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INTRODUCTION

Dramatic advances in neonatal medical information and technology occur daily and these advances are being implemented almost immediately. Despite the dramatic technological advances, diagnostic and prognostic certainty for many neonatal conditions remains illusive. As a result, the appropriate decision-makers have to decide whether some handicapped newborns, such as those with congenital anomalies, low-birth-weights, and genetic defects, should be treated aggressively or not at all. This uncertainty has led to many handicapped newborns with serious congenital anomalies being treated aggressively. This treatment prolongs the lives of many newborns when in the past they would have been allowed to die. Such life-prolonging treatment decisions have far-reaching ramifications. One thing that is clear to serious observers in the field is that the implementation of medical advances and technology for some newborns is a mixed blessing at best. Despite proposed federal regulations (1984 Child Abuse Law)¹ and medical guidelines (American Academy of Pediatrics),² that have helped to clarify treatment issues, there is still no consensus among responsible decision-makers on a moral criterion to assist parents and health care professionals on treatment decisions. There is general agreement within the medical, legal, and ethical professions that there are some handicapped newborns, in particular situations, whose lives need not be saved. Consensus ends, however, when an attempt is made to determine which specific newborns should receive or not receive medical treatment. This diversity of opinions has brought to the forefront the urgent need for a normative moral criterion to assist decision-makers in their discernment of treatment decisions for these never-competent patients.³

Today, parents and health care professionals are often forced to draw lines between newborns who will be treated and those who will not be. If these lines are being drawn, then ethicist Richard A. McCormick argues, "it is of public importance that we find out the criteria by which they are being drawn. My attempt is to search our tradition on the meaning of life and so forth and see if we couldn't develop criteria."⁴ Realizing the magnitude of this problem, McCormick has established a moral criterion for treatment decisions regarding handicapped newborns as a "revised" natural-law ethicist in the Roman Catholic tradition.

¹ For a more detailed analysis of the 1984 Child Abuse Law, see Department of Health and Human Services, "Child Abuse and Neglect: Prevention and Treatment," reprinted from *The Federal Register* 50 (April 15, 1985), no. 72: Rules and Regulations, part 1340, 14887-14892.

² For a more detailed analysis of the guidelines of the American Academy of Pediatrics, see American Academy of Pediatrics, "Joint Policy Statement: Principles Of Treatment Of Disabled Infants," *Pediatrics* 73 (1984): 559-560; and American Academy of Pediatrics, "Guidelines For Infant Bioethics Review Committees," *Pediatrics* 74 (1984): 306-310.

³ There is an ethical distinction regarding competent, noncompetent and never-competent patients. A competent patient is one who can make decisions regarding health care for him or herself. A noncompetent patient is one who was once competent, but now lacks that decision-making capacity. A never-competent patient is one who never had this decision-making capacity and never will have it in the future.

⁴ James Castelli, "Richard A. McCormick, S.J., And Life/Death Decisions," *St. Anthony Messenger* 83 (August 1975): 34. McCormick, as interviewed by Castelli

As a “revised” natural-law ethicist, McCormick has always sought a balanced middle course between extreme positions--a course which he understands as characteristic of the Judeo-Christian tradition.⁵ Few, if any, physicians are willing to make substantive criteria when it comes to treatment decisions for handicapped newborns. On the other hand, moral theologians, in their concern to avoid total normlessness and arbitrariness, can easily become quite dogmatic.⁶ Between the two extremes of the physician’s lack of concrete criteria and the theologian’s dogmatism, it can be argued that there is a middle course that entails substantive criteria to assist decision-makers regarding treatment decisions for handicapped newborns. McCormick has proposed a patient-centered, quality-of-life criterion that can be used by appropriate decision-makers in determining treatment decisions for handicapped newborns. The significance of McCormick’s quality-of-life criterion is that it offers the appropriate decision-makers, for never-competent newborns, a practical, beneficial, and appropriate moral criterion that is not only reasonable and coherent but is grounded in a tradition that promotes the “best interests” of handicapped newborns.

The purpose of this article is threefold: first, to present a case of a child born with thanatophoric dysplasia; second to examine McCormick’s moral criterion as it applies to the anomaly presented and to five diagnostic treatment categories, established by this author, which span the spectrum of neonatal defects; third, to assess whether McCormick’s moral criterion is an appropriate moral criterion for the decision-makers of handicapped newborns.

CASE STUDY – THANATOPHORIC DYSPLASIA

On September 25, 2004 Baby X was born with a genetic condition called thanatophoric dysplasia. His condition was diagnosed in utero and upon birth he was placed on mechanical ventilation to give the medical team additional time to confirm the diagnosis. Besides mechanical ventilation the child also received artificial nutrition and hydration through a feeding tube and was kept unconscious and sedated for comfort. After numerous consultations from various pediatric specialists the medical team decided that to continue aggressive medical treatment was futile and only prolonged the child’s dying process. The child’s mother was unsure if withholding aggressive medical treatment was ethical and sought additional guidance.

