly in the context of an extremely unusual case, is not the job of a lower court judge.

If one understands Johnson J. as attempting to make the best of a bad jurisprudential situation, rather than as opportunistically extending the presuppositions of *Bland* into new aspects of medical-moral decision making, one can find much in his opinion that is congenial to a Catholic perspective on end-of-life issues. More specifically, if his opinion is read as a whole in this light, it seems not only to be very respectful of Mary's dignity as a human person, but also to be making treatment decisions on her behalf in a way that is highly consistent with the Catholic distinction between ordinary and extraordinary means. More specifically, it affirms the equal dignity of all human beings, while simultaneously recognizing that one need not always give priority to preserving one's mortal life at the expense of other values.

Physicians testified both before the lower court and the Court of Appeal that Mary's state at birth was very different than Jodie's. Not only were her heart and lungs essentially nonfunctional, she was severely brain-damaged. Under no possible scenario would she have the prospect of a normal life span—much less a normal life—before her. With the operation, she would die instantaneously and painlessly during the course of the surgical separation. Without it, she might live for another few months at most, under increasingly difficult circumstances. Doctors testified that she had at least a 75 percent chance of developing hydrocephalus, which would be extremely difficult to treat because of her other abnormalities; consequently, her brain damage would likely increase. Lack of oxygen also would cause progressive cellular and brain damage. She would be at risk of suffering epileptic fits. Most significantly, it was not clear to the

physicians involved whether she was able to suffer pain (Re A (children) (conjoined twins) (Ward LJ) [2000] 4 All ER 961, 982–85).

As Cardinal Murphy-O'Connor (2000, pp. 270–71) notes, Johnson J. does say that “the few months of Mary’s life not separated from her twin would not simply be worth nothing to her, they would be hurtful” (Central Manchester Healthcare Trust and Mr. and Mrs. A and Re A Child. [2000] Case No. FD0P10893 (High Court Justice-Family Division), p. 5). In fairness, he ought to have noted in addition that Johnson J. never said that Mary herself was worth nothing as a person. Moreover, he also ought to have noted that the decisive factor in Johnson J.’s judgment that Mary would be hurt by living a few more months was not her lack of intelligence, her facial deformation, or any other abnormality that she suffered. In fact, it was not the many ways in which Mary might differ from a “normal” baby that counted for him, but the one way in which she might be exactly the same: Johnson J. was worried that she might have a capacity to suffer pain. He writes:

So I asked, what would happen as the weeks went by and Jodie moved, tried to crawl, to turn over in her sleep, to sit up. Would she not, I asked be pulling Mary with her. Linked together as they are, not simply by bone but by tissue, flesh and muscle, would not Mary be hurt and be in pain. In pain but not able to cry. One very experienced doctor said she thought it was a horrendous scenario, as she put it, being dragged around and not able to do anything about it. (Central Manchester Healthcare Trust and Mr. and Mrs. A and Re A Child. [2000] Case No. FD0P10893 (High Court Justice-Family Division), p. 5)

To Johnson J., it ultimately did not matter whether Mary was mentally gifted or mentally damaged. In the end, it only mattered that she was a baby who was dying. Consequently, he recognized that the only relevant question was whether she would die quickly and peacefully or “in pain but not able to cry.” This is not an invidious judgment that denigrates Mary on the basis of her handicap. It is a judgment that one would make about *any* dying baby, no matter what her state of “normalcy.”

In sum, the quality-of-life judgments made with respect to Mary do not seem to raise any of the three worries that I have discussed about such judgments being made by surrogate decision makers in the case of incompetent patients. First, there was little or no danger that the surrogate decision makers—whether parents or the state—would inappropriately privilege their own interests by adopting the course of action that would result

in her shortened life. At most, she was predicted to live another few months. Second, there was little or no danger that the surrogate decision makers would surreptitiously impose their own value judgments about dignity in discerning the burdens of Mary's continued existence. No decision maker would ever face the few months of babyhood left for Mary; there was no chance that she would grow up handicapped in a way that they could analogize to their own situation. Third, the "burdens" considered by the judge are not the sort likely to be invidiously discriminatory—they focus on whether she will suffer physical pain if she lives, not on whether she will be unjustly humiliated for being "different."

