

# On Charlie Gard: Ethics, Culture, and Religion

PETER A. CLARK, SJ, PH.D.<sup>1</sup> MARVIN J. H. LEE, PH.D.<sup>2</sup> AND OLIVIA NGUYEN<sup>3</sup>

*peter.clark@sju.edu,<sup>1</sup> marvin.lee@sju.edu,<sup>2</sup> olivia.nguyen@sju.edu<sup>3</sup>*

*<sup>1, 2, 3.</sup> The Institute of Clinical Bioethics, Saint Joseph's University, Philadelphia, Pennsylvania, U.S.A.*

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**Abstract:** *The 2017 story of Charlie Gard is revisited. Upon the British High Court's ruling in favor of the physicians that the infant should be allowed to die without the experimental treatment, the view of the public as well as the opinions of bioethicists and Catholic bishops are divided, interestingly along with a cultural line. American bioethicists and Catholic bishops tend to believe that the parents should have the final say while British/European bioethicists and Catholic bishops in general side with the court's decision. The paper explores the place of culture in bioethical reasoning between the UK/Europe and the US while claiming that cultural differences are more important than geopolitical or religious differences to understand the bioethical positions of a group. In addition, the authors introduce a decision-making program for handicapped neonates which is developed by the American Jesuit Bioethicist, Richard McCormick, and modified further by the contemporary American Jesuit Bioethicist, Peter A. Clark, in an attempt to see if the program's normalizing categories can contribute to the culture-laden ethical discussions on Charlie's case. However, it is admitted that the McCormick-Clark device is borne out of the American and Catholic theological context.*

## I. INTRODUCTION

The 2017 story of Charlie Gard sparked an international conversation among health providers, bioethicists, religious leaders, and legal professionals about an end of life issue, as it also shows the symptom of the current social media age that a legal battle, scrutinized by the global news media, can spiral out of control. The more recent, 2018 case of Alfie Evans is highly similar to the Gard case in that the parents of both children lost legal challenges to the court rulings as the British High Court allowed the hospital to withdraw treatment from the babies against their parents' wills. The High Court stopped Charlie and Alfie from flying respectively to the U.S. and the Vatican to get further treatments.

The parents of both infants seemed to fall victims of the tragic situations due to the media while the cases also resurface the thorny questions not unambiguously responded to in the field of contemporary bioethics. Who should have the final say in irreconcilable disputes over the treatment of sick children? Parents? Physicians? Courts? Or a combination? At what point should the limits of medicine be recognized, and the patients be compelled to let go? Under what conditions should parents allow minors to receive experimental treatments? Is the child a patient or a research subject? Are there possible conflicts of interest which can be financial or academic or social? When do individual goods conflict with the common good, as benefits to the individual child and those for society as a whole conflict with each other? Was this a case of health care rationing such as universal health care vs. a money-driven-system? Note that the U.K has a single-payer system which covers all citizens in health care. Was this the medical vitalism trap, i.e., the prioritization of the prolongation of human life at all costs, regardless of pain and suffering? Can we apply the theological notion of ordinary and extraordinary treatments in this case? Was this a case of medical futility?

\*Address correspondence to: Peter A. Clark, SJ, Ph.D., The Institute of Clinical Bioethics, Saint Joseph's University, 5600 City Avenue, Philadelphia, PA 19131, U.S.A. E-mail: peter.clark@sju.edu.

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Focusing on the Gard Case, we delimit our scope to the lexical ordering of moral norms and to the issue of deciding authority in the U.K./Europe and the U.S. Thus, the single question we attempt to answer is “Who should make the final treatment decision and what should be the decision?” As the U.K. court has ruled in favor of the physicians to let Charlie die without the treatment, the opinions of the ethicists and the public are divided alongside the cultural line. Europeans, in general, including European Catholics (e.g., Paglia, the head of the Pontifical Academy for Life, and the Catholic Bishops’ Conference of England and Wales), tend to understand the British court’s decision as acceptable. On the other hand, the American public, together with American Catholics (American Catholic and secular bioethicists), raise a strong voice that Charlie’s parents should be the final authority over the treatment decision for the child. Alternatively put, in the case where patient autonomy (parental autonomy in Charlie’s case) and physicians’ paternalistic beneficence are in tension or conflict with each other, European culture tends to lexically rank the physicians’ beneficence higher than the parents’ autonomy whereas American culture does the opposite.