Thanatophoric dysplasia (TD), also called thanatophoric dwarfism, was discovered in 1967 by Pierre Maroteaux and his coworkers who used the Greek term “thanatophoric” meaning death-bringing. It is the most common form of skeletal dysplasia in humans. It occurs in 3 to 4 per 100,000 live births and is due to autosomal dominant sporadic de novo mutations in the fibroblast growth factor receptor 3 (FGFR3) gene mapped to chromosome band 4p16.3. This gene codes for the FGFR3 transmembrane receptor expressed largely by skeletal and brain tissues in the developing fetus where it is involved with growth regulation.⁷ Male and female fetuses are equally affected. There are two subtypes, TD1 and TD2, based on genetic-phenotypic differences, although features may overlap. TD1 is associated with radiographic findings of short curved (“telephone receiver”) femurs, with or without a clover-leaf skull deformity. TD2 is associated with straight, longer femurs, and clover-leaf skull. The genetic mutation responsible for TD1 leads to an arginine to cysteine amino acid substitution at position 248, whereas for TD2, it leads to a lysine to glutamine substitution at position 650 of the FGFR3 receptor.⁸ However, the distinction does not alter the management.

Neonates with TD invariably develop severe respiratory distress at birth due to lung hypoplasia requiring ventilation. The only means available to treat this condition is respiratory support. If the diagnosis is known ante-natally, then the parents would have the option of withholding active resuscitation. However, if the diagnosis is uncertain then, active resuscitation will buy time for further investigations until the diagnosis is determined. Physical findings manifest at birth include a bulging forehead, proptosis, flat nasal bridge, narrow chest, protuberant abdomen, and short limbs. A babygram should be done which may reveal characteristic telephone receiver femurs, flaring of the long bone metaphyses, short ribs, flat vertebral bodies, widened intervertebral disk spaces, a short pelvis with small sacroiliac notch, and cloverleaf skull deformity.⁹

⁵ McCormick uses as an example the traditional obligation to preserve life. He argues that the Christian tradition “has always strived to maintain a middle course between two extremes: medical-moral utopianism, i.e., sustaining life at all costs and with all means because when life is over everything is over and death is an absolute end, and its opposite, medical-moral pessimism, i.e., there is no point in sustaining life if it is accompanied by suffering, lack of function, etc. Both of these extremes are basic devaluations of human life because they remove life from the context which gives it its ultimate significance. The middle path is recognition of the facts that human life is a basic value, the most basic value, because it is the foundation for all other values and achievements, but that life is not the absolute good and death the ultimate and absolute evil.” McCormick, “A Proposal For ‘Quality Of Life’ Criteria For Sustaining Life,” *Hospital Progress* 56 (September 1975): 76.

⁶ Richard A. McCormick, “To Save or Let Die,” *How Brave a New World?: Dilemmas in Bioethics*, (Garden City, N.Y.: Doubleday, 1981), 342.

⁷ D. W. Bianchi, T.M. Crombleholme, M.E. D’Alton ME, “Thanatophoric Dysplasia,” in D.W. Bianchi, T.M. Crombleholme, M.E. D’Alton, editors *Fetology: Diagnosis and Management of the Fetal Patient* (New York: McGraw-Hill, 2000): 751-759.

⁸ *Ibid.*

⁹ *Ibid.*

Most babies with TD die within the first few hours of life from respiratory insufficiency secondary to reduced thoracic capacity or compression of the brainstem. Management concerns are limited to extreme life support measures for the newborn. In the rare cases of long-term survival (a 4.7 year male and 3.7 year female),¹⁰ the management consists in treatment of manifestations: respiratory support (tracheostomy, ventilation); medication to control seizures; shunt placement when hydrocephaly is identified; suboccipital decompression for relief of craniocervical junction constriction; hearing aids when hearing loss is identified and orthopedic evaluation upon development of joint contractures of joint hypermobility.¹¹

This case is an excellent example of how parents in consultation with health care professionals struggle to decide whether certain medical treatments are medically proportionate or disproportionate and in the best interest of the child.

MCCORMICK'S CRITERION

McCormick will determine how treatment decisions are made for handicapped newborns by proposing his normative understanding of best interests which evolves gradually into his quality-of-life criterion. This is a patient-centered, teleological assessment, which is based on a normative understanding of what reasonable persons ought to choose in a particular situation for the never-competent patient.¹² It appears that McCormick's quality-of-life criterion is nothing more than a further specification of his normative understanding of "best interests."¹³ McCormick has a normative understanding of "best interests" because, "as social beings, our good, our flourishing (therefore, our best interests) is inextricably bound up with the well-being of others."¹⁴ The "best interests" category is a composite category that involves quality-of-life considerations, benefit-burden considerations, and the use of proportionate reason as a tool for establishing what is promotive or destructive for the good of the person "integrally and adequately considered."¹⁵ McCormick understands "quality of life" to be an elusive term whose meaning varies according to context. However, at a more profound level, when the issue is preserving human life, the term assumes a more basic meaning. "Just as life itself is a condition for any other value or achievement, so certain characteristics of life are the conditions for the achievement of other values. We must distinguish between two sets of conditions: those that allow us to do things well, easily, comfortably, and efficiently, and those that allow us to do them at all."¹⁶ The quality-of-life criterion is ethically significant for parents and health care professionals, because it represents not only the value of the whole person, but it affirms that respect for the human person entails considering all the relevant factors and circumstances that are involved in any situation.