In contrast, as noted above, the quality-of-life judgments made with respect to Jodie do raise serious problems on all three counts. But these are very difficult to see if the case is viewed only through the lens provided by a Bland analysis. More specifically, if we follow the Bland analogy too closely, the prospect that Jodie could be the object of invidious quality-of-life judgments will simply not occur to us, because she will be cast not in the personal role of "vulnerable patient," which has been assigned to Mary, but rather in the instrumental role of "life support" to be withdrawn or continued. Indeed, the degree to which Cardinal Murphy-O'Connor's submission disregards Jodie's well-being is striking. The vast majority of the submission is devoted to defending Mary's dignity against the perceived attack by Johnson J.; Jodie appears as a subject of concern only in a cursory comment that her care might be an excessive burden if she survived (Murphy-O'Connor 2000, p. 270).

Unfortunately, by focusing upon the larger structure of Johnson J.'s opinion—and particularly its invocation of Bland—one may lose the trees for the forest in a way that is uncharacteristic of the Catholic casuistical tradition at its best. By too quickly assuming that the case of the conjoined twins is adequately treated as an instantiation of the Bland case, one risks subsuming concern for the well-being of these particular babies into a broader debate about the appropriate legal framework for end-of-life decision making. That debate, of course, is extremely important, and must be engaged—but not at the expense of full and fair consideration of complicated cases on their own terms. In both law and moral theology, the strength of a casuistical approach is its willingness to do justice to the exigencies of a single situation in all its particularity. In my view, true respect for the dignity of each incompetent person in all her uniqueness demands nothing less.

CONCLUSION

In this article, I have attempted to apply the distinction between ordinary and extraordinary means of prolonging life to one of the most highly publicized medical-moral cases to have arisen in the past several years: the case of Jodie and Mary, the Maltese conjoined twins. In so doing, I have attempted both to critique and to extend the Roman Catholic tradition's use of that distinction by reasoning analogously from that case to other cases that have received much attention from Catholic moralists in recent years. I hope my analysis can shed some light both on the particular cases at issue and on the broader methodological question of the role of casuistry in moral analysis.

In my view, the surgical separation should be viewed as an ordinary—not an extraordinary—means of preserving Jodie's life. In this essay, I have not considered all the factors that need to be taken into account to support such a conclusion, nor defended each of my judgments with respect to them. Instead, I have focused my attention on two reasons commonly given to support the judgment that the surgical separation is an extraordinary means: the possibility that Jodie's long-term treatment would require her prolonged or even permanent separation from her parents and the fear that she would be unjustly discriminated against on the basis of handicap once she returned to her family home in Malta. While the first of these arguments need to be taken seriously, it is not ultimately compelling with respect to Jodie's situation. The second argument is, I have argued, a clear example of an invidious quality-of-life judgment.

First, I have suggested that it is instructive to compare the way that some Catholic moralists have assessed the motivations of women who would rather lose their children to abortion than to adoption, on the one hand, with the assessment given to the sentiment expressed by the twins' parents that it would be better for Jodie to die than to relinquish custody of her, on the other. As a result of the comparison, I concluded that one needs to be rather more charitable in interpreting the sentiment expressed by an overwhelming number of women facing crisis pregnancies that putting up the baby for adoption is an unacceptable option, and rather more suspicious of the reluctance indicated by the twins' parents to abandon their only living daughter to be raised by someone else. More broadly, I believe that this comparison suggests that wise analyses of cases requires one to be critically aware of one's own assumptions regarding the character of the agents whose actions are being evaluated. One may be too harsh with respect to women facing crisis pregnancies based on the assumption

that they are selfish and irresponsible and too deferential to the twins' mother and father based on the assumption that they are loving and self-abnegating parents.

Second, I have argued that assessments of the quality-of-life judgments made about Mary and Jodie can be checked by comparing them to the reactions to similar judgments made about Baby Doe, a boy born about 20 years ago with Down's syndrome and an esophageal atresia and tracheoesophageal fistula. At the concrete level of the cases, I argued that the quality-of-life judgments made about Mary were not invidiously discriminatory, because they focused on the pain that she might suffer in the few remaining months of her life. In contrast, I suggested that the judgments made about Jodie's quality of life were even more problematic than those made about Baby Doe: they focused mainly upon the psychological burdens involved in raising a child perceived to be abnormal in a society that perceives the abnormal as malevolently different from everyone else. On a more abstract, methodological level, I argued that the failure of some Catholic moralists—including Cardinal Murphy-O'Connor—to recognize this situation can be attributed to the fact that they too quickly assimilated the particular details of the conjoined twins' case to the broad contours of the public policy debate about ethics and law at the end of life.