To address the comparative cultural issue more deeply, we will elaborate the moral diversity between the two cultures (the U.K./Europe and the U.S.) through some historical accounts and display how the cultural difference is reflected in the views of the contemporary Catholic bioethicists and bishops. Then, we will introduce the work of the American Jesuit Bioethicist, Richard McCormick, to see if his program where the infant’s parent is viewed as a beneficent third-party agent whose concern is naturally bound to the best interest of the child can contribute to the case beyond the culture-laden ethical discussion. In so doing, we will use an upgraded variation of the McCormick’s program which we may call “McCormick-Clark Program,” where the contemporary Jesuit Bioethicist, Peter A. Clark, has suggested to complement McCormick’s thesis. Finally, we give our ethical verdict about the case that Charlie’s parents, not the doctors, should have the final say, but should allow withdrawal of the treatment.

## II. FOUNDATIONAL ETHICAL ANALYSIS

### A. *The Lexical Ordering of Moral principles*

For most Americans, the rationale behind the British courts’ ruling is hard to understand. There is no doubt that the American court, had the case had occurred in the U.S., would have allowed the parents to access the experimental therapy even though the court had acknowledged its low therapeutic efficacy. For, as widely discussed in bioethics literature, in the U.S. patient autonomy including surrogate autonomy of the patient (like a parental proxy) is considered weightier than the physician’s paternalistic beneficence. But it is the opposite in Britain as well as Europe. It is normal for the courts in Europe to intervene when parents and doctors disagree on the treatment of a child and rule in favor of the physicians.

Many scholars have already explored the difference between the American and European ethical-legal mind. For example, in the 1989 study of different moral attitudes of European and American physicians, Dorothee Wertz and John Fletcher compare French and American neonatologists and conclude that American doctors tend to defer to the parents’ opinion while French doctors believe that they are entitled to override the parents’ request.<sup>1</sup> French/European doctors think that they have a special responsibility towards the infant or a fetus who has a right to be protected from parental desires. When it comes to the case of severely handicapped newborns, French neontologists also consider themselves to be in the best position to make the appropriate decision for the babies. The paternalistic attitude is clearly shown in their conviction that “to entrust parents with such an emotional decision would be too much for them.”<sup>2</sup>

Besides, it is interesting to see how the terms “medical futility” and “palliative care” are understood differently in Europe and America. Wertz and Fletcher say that the way Americans use the term “medical futility” is not familiar to French people and that the debate on medical futility is summed up as *l’acharnement thérapeutique*, translated into English by “therapeutic harassment,” which expresses an indignation about the type of horrific death resulted from overtreatment that many patients must go through. To prevent such “an indignity of the medicalization of death,” palliative care is suggested for its solution.<sup>3</sup> Thus, medical futility is

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<sup>1</sup> Dorothee Wertz and John C. Fletcher, *Ethics and Human Genetics: A Cross-Cultural Perspective* (Berlin: Springer-Verlag, 1989), 186.

<sup>2</sup> *Ibid.*

<sup>3</sup> Hubert Doucet, “How Theology Could Contribute to the Redemption of Bioethics from an Individualist Approach to an Anthropological Sensitivity,” *Proceedings of the Catholic Theological Society of America* 53 (1998): 59.

considered something physicians should prevent on behalf of the patients. Some suggest that “futility of treatment” in France/Europe is an “expression coined by doctors to express their opposition to requests coming from patients or their families who require, in the name of their autonomy, treatments which physicians consider useless.”<sup>4</sup>

In the U.K., the same sentiment is shared. According to a 2001 survey conducted in the U.S. and U.K., the American and British practitioners are found to “disagree sharply about whether clinicians must provide medically futile treatment if dying people and their families demand it.”<sup>5</sup> Most American clinicians “agree or strongly agree that they are required to provide medically futile treatment” if the treatments are “requested by dying patients or their families,” but 54% of the British clinicians “agree or strongly agree that medically futile treatment is not obligatory even if patients and families disagree.”<sup>6</sup> The English law is generally against the case that physicians “act against their clinical judgment in providing futile treatment.”<sup>7</sup> In other words, “medical futility” and “palliative care” in Europe are used to refer to the case that physicians protect patients against the unduly requests derived from the patient and family’s unreasonable requests.