¹⁰I.M McDonald, A.G. Hunter, P.M. MacLeod et al., "Growth and Development in Thanatophoric Dysplasia," *American Journal of Medical Genetics* 33 (1989): 508-512.

¹¹Elio Liboi, Patricia Lievens, "Thanatophoric Dysplasia," *Orphanet Encyclopedia*, September 2004, 1-6.
<http://www.prpha.net/data/patho/GB/uk-Thanatophoric-dysplasia.pdf>

¹²The structure and individual components that makeup McCormick's moral criterion for decision-making are normative; they center on what "ought" to be the case, not what "is" the case. By normative McCormick means what the never-competent patient would want because he or she "ought" to want it. The never-competent patient "ought" to make this choice because it is in his/her "best interests." For a more detailed analysis of McCormick's position on a normative understanding of his patient-centered approach, see McCormick, "The Rights of the Voiceless," *How Brave A New World?* 99-113.

¹³Ethicist Robert Weir disagrees with McCormick on this point. Weir argues that the quality-of-life criterion and best interest's criterion are distinct and separate. McCormick responds to Weir by stating: "I believe Weir is wrong when he asserts that for those who use quality-of-life assessment, 'it is not necessary to consider the best interest of the neonate.' It is precisely because one is focused on best interests that qualitative considerations cannot be ignored but indeed are central. Weir is clearly afraid that quality-of-life considerations will be unfair. But they need not be. It all depends on where the line is drawn. I am all the more convinced of the inseparable unity and general overlap of best interests and quality-of-life considerations when I study Weir's clinical applications of his ethical criteria." McCormick, review of *Selective Nontreatment of Handicapped Newborns*, by Robert Weir, in *Perspectives In Biology And Medicine* 29 (Winter 1986): 328.

¹⁴McCormick, "The Rights of the Voiceless," *How Brave A New World?* 101. It should be noted that McCormick's understanding of "best interests" is grounded in his "revised" natural law position. "I believe we do have reasons for assuming we know in many cases what an incompetent would want. We may assume that most people are reasonable, and that being such they would choose what is in their best interest. At least this is a safe and protective guideline to follow in structuring our conduct toward them when they cannot speak. The assumption may be factually and per accidens incorrect. But I am convinced that it will not often be. . . . I believe most of us want to act reasonably within parameters that are objective in character, even though we do not always do so. Or at least I think it good protective policy to assume this." *Ibid*, 104-105.

¹⁵It should be noted that when McCormick refers to benefits in his "best interests" category it is not restricted to medical benefits. Benefits also apply to social and familial benefits. This notion of a benefit originates in Pellegrino's four components of "best interests" that McCormick has incorporated into his "best interests" category. For a more detailed analysis of Pellegrino's position, see Edmund Pellegrino, M.D., "Moral Choice, The Good of the Patient and the Patient's Good," in *Ethics and Critical Care Medicine*, eds. J.C. Moskop & L. Kopelman (Dordrecht, Netherlands: D. Reidel, 1985), 117-138.

¹⁶McCormick, "A Proposal for "Quality Of Life" Criteria for Sustaining Life," 77-78.

There are real difficulties in trying to establish a perfectly rational criterion for making quality-of-life judgments. To make his quality-of-life criterion more concrete, McCormick will establish two guidelines and four norms that will further specify his criterion. The first guideline developed for dealing with never-competent patients focuses on the potential for human relationships associated with the infant's condition. By relational potential McCormick means "the hope that the infant will, in relative comfort, be able to experience our caring and love."¹⁷ Specifically, he proposes that "if a newborn baby had no potential for such relationships or if the potential would be totally submerged in the mere struggle to survive, then that baby had achieved its potential and further life-prolonging efforts were not mandatory, that is, would no longer be in the best interests of the baby."¹⁸ Therefore, according to this guideline, when a never-competent patient, even with treatment, will have no potential for human relationships, the appropriate decision-makers can decide to withhold treatment and allow the patient to die.¹⁹ McCormick claims this quality-of-life approach has its foundation in the traditional ordinary-extraordinary means distinction that was later clarified by Pius XII.²⁰ This is not an easy guideline to apply, especially in the case of never-competent patients. In essence, this guideline requires that the appropriate decision-makers must be able to determine if a minimally accepted "quality of life" can be expected. This determination ought to be made on the basis of the never-competent's "best interests" understood normatively. This guideline does not depreciate the value of the never-competent individual but affirms that a genuine respect for the person demands attention to the prospects held out by continued life.²¹

This guideline of the potential for human relationships has been criticized for being too general and open to possible abuse.²² McCormick himself stated when he advanced this guideline that it was general and rather vague. But this is the way it is with all moral norms.²³ Despite being convinced that this guideline is fundamentally sound, McCormick understood that he must further concretize it. Specifically, there are those circumstances when the never-competent patient has the potential for human relationships, but the underlying medical condition is critical and will result in imminent death, or after treatment has been initiated it becomes apparent that the treatment is medically futile.²⁴ In these two situations it is clear that, besides the potential for human relationships, McCormick must incorporate an additional guideline that can weigh the benefits and burdens of certain treatments.