In my view, however, the tendency to do precisely that must be firmly resisted. In the present era of international media and instantaneous communication, it is tempting to treat the case of the conjoined twins as the latest instantiation of a familiar "clash of values": sanctity of life versus quality of life, the culture of life versus the culture of death, religion versus science. In so doing, we fail to recognize that the central figures in this case are not shadowy symbols of humanity but real babies with real claims on us in justice and in love. In resolving their claims, we may find that the conflicts for which we steel ourselves do not in fact materialize.

NOTES

1. The opinions issued by the judges in the Court of Appeal meticulously review the diagnosis and prognosis with respect to both twins. It is significant to note that these opinions reveal not even a hint of disagreement with respect to these issues.
2. This decision to locate decision-making authority in the patient does not mean that the judgment about whether a given means is ordinary or extraordinary is entirely subjective—i.e., that it is *constituted* by the patient's preferences in this regard. One might decide, for a variety of reasons, to locate

decision-making authority in the patient while simultaneously affirming that the patient should view the decision as a determination that she should make objectively, but by taking into account her subjective experience of the weight of certain burdens and burdens, as well as the experience of other people affected by her decision. To say that a decision to forgo treatment is not entirely subjective allows for the possibility of challenging a particular patient's decision. For example, one could say that a patient who views a treatment option as a burden because it requires her to be examined by a physician of a different race is objectively mistaken, despite her subjective experience in this regard. Needless to say, even the correct judgment that a competent patient's judgment to forgo a treatment option is mistaken does not by itself justify overriding it by forcing the unwanted treatment upon her. Indeed, the *Ethical and Religious Directives* do not contemplate taking this course of action, which would be considered a battery under American law.

3. "[W]eight should also be given to the likely burdensome consequences of surgery for Jodie and her parents" (Murphy-O'Connor 2000, p. 270).
4. Christopher Kaczor (forthcoming) explicitly and uncritically draws upon this argument in contending that the surgery counts as an extraordinary means. See, also, Latovic and Nelson (2001) for a very helpful, if somewhat dated, survey of Catholic opinion on the case.
5. The most direct criticism in the Catholic literature that I have seen is found in Latovic and Nelson (2001, p. 608): "While considerable, we do not think that these burdens were any more than other parents deal with in caring for handicapped children, some of whom are even in worse conditions." I have come across only one pointed challenge to the wish on the part of the parents and others to let Jodie die on the grounds that it was discriminatory against the disabled (Toolis 2000). This reason for the parental refusal was noted in the judgment issued by the lower court judge who heard the case (High Court Justice-Family Division 2000, p. 5) and so was at issue when the submission on behalf of Archbishop Murphy-O'Connor was being prepared. His statement, however, makes no mention of discrimination against the handicapped being an issue with respect to Jodie.
6. See e.g., Lyon (1985), McHaffie and Fowle (1996), Ramsey (1978), Sparks (1988), Walter and Shannon (1990), and Weir (1984). For a helpful summary of the legal issues, see Merrick (1995).
7. He was a "blue baby," and his initial Apgar score—used to evaluate a newborn's physical state—was 2 out of a possible 10. The baby also had an abnormally enlarged heart, which was not unexpected since cardiac defects are not uncommon in babies with Down's syndrome—one of the reasons

that their life expectancy is substantially shorter than that of others (Lyon 1985, pp. 23–26).

8. Baby Doe's parents were not wealthy people; they also had two other children. At the time they made their decision—well before the passage of the Americans with Disabilities Act—public services and facilities for persons with Down's syndrome in the United States were not extensive. In contrast, it was unlikely that the financial burdens associated with caring for Jodie would have been particularly onerous. Due to the special circumstances of her birth, it was likely that most of the special care that Jodie would need would have been provided by the English medical system. In addition, as was predictable given the tremendous media coverage the case had received, her parents were able to work out an arrangement for an exclusive interview, for which they were paid a great deal of money that would cover future expenses associated with her care.
9. The three judges who heard the case for the Court of Appeal rejected Justice Johnson's analogy of the surgical separation to withdrawal of treatment, largely because they could not bring themselves to analyze the operation an "omission"—how withholding and withdrawing treatment are characterized under the law—rather than as an "act."

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