However, American bioethics is different. The de-facto practice in the U.S. hospitals has been that patient autonomy trumps clinicians’ paternalistic beneficence though American bioethics have insisted that interpreting medical futility is finding a delicate balance between the physician’s objective medical judgment and the patient’s family’s subjective value. The late Georgetown bioethicist, Edmund Pellegrino’s criteria for determining medical futility is representative of the American approach to bioethics. According to Pellegrino, the three facets should be inspected: 1. Objective Effectiveness (an objective estimate of the capacity of the medical treatment to alter the natural history of the disease or symptoms in a positive way). 2. Subjective Benefit (what is valuable to the subjective perception of the patient and his/her surrogate on the value of the treatment). 3. Contextual Burden (emotional, fiscal or social tolls on the patient by the medical treatment).<sup>8</sup>

In its historical origin, American bioethics was born as patients’ protest against doctors, as the doctors were using the patients “as [a] means for the benefit of scientific progress and their own promotion.”<sup>9</sup> The Belmont Report (1978), the first bioethical document created by the first U.S. federal bioethics council, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, was a reaction to the infamous U.S. government project, Tuskegee Study of Untreated Syphilis in the Negro Male (1932–1972). In other words, American bioethics was developed to protect patients from physicians’ abuse rationalized under the name of paternalistic beneficence. Thus, the primary focus of American bioethics is always if the treatment in question advances or promotes patient autonomy even though the patient or family’s request may merely reflect emotional concerns. Accordingly, if Gard’s family were Americans and the case was heard in the U.S. court, the court ruling must have been the opposite.

### **B. The Deciding Authority**

So far, we have discussed the different lexical ordering of moral principles between the U.K./Europe and the U.S. In general, physician beneficence is prioritized over patient autonomy in the U.K./Europe, but vice versa in the U.S. However, a more nuanced distinction between the two cultures can be shown by addressing the two cultures’ difference about “deciding authority” in bioethical issues. In the U.K./Europe, the highest deciding authority is generally at the level of society whereas in the U.S. an individual patient is deemed to be the highest authority. In other words, Europeans tend to understand that a collective social agreement is required to resolve bioethical problems while Americans tend to see the bioethical issues as private matters.

This moral variation is understandable when we look at the ethnic identity of the U.K./Europe and the U.S. Almost all European countries are ethnic nations while the U.S. is an immigrant country. To narrow our focus on the U.S. and U.K. (which happened to be

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<sup>4</sup> Ibid.

<sup>5</sup> Donna L. Dickenson, “Practitioner Attitudes in the United States and United Kingdom Toward Decisions at the End of Life: Are Medical Ethicists Out of Touch?” *The Western Journal of Medicine* 174 No. 2. pp. 103–109, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071268/>

<sup>6</sup> Ibid.

<sup>7</sup> Ibid.

<sup>8</sup> Edmund Pellegrino, “Decisions at the End of Life: The Abuse of the Concept of Futility,” *Practical Bioethics* No. 1 Vol. 3 (2005): 93

<sup>9</sup> Doucet, “How Theology Could Contribute,” 60.

two leading industrialized nations in the world), the U.S. is a highly sophisticated immigrant country whose founding ideal and sustaining ethical-legal structure are set to secure the diversity of cultural and religious values that the immigrants have brought with them. In the absence of a single ethnic culture or tradition to claim “American,” the American public has found its cultural authenticity in its respect for the autonomy of individual citizens whose moral values can be different from one another. Therefore, in a clinical context, it is genuinely American to treat an individual patient’s autonomous wishes as the utmost moral value. Accordingly, the ultimate deciding authority in the U.S. is an individual.