¹⁷ McCormick, "To Save or Let Die," 351.

¹⁸ McCormick, "The Best Interests of the Baby," Second Opinion 2 (1986): 23.

¹⁹ This does not mean that once a decision has been made to forego or discontinue treatment, that the dying person is not treated with dignity and respect. For McCormick, even though a person has reached his or her potential and no treatment is recommended, as members of society we still have a moral obligation to give comfort to the person while he or she is in the dying process. That comfort would consist in palliative care. Palliative care is aimed at controlling pain, relieving discomfort, and aiding dysfunction of various sorts.

²⁰ McCormick quotes Pius XII as saying that an obligation to use any means possible "would be too burdensome for most men and would render the attainment of the higher, more important good too difficult." Pius XII, "The Prolongation of Life," *Acta Apostolicae Sedis* 49 (1957): 1,031-1,032. McCormick understands Pius XII to say that certain treatments may be refused because it would lead to a life that lacks the proper quality. Leonard J. Weber, *Who Shall Live?: The Dilemma Of Severely Handicapped Children And Its Meaning For Other Moral Questions*, (New York: Paulist Press, 1976), 69.

²¹ Lisa Sowle Cahill, "On Richard McCormick: Reason and Faith in Post-Vatican II Catholic Ethics," in *Theological Voices In Medical Ethics* eds. Allen Verhey & Stephen Lammers (Grand Rapids, MI.: William B. Eerdmans Publishing Co., 1993): 91. The potential for human relationships is based in the Catholic tradition. McCormick bases this potential for human relationships in the Catholic tradition. The Christian story does not yield concrete answers and fixed rules, but it does yield various perspectives and insights that inform human reasoning. One such insight is that human life is a basic good but not an absolute good. Since human life is a relative good, and the duty to preserve it is a limited one, then it is not always morally obligatory to use all means to preserve human life if a person cannot attain the higher more important good. For McCormick, the "higher" more important good is the capacity for relationships of love. The core of this guideline is developed from the love commandment found in the New Testament.

²² Both Leonard Weber and John Connery have criticized McCormick's quality-of-life criterion. For a more detailed analysis, see Weber, *Who Shall Live?: The Dilemma Of Severely Handicapped Children And Its Meaning For Other Moral Questions* (New York: Paulist Press, 1976) and John Connery, "Quality Of Life," *Linacre Quarterly* 53 (February 1986): 26-33.

²³ "They really root in general assertions that must be fleshed out by experience, modified by discussion and consultation, propped up and strengthened by cautions and qualifications. It is in the process of their application that moral norms take on added concreteness." McCormick, "To Save Or Let Die: State Of The Questions," *America* 131 (October 5, 1974): 171.

²⁴ It should be noted that the term "medically futile" is an elusive and ambiguous term. There are four major types of medical futility. First, physiological futility--an intervention cannot lead to the intended physiological effect. Second, imminent demise futility--an intervention may be futile if despite that intervention the patient will die in the very near future (this is sometimes expressed as the patient will not survive to discharge, although that is not really equivalent to dying in the near future). Third, lethal condition futility--an intervention may be futile if the patient has an underlying lethal condition which the intervention does not affect and which will result in death in the not too far future (weeks, perhaps months, but not in years) even if the intervention is employed. Fourth, qualitative futility--an intervention may be futile if it fails to lead to an acceptable quality of life. For a more detailed analysis of medical futility, see Baruch A. Brody and Amir Halevy, AIs Futility "Futile Concept?" *Journal of Medicine and Philosophy* 20 (April 1995): 126-129.

The second guideline of McCormick's quality-of-life criterion is the benefit-burden evaluation. "Where medical procedures are in question, it is generally admitted that the criterion to be used is a benefits-burdens estimate . . . The question posed is: Will the burden of the treatment outweigh the benefits to the patient? The general answer: If the treatment is useless or futile, or it imposes burdens that outweigh the benefits, it may be omitted."²⁵ As is the case with his first guideline, McCormick claims the benefit-burden evaluation emerges out of the "ordinary-extraordinary means" distinction.

McCormick believes that his notion of benefit-burden evaluation within his quality-of-life criterion is a logical development of the "ordinary-extraordinary means" distinction, or what he refers to as an extension of the tradition into new problem areas.²⁶ McCormick believes that the "ordinary-extraordinary means" distinction has an honorable history and an enduring validity. However, he argues that these terms summarize and promulgate judgments drawn on other grounds. It is these "other grounds" that cry out for explication.²⁷

To further explain these "other grounds," McCormick reformulates the "ordinary-extraordinary means" distinction by advancing his benefit-burden evaluation. An extraordinary means is one that offers the patient no real benefit, or offers it at a disproportionate cost. For McCormick, one is called to make a moral judgment: Does the benefit of a proposed medical intervention really outweigh the harm it will inevitably produce? This is a quality-of-life judgment. The benefit-burden interpretation is not a departure from the Catholic tradition. It is a reformulation of the tradition in order to deal with contemporary bioethical problem areas.²⁸

The reason for this reformulation of the tradition is that over the centuries the "ordinary-extraordinary means" distinction has become less objective and more relative because medicine and technology have become more sophisticated. The medical profession is committed to curing disease and preserving life. Today, we have the medical technology to make this commitment a reality. However, McCormick argues that "this commitment must be implemented within a healthy and realistic acknowledgment that we are mortal."²⁹ Therefore, there is a need to reformulate the basic value of human life under new circumstances. For many contemporary ethicists the traditional terminology of ordinary-extraordinary means has outlived its usefulness and could take us only so far, especially in the case of handicapped newborns.³⁰ Focusing on the value of human life, McCormick sought to reformulate the "ordinary-extraordinary means" distinction without abandoning the tradition. Contemporary medical problems no longer only concern newborns for whom biological death is imminent. Modern medicine and technology have the ability to keep almost anyone biologically alive. Therefore, a gradual shift has occurred from the means to reverse the dying process to the quality of life sustained and preserved as the result of the application of medical technology.³¹ Today, because of the advancements in medicine and technology, the focus is on the quality of life thus saved that establishes a means as extraordinary.

To address this shift in the problem from means to quality of life preserved, McCormick has reformulated the "ordinary-extraordinary means" distinction to mean the "benefit-burden evaluation."³² For McCormick, "it is clear that the judgments of

²⁵ Richard A. McCormick, S.J., "Technology and Morality: The Example of Medicine," *New Theology Review* 2 (November 1989): 26.

²⁶ McCormick writes: "A basic human value is challenged by new circumstances, and these circumstances demand that imagination and creativity be employed to devise new formulations, a new understanding of this value in light of these new circumstances while retaining a basic grasp upon the value. For example, in-vitro fertilization poses questions about the meaning of sexuality, parenthood, and the family because it challenges their very biological roots." McCormick, "A Proposal For 'Quality Of Life' Criteria For Sustaining Life," 76.

²⁷ McCormick, "The Best Interests of the Baby," 19. McCormick further states: "We must admit that the terms 'ordinary' and 'extraordinary' are but code words. That is, they summarize and are vehicles for other judgments. They do not solve problems automatically. Rather they are emotional and mental preparations for very personal and circumstantial judgments that must take into account the patient's attitudes and value perspectives, or 'what the patient would have wanted.' 'Ordinary' and 'extraordinary' merely summarize other underlying judgments. They say very little in and of themselves." McCormick, "A Proposal For 'Quality Of Life' Criteria For Sustaining Life," 77.

²⁸ McCormick further states that: "It must be remembered that the abiding substance of the Church's teaching, its rock bottom so to speak, is not found in the ordinary means-extraordinary means terminology. It is found in a basic value judgment about the meaning of life and death, one that refuses to absolutize either. It is that judgment that we must carry with us as we face the medical decisions that technology casts upon us." McCormick, "Technology and Morality: An Example of Medicine," 29. Emphasis in the original.

²⁹ Richard McCormick, *The Critical Calling: Moral Dilemmas since Vatican II* (Washington, D.C.: Georgetown University Press, 1989), 365.

³⁰ McCormick argues there are two reasons for this: First, the terminology too easily hides the nature of the judgment being made. The major reference point in factoring out what is "reasonable" (benefit) and "excessive" (burden) is the patient--his or her condition, biography, prognosis, and values. The terminology, however, suggests that attention should fall on the means in an all too mechanical way. Second, many people misinterpret the terms to refer to "what physicians ordinarily do, what is customary." This is not what the term means. In their ethical sense, they encompass many more dimensions of the situation. Richard McCormick, *Health and Medicine In The Catholic Tradition*, (New York: Crossroad Press, 1987), 145.

³¹ McCormick, "To Save or Let Die," *How Brave A New World?* 345.

³² Besides McCormick's benefit-burden evaluation, other ethicists have suggested various terms to reformulate the ordinary-extraordinary means distinction. Paul Ramsey suggests that the morally significant meaning of ordinary and extraordinary medical means can be reduced almost without remainder to two components--a comparison of treatments to determine if they are "medically indicated" and a patient's right to

burden and benefit are value judgments, moral choices. They are judgments in which, all things considered, the continuance of life is either called for or not worthwhile to the patient.”³³ In making these moral judgments one can see how proportionate reason is used as a tool for determining whether a particular life-sustaining treatment is a benefit or a burden, that is, in the “best interests” of the never-competent patient and those involved in the decision-making process.