On the other hand, the U.K. is a cosmopolitan ethnic nation. Like the other developed ethnic European nations alongside Germany and France, Britain’s current socio-political infrastructure is the outcome of their thousand-year history of intellectual struggles in regards to how to best govern their own country (despite the current problem of social integration due to the influx of a great number of immigrants). Thus, British people have a strong sense of ethnic congeniality and pride among the citizens. As a result, it is the general social atmosphere that British people see their political and social leaders as paternalistic figures. Accordingly, despite individuals’ dissents on certain cases, the British court ruling against patient/family autonomy is considered generally justifiable because it is the measure done for the sake of survival and thriving of their people.

This characteristic feature is exhibited as we observe how European bioethicists have reacted to Beauchamp and Childress’ principlism, the biomedical method of decision-making immensely popular in the U.S. In Europe, principlism has never been popular although some European bioethicists appreciated the practical simplicity of the method and tried to use its modified version to fit their socio-cultural context.<sup>10</sup> The reason for the unpopularity of principlism is, in fact, obvious. Europeans find problematic principlism’s methodological confidence in the *prima facie* common morality where doctor-patient relationship is portrayed in a polarized state. In principlism, patient autonomy is treated as a separate, independent value from physician beneficence so that we can balance one value over against the other. As principlism has been updated throughout the seven editions of *Principles of Biomedical Ethics* (its most recent edition published in 2012), Beauchamp and Childress attempted to provide better justifications for the common morality thesis while keeping the polarizing framework intact – patient autonomy is still considered in tension or conflict with physician beneficence.<sup>11</sup> Fundamentally, what makes this framework possible is the American cultural ideal inherent in principlism that an individual patient holds the deciding authority; it is the patient who makes the final call as the patient him/herself juxtaposes and ponders upon the two competing concerns – that is, what I want as a patient vs. what the doctors say to me.

However, for Europeans, the treatment decision is fundamentally communal. It is true that patient autonomy is distinguished conceptually from physician beneficence. However, they are not separate, independent values from each other; what the patient/family wants is part of the communal decision-making process without clearly specifying who has the final say. However, when the agreement is not reached between the patient/family and doctor, the court generally honors the opinions of doctors over the patient/family, believing that the doctors’ view can serve the common good of society impartially. This is the reason that some European bioethicists say, rather disparagingly, identify the meaning of patient autonomy used in the U.S. as equivalent to a patient’s permission to doctors. They argue that patient autonomy should always be used together with patient dignity or integrity to truly understand the meaning of the autonomy.<sup>12</sup>

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<sup>10</sup> Raanan Gillon, the Emeritus Professor of Medical Ethics at Imperial College London, may be the strongest ally with Beauchamp and Childress. See Gillon, “Defending the Four Principles’ Approach to Biomedical Ethics,” *Journal of Medical Ethics* 21 No. 6 (1995).

<sup>11</sup> Marvin Lee, “The Problem of ‘Thick in Status, Thin in Content’ in Beauchamp and Childress’ Principlism,” *Journal of Medical Ethics* 36 no. 9 (2010): 525-52.

<sup>12</sup> Jacob Rendtorff, “Basic Ethical Principles in European Bioethics and Biolaw: Autonomy, Dignity, Integrity and Vulnerability,” *Medicine, Health Care and Philosophy* (2002), 235. In the same vein, Rendtorff and his colleague, Peter Kemp, attempt to elucidate five different senses of autonomy, partly to say how absurd the simple, American notion of autonomy is: “1) autonomy as capacity of creation of ideas and goals for life, 2) autonomy as capacity of moral insight, ‘self-legislation’ and privacy, 3) autonomy as capacity of decision and action with lack of outer constraint, 4) autonomy as capacity of political involvement and personal responsibility, 5) autonomy as capacity of informed consent.” Then, acknowledging the ethnic uniqueness of each European state, they recommend that “each European state [should] makes use of the principles according to the particularity of their specific convictions” embedded in local variations while incorporating the values of patient’s dignity, integrity, and vulnerability. See Jacob Rendtorff and Peter Kemp, *Basic Ethical Principles in European Bioethics and Biolaw Vol. I: Autonomy, Dignity, Integrity, and Vulnerability* (Copenhagen, Barcelona: Centre for Bioethics and Law, 2000), 235.

**C. Divisive Opinions among Catholic Bioethicists and Bishops**

We now turn to the Catholic theological views on the issue. Monsignor Vincenzo Paglia, the head of the Vatican's Pontifical Academy for Life, which is the Pope's bioethics advisory panel, states on June 30, 2017:

We must do what advances the health of the patient, but we must also accept the limits of medicine and, as stated in paragraph 65 of the encyclical *Evangelium Vitae*, avoid aggressive medical procedures that are disproportionate to any expected results or excessively burdensome to the patient or the family... [In Charlie's case] the wishes of parents must be heard and respected, but they too must be helped to understand the unique difficulty of their situation and not be left to face their painful decisions alone. If the relationship between doctor and patient (or parents as in Charlie's case) is interfered with, everything becomes more difficult and legal action becomes a last resort, with the accompanying risk of ideological or political manipulation, which is always to be avoided, or of media sensationalism, which can be sadly superficial.<sup>13</sup>

In other words, the official Vatican position is that the couple should be helped to acknowledge the medically futile condition of their child so that the child could face natural death peacefully without being manipulated by confusing external forces such as the media and political interest groups. Thus, the Holy See understood that the doctors might justifiably override the parental wish.

This position is supported by quite a few British Catholic authorities and intellectuals. The Anscombe Bioethics Centre, a Roman Catholic bioethics institute based in Oxford, England, makes its press statement on Charlie's case on July 5, 2017. The organization expresses two concerns about the language of the court opinions, as it says that the court seems, first, to "refer not to the worthwhileness of treatment but to the worthwhileness of Charlie's life"<sup>14</sup> and, second, to treat Charlie's parents unreasonable. However, they agreed with the court decision on the treatment, as they state that:

Nevertheless, the final decisions in this case – to withdraw ventilation and not to seek experimental treatment – are decisions that parents in this situation could reasonably make on behalf of their child. [Thus,] The decisions [of the court] themselves are morally defensible. The Catholic moral tradition does not oblige the use of medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome.<sup>15</sup>

Also, the Catholic Bishops' Conference of England and Wales (CBCEW) makes a statement on July 24, 2017. The bishops talk mainly about the parents' suffering and their loss while acknowledging "the joint nature of the decision-making which was in Charlie's best interests." It states that "all involved in these agonizing decisions have sought to act with integrity and for Charlie's good as they see it."<sup>16</sup> In brief, the British Catholic bioethicists, alongside the bishops, see no ethical issues about the court decision in and of itself because they believe the court ruling as a beneficent resolution reached by the British society as a whole.

By contrast, Pope Francis endorses the parents' fight. The Vatican press says, the Pope "is following with affection and sadness the case of little Charlie Gard and expresses his closeness to his parents. For this he prays that their wish to accompany and treat their child until the end is not neglected."<sup>17</sup> Some say that the Pope reversed the Vatican's decision because Paglia's statement had met strong opposition from some conservative Catholic bishops although what the Pope "really" thought was the same as Paglia's.

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<sup>13</sup> "Vatican's Academy for Life Issues Statement on Baby Charlie Gard" Vatican Radio, June 28, 2017, [http://en.radiovaticana.va/news/2017/06/29/vaticans\\_academy\\_for\\_life\\_issues\\_statement\\_on\\_charlie\\_gard/1322138](http://en.radiovaticana.va/news/2017/06/29/vaticans_academy_for_life_issues_statement_on_charlie_gard/1322138)

<sup>14</sup> "Charlie Gard: Doing the Right Thing for the Right Reasons" (Press Statement), The Anscombe Bioethics Centre, July 5, 2017, [http://www.bioethics.org.uk/images/user/charlie\\_gardstatement.pdf](http://www.bioethics.org.uk/images/user/charlie_gardstatement.pdf).

<sup>15</sup> Ibid.