The benefit-burden evaluation was also proposed by the Sacred Congregation for the Doctrine of the Faith in its Declaration on Euthanasia and by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its *Deciding to Forego Life-Sustaining Treatment*.³⁴ The issuance of the Declaration on Euthanasia in 1980 by the Magisterium gave McCormick further justification for incorporating the benefit-burden evaluation into his quality-of-life criterion.³⁵ It also gave him further proof to anchor his guideline and thus his criterion for treatment decisions in the benefit-burden evaluation. Medical treatments are not morally mandatory if they are either gravely burdensome or useless for the patient.³⁶ McCormick has a normative understanding of medical futility, which considers whether the agreed on potential effect is of any value and benefit to the newborn, that is, in the newborn’s “best interests” normatively understood. For McCormick, a medical treatment might be successful in achieving an effect (physiologically effective), but the effect might not be beneficial to the patient (qualitatively effective). Since the goal of medical treatment is to benefit the patient, it follows that nonbeneficial treatment is medically futile.³⁷ This entails making a value judgment and the evaluation of whether a treatment is a benefit or a burden can be open to personal interpretation. That means these evaluations can be “borderline and controversial.”³⁸

The two guidelines of McCormick’s quality-of-life criterion, even though he argued they were both reformulations of the “ordinary-extraordinary means” distinction, continued to be criticized by ethicists Leonard Weber, John Connery and Warren Reich for being too relative, subjective, and consequential in nature. To address this criticism McCormick, along with ethicist John Paris, S.J., proposed the following norms that would further specify the capacity for human relationships and the benefit-burden evaluation:

- (1) Life-saving intervention ought not to be omitted for institutional or managerial reasons. Included in this specification is the ability of this particular family to cope with a badly disabled baby.

refuse treatment. See Paul Ramsey, *Ethics at the Edges of Life: Moral And Legal Intersections*, (New Haven, CT.: Yale University Press, 1978), 153-160. Robert Veatch maintains that the terms “ordinary” and “extraordinary” are “extremely vague and are used inconsistently in the literature.” Beneath this confusion he finds three overlapping but fundamentally different uses of the terms: usual versus unusual, useful versus useless, imperative versus elective. See Robert Veatch, *Death, Dying And The Biological Revolution*, (New Haven, CT.: Yale University Press, 1976), 110-112. For further examples, see McCormick, “The Quality Of Life, The Sanctity Of Life: How Brave A New World?,” 393-405.

³³ McCormick and John Paris, “Saving Defective Infants,” *How Brave A New World?*, 360.

³⁴ See President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, “*Deciding To Forego Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions*,” (Washington, D.C., U.S. Printing Office, March 1983): 218-219.

³⁵ The Congregation concludes that, “it will be possible to make a correct judgment as to the means by studying the type of treatment being used, its degree of complexity or risk, its cost and possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.” Congregation for the Doctrine of the Faith, “*Declaration on Euthanasia*,” *Origins* 10 (August 1980): 263.

³⁶ Ethicists Warren Reich, John Connery, S.J., Leonard Weber, and Donald McCarthy disagree with McCormick’s interpretation of the tradition on the benefit-burden distinction. Ethicist Richard Sparks writes: “For Reich, Weber, Connery, and McCarthy the limiting factor is the quality of life, which, if judged to be excessively burdensome, can make the presumably beneficial treatment extraordinary and optional, [sic] must be caused by or directly related to the use of the means contemplated. In other words, ‘the burden must be the burden of medical treatment, not the burden of handicapped existence.’” Richard Sparks, *To Treat or Not to Treat?: Bioethics and the Handicapped Newborn*, (New York: Paulist Press, 1988), 110; see also Donald G. McCarthy, “*Treating Defective Newborns: Who Judges Extraordinary Means?*” *Hospital Progress* 62 (December 1981): 45-50; John Connery, S.J., “*Prolongation Of Life: A Duty And Its Limits*,” *Linacre Quarterly* 47 (May 1980): 151-165; Leonard Weber, *Who Shall Live?* 88-98; and Warren Reich, “*Quality Of Life and Defective Newborn Children: An Ethical Analysis*,” in *Decision-Making and the Defective Newborn*, ed. Chester A. Swinyard (Springfield, IL.: Thomas, 1978), 488 -511.

³⁷ For McCormick, medical futility is determined by the parents in consultation with the health care professionals, because a determination must be made of the patient’s medical status and an evaluation must be made of the medical intervention. The determination of medical futility entails balancing the values of patients, the values of medicine, and the fact that there is much uncertainty in making “predictive medical judgments.” McCormick’s notion of medical futility is also rooted in his understanding of the principles of beneficence and nonmaleficence--do no harm to the patient. For a more detailed analysis of medical futility, see James F. Drane and John L. Coulehan, *The Concept Of Futility: Parents Do Not Have The Right To Demand Medically Useless Treatment*, *Health Progress* 74 (December 1993): 32; Robert Veatch and Carol Mason Spicer, “*Futile Care: Physicians Should Not Be Allowed To Refuse To Treat*,” *Health Progress* 74 (December 1993): 22-27 and Glenn G. Griener, “*The Physician’s Authority To Withhold Futile Treatment*,” *Journal Of Philosophy And Medicine* 20 (April 1995): 209.

³⁸ McCormick and Paris, “*Saving Defective Infants*,” *How Brave a New World?* 358.