<sup>16</sup> Austen Ivereigh, "Is British or American View of Charlie Gard Tragedy More Catholic?" *Crux*, July 25, 2017, <https://cruxnow.com/commentary/2017/07/25/british-american-view-charlie-gard-tragedy-catholic/>

<sup>17</sup> Nicole Winfield, "Pope Reverses Vatican Stand on British Sick Baby Case," *US News*, July 2, 2017, <https://www.usnews.com/news/world/articles/2017-07-02/pope-reverses-vatican-stand-on-british-sick-baby-case>.



However, it is best to accept what the Pope said as his own position; otherwise, we will make him a fame-seeking politician trying to please everyone or involved in some political conspiracy.<sup>18</sup>

Meanwhile, most American Catholics seem to agree with the Pope regardless of their faith orientation (both liberal and conservative). Nevertheless, the American bioethicists who identify themselves as conservative have happened to be most vocal about the issue, as they pronounce that the true Catholic position should be to allow the parents to choose, not the doctors or courts, criticizing the Vatican position.<sup>19</sup> One of the most trenchant criticisms of this kind may be found in an article published in the Catholic news media, *National Review*. In “The Vatican’s Statement on the Charlie Gard Case Is a Disgrace,” Michael Dougherty, its senior writer and American conservative Catholic himself, writes that Paglia’s statement is “patronizing” and “a gross distortion of the situation” because “it portrays the Gards as acting alongside the doctors, but subject to outside manipulation.” And he also argues that it entirely missed a crucial issue, i.e., the hospital and the courts had intervened against the parents’ wishes.<sup>20</sup>

This view that the primary moral problem is not giving proper attention to parental autonomy is theologically better spelled out by the statement made by National Catholic Bioethics Center (NCBC), an American conservative Catholic bioethics institute in Philadelphia, PA. In their statement on Charlie Gard published on July 7, 2017, the ethicists at NCBC render their opinion as follows. The Magisterium teaches in Paragraph 65 of *Evangelium Vitae* that it is not morally obligatory to provide extraordinary treatment, the disproportionate medical care. Also, Directive 56 of *the Ethical and Religious Directives for Catholic Health Care Services (ERD)* by the US Conference of Catholic Bishops (USCCB) says that “[p]roportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden.” Therefore, particularly “[w]ith no evidence that the continuing [NBT] interventions are physically doing harm or causing significant pain, the judgment of the patient or the patient’s proxy should be followed, rather than that of a court or hospital or insurance company.”<sup>21</sup> Therefore, the Vatican’s position, they conclude, is wrong. The NCBC’s statement also includes that the couple’s request to bring the child home to die should be respected “rather than leaving the child in the midst of hospital machinery.” However, we believe, considering the time that the statement was issued (July 7, 2018), the ethicists there were not able to access the court opinion about the issue made on July 25. The court refused the parents’ request because it acknowledged that the invasive ventilation would require a team of intensive care specialists and that the machine cannot enter the family’s home. Thus, we focused on the NCBC ethicists’ core view – that is, the parent should decide, not the doctors.<sup>22</sup>

In sum, the Pontifical Academy for Life and British Catholics believe that the court ruling in Charlie’s case is ethically licit. On the other hand, the American Catholics think that the parents should decide. This polarity has led not only the public but also Catholics in the world to be confused about the issue. Austen Ivereigh, a British Catholic journalist, writes “Is British or American View of Charlie Gard Tragedy More Catholic?”<sup>23</sup> As Ivereigh compares the divisive opinions of Catholic authority and bioethicists between the U.K. and the U.S., he leaves the question unanswered. But it seems obvious that this division is made along with the cultural membership line. We refrain from categorizing the Pope’s position by reference to culture because it requires strong evidence (which we do not have) to say that the Pope holds a culture-influenced ethical view. Other than that, the European Catholics, the Italian Paglia, and British Catholics, side with the British court while the American Catholics and bioethicists join with the parents. Nevertheless, we do not mean that culture dictates a theological-ethical stance or that religious faith is irrelevant to one’s ethical positions. Rather, we argue that cultural variation is one important factor that determines a religious person’s interpretation of the theological-ethical guideline.