- (2) Life-sustaining interventions may not be omitted simply because the baby is retarded. There may be further complications associated with retardation that justify withholding life-sustaining treatment.
- (3) Life-sustaining intervention may be omitted or withdrawn when there is excessive hardship on the patient, especially when this combines with poor prognosis.
- (4) Life-sustaining interventions may be omitted or withdrawn at a point when it becomes clear that expected life can be had only for a relatively brief time and only with continued use of artificial feeding.³⁹

These norms or rules do not mandate certain decisions, nor do they replace the role of prudence and eliminate conflicts and decisions. They are simply attempts to provide outlines of the areas in which prudence should operate.⁴⁰ McCormick further specified his quality-of-life criterion to help enlighten medical situations for the appropriate decision-makers. However, guidelines, even specified by concrete norms, cannot cover all circumstances and every possible situation. McCormick's quality-of-life criterion assists the appropriate decision-makers by giving them a range of choices. As rational persons, it is up to the appropriate decision-makers to examine each situation using proportionate reason, and the guidelines advanced by McCormick in his quality-of-life criterion, to determine what is in the "best interests" of the never-competent patient and those involved in the decision-making process. McCormick makes clear that no criterion can cover every instance where human discretion must intervene to decide. There is always the possibility of human error because we are finite and sinful people. For McCormick, "the margin of error tolerable should reflect not only the utter finality of the decision (which tends to narrow it), but also the unavoidable uncertainty and doubt (which tends to broaden it)."⁴¹ With the assistance of these guidelines and norms, McCormick believes that the appropriate decision-makers will be given the necessary guidance to act responsibly.

To assist parents and health care professionals further in medical decision-making for handicapped newborns five specific diagnostic treatment categories of handicapped newborns have been established. These categories attempt to encompass, as far as possible, the entire spectrum of handicapped newborns. They are based on McCormick's moral criterion of the potential for human relationships.

McCormick has plotted the two extreme positions on this spectrum of handicapped newborns, but has left the "conflictual middle," to be filled in by health care professionals and bioethicists.⁴² These diagnostic categories will attempt to complete the "conflictual middle." The "conflictual middle" pertains to those neonatal anomalies that fall into the "gray area" of treatment decisions.⁴³ These diagnostic treatment categories have been arranged in a way that demonstrates the application of McCormick's "best interests" category. There is a logical progression on the spectrum from the newborn who does not warrant medical treatment to the newborn who does warrant medical treatment. The five diagnostic treatment categories are:

1. The handicapped newborns whose potential for human relationships is completely nonexistent.
2. The handicapped newborn who has a potential for human relationships but whose potential is utterly submerged in the mere struggle for survival.
3. The handicapped newborn who has a potential for human relationships but the underlying medical condition will result in imminent death.
4. The handicapped newborn who has the potential for human relationships but after medical treatment has been initiated, it becomes apparent that the treatment may be medically futile.
5. The handicapped newborn who has the potential for human relationships and has a correctable or treatable condition.⁴⁴

³⁹ Ibid., 358-359.

⁴⁰ Ibid., 359.

⁴¹ Ibid., 360.

⁴² McCormick writes: "It is the task of physicians to provide some more concrete categories or presumptive biological symptoms for this human judgment. For instance, nearly all would likely agree that the anencephalic infant is without relational potential. On the other hand, the same cannot be said for the mongoloid infant. The task ahead is to attach relational potential to presumptive biological symptoms for the gray areas between such extremes." McCormick, "To Save Or Let Die," *How Brave A New World?* 349-350.

⁴³ This would include anomalies in which the newborn has the potential for human relationships, but the potential is utterly submerged in the mere struggle for survival, or the medical condition will result in imminent death, or it has been determined that further treatment is medically futile. Certain anomalies that would fall within this category would be spina bifida, hypoplastic left heart syndrome, trisomy 13, trisomy 18, Lesch-Nyhan syndrome, etc.

⁴⁴ For a more complete analysis of these five diagnostic categories see, Peter A. Clark, *To Treat Or Not To Treat: The Ethical Methodology of Richard A. McCormick, S.J. As Applied To Treatment Decisions For Handicapped Newborns*, (Omaha, Ne.: Creighton University Press, 2003).

Establishing a full set of diagnostic treatment categories is not a panacea for determining treatment decisions for handicapped newborns. Not all medical conditions can be placed in specific categories; there is a marked difference in the severity of conditions within each category. Not all health care professionals or even bioethicists could or would agree to these specific categories. Nevertheless, as McCormick argues, “we ought to attempt, as far as possible, to approach neonatal disabilities through diagnostic categories, always realizing that such categories cannot deflate important differences and that there will always remain gray areas.”⁴⁵ The establishment of these five diagnostic treatment categories is an attempt to meet the challenge set before health care professionals and bioethicists to assist parents and medical professionals in making treatment decisions for handicapped newborns.

ETHICAL EVALUATION

In the case of Baby X, the medical professionals have ascertained after five months that any further aggressive medical treatment would be medically futile for this child. According to the physicians, Baby X has severe underdeveloped lungs, ribs too tiny to allow normal breathing and pressure on the spinal cord that disrupts brain signals controlling respiration. Thus, Baby X is in a terminal condition and is slowly suffocating. Mechanical ventilation at this point is only prolonging the dying process. It would appear that Baby X would fit under diagnostic category four.

In this fourth diagnostic treatment category, since the potential for human relationships is present, McCormick’s second guideline of his quality-of-life criterion--the benefit-burden evaluation--would be applied to determine whether Baby X ought to be treated. What is to be determined is whether the benefit of the treatment will outweigh the burden to the newborn. If the parents in consultation with the health care professionals determine that further medical treatment would not improve the newborn’s prognosis, or benefit the overall well-being of the newborn, then, all things considered, parents should decide that further treatment would not be in the “best interests” of the newborn. A newborn diagnosed with thanatophoric dysplasia is in a terminal condition and according to medical authorities, further medical treatment is medically futile, that is, any possible medical effect is of no benefit to the newborn. To support this position McCormick’s third norm, that further specifies the burden-benefit evaluation, can be applied. “Life sustaining interventions may be omitted or withdrawn when there is excessive hardship, especially when this combines with poor prognosis.” Therefore, it appears that further treatment for Baby X is not morally obligatory, because it is a disproportionate means.

The notion of a normative understanding of “best interests” considers not only the relevant medical facts but also the relevant social and familial factors. Financial and emotional costs ought to be considered. That means, if the social factors are excessive, then the newborn should not and would not want to be treated, because it would place excessive burdens on those who must care for the newborn’s existence. What the newborn “ought” to want should encompass the needs of those who will care for this child. Baby X is in a terminal state and further aggressive treatments will only prolong the dying process. Both social and familial factors ought to play a proportionate role in determining the benefit/burden evaluation.⁴⁶

In conclusion, when a handicapped newborn has the potential for human relationships but after initiating treatment, it becomes apparent that the treatment is medically futile, parents in consultation with health care professionals are not morally obliged to continue medical treatment. This is a value judgment that is based on McCormick’s guidelines of relational potential and benefit/burden evaluation. McCormick’s moral criterion sets basic parameters and enlightens the particular medical situation. Ultimately, the parents will use prudence to examine the medical facts and to weigh, all things considered, whether the burdens of treatment outweigh the benefits to the newborn. In this diagnostic treatment category, the burdens and benefits need to be weighed carefully. However, with the severity of this particular medical anomaly the burdens clearly outweigh the benefits to the newborn. Therefore, in the “best interests” of the newborn, and all concerned, parents in consultation with health care professionals have the moral obligation to forgo or withdraw treatment for a newborn in these circumstances.

McCormick argues that his moral criterion is appropriate for decision-makers because it considers not only the relevant medical facts and the pertinent circumstances of the situation, but also familial and social factors, such as, religious, cultural, emotional, and financial factors. Parents in consultation with health care professionals can best determine what the handicapped newborn ought to want and protect his or her “best interests” by using McCormick’s quality-of-life moral criterion. As reasonable

⁴⁵ McCormick, “The Best Interests of the Baby,” 24.

⁴⁶ It should be noted that McCormick’s position on social and familial factors has been criticized for being too restrictive and deviating from both the Catholic tradition and from his own normative understanding of “best interests.” McCormick claims that his restrictive notion of social and familial factors, as they pertain to treatment decisions for handicapped newborns, is due to the fact that a broader interpretation could lead to social utilitarianism. This caution is certainly relevant because the possibility of potential abuse is always present. However, the safeguards McCormick has built into his quality-of-life criterion--guidelines and norms--should help to alleviate the possibility of such abuse. In addition, health care professionals serve as a safeguard in that they can act as the newborn’s advocate should they suspect abuse.

people, parents are most knowledgeable about the family situation into which the newborn is born. This includes knowing the financial, emotional, and social factors. Parents can also weigh and balance the religious and cultural values that inform their decision-making. Health care professionals have the specialized medical knowledge and clinical expertise that can assist parents in the decision-making process. They also have a level of objectivity that parents may lack because of the overwhelming emotional stress of the situation. Together, parents and health care professionals are able to determine what are the appropriate needs of this newborn, to assess these needs, and to determine whether medical treatment is in the “best interests” of the newborn “integrally and adequately considered.”

CONCLUSION

McCormick’s moral criterion is appropriate for Christian decision-makers because it emphasizes “the reasonable” from within a Christian context. It stresses the need for decision-makers to examine the medical facts, the circumstances of the situation, foreseeable consequences, social and familial factors, and other pertinent data before deciding on an appropriate course of action. McCormick’s moral criterion also stresses that these facts are to be considered always within the context of the Christian story, so that the “best interests” of the handicapped newborn are always promoted and protected. Treatment decisions for handicapped newborns are value judgments that must be based on the appropriate needs of the newborn. These value judgments can possibly become distorted by self-interested perspectives and technological considerations. Christian decision-makers who use McCormick’s moral criterion are not immune from making mistakes. We are a finite and sinful people. What is being said is that because the content of this moral criterion is reasonable, and because these decisions are made within the context of the Christian story, less chance exists that such treatment decisions will be pushed to the extremes. McCormick’s moral criterion is appropriate for Christian decision-makers because it protects the “best interests” of the handicapped newborns by promoting value judgments that are grounded in reason and informed by the Christian story.

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