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<sup>18</sup> Andrew Brown, “The War against Pope Francis,” *The Guardian*, Oct. 27, 2017, <https://www.theguardian.com/news/2017/oct/27/the-war-against-pope-francis>.

<sup>19</sup> Note that since the Pope’s dissent to the Pontifical Academy reported by the Vatican press as well as his tweets are not his utterances rendered *ex cathedra*, which are to be considered infallible according to the Roman Catholic Catechism. It is understood that the Pope’s view is considered his personal opinion. Thus, the official Vatican position should be that of the Pontifical Academy.

<sup>20</sup> Michael Brendan Dougherty, “The Vatican’s Statement on the Charlie Gard Case Is a Disgrace,” *National Review*, June 30, 2017, <https://www.nationalreview.com/2017/06/vatican-charlie-gard-statement-catholic-church-family-life-euthanasia/>

<sup>21</sup> “Statement of The National Catholic Bioethics Center on the Charlie Gard Case,” The National Catholic Bioethics Center, July 7, 2017, <https://www.ncbcenter.org/resources/news/statement-national-catholic-bioethics-center-charlie-gard-case/>.

<sup>22</sup> *Ibid.*

<sup>23</sup> Ivereigh, “Is British or American View of Charlie Gard Tragedy More Catholic?”

For example, the theological guideline of the Magisterium on Charlie’s case seems found in Paragraph 65 of *Evangelium Vitae* [EV 65]:

[It is not morally obligatory to provide] medical procedures which no longer correspond to the real situation of the patient, either because they are by now *disproportionate to any expected results* or *because they impose an excessive burden on the patient and his family*. In such situations, when death is clearly imminent and inevitable, one can in conscience “refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.” . . . It needs to be determined whether the means of treatment available are *objectively proportionate to the prospects for improvement*. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.<sup>24</sup>

Here, EV 65 does not require extraordinary treatment without specifying who should decide whether the treatment in question is extraordinary (in Charlie’s case, the parents or doctors or court/state when the agreement is not reached). However, it provides the language whereby we can discuss on who should make the final call. In the text, EV 65 defines the extraordinary treatment as the “treatment that would only secure a precarious and burdensome prolongation of life” Note that the sentence here is the EV’s affirmation of *Declaration on Euthanasia* (1980) by Congregation for the Doctrine of the Faith.

And to decide if the treatment provides merely the precarious and burdensome prolongation of life, it enjoins to take into consideration both objective and subjective aspects of it – objectively if the treatment is “disproportionate to any expected [beneficial medical] results” or “objectively proportionate to the prospects for [medical] improvement” and subjectively if the treatment imposes “an excessive burden on the patient and his family.” Although the grammatic determiner used in EV 65 is “or.” It makes theologically common sense to understand it as “and/or” because it is apparent that the sentence intends to capture both subjective and objective aspects of the topic.

In other words, the extraordinary treatment can be determined by the patient/family as they reason if the considered treatment for the dying patient will impose any excessive burdens on them in their unique circumstances which include financial problems, emotional values, spiritual concerns, etc. and/or can be assessed objectively by the physicians’ objective medical diagnosis/prognosis. Therefore, EV 65 leaves room for an individual Catholic’s interpretation of it. To resolve the ambiguity, the U.S. bishops took one step closer by stating in the Paragraph 61 of *the ERD* [ERD 61] that “patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die.”

Compared to the case of USCCB, any documented attempt to interpret EV 65 is not found in the Catholic Bishops’ Conference of England and Wales [CBCEW] or the Commission of the Bishops’ Conferences of the European Community [CBCEC] or Commission of the Episcopates of the European Community [COMECE]. Rather, the European bishops tend to honor the communal nature of the societal decision-making while acknowledging the hermeneutical sensitivity involved in the issue. For instance, the COMECE states, “For nearly 500 years, different criteria have been formulated for legitimising the withdrawal of medical treatment. The usual distinction is between ‘ordinary’ and ‘extraordinary’ means, and the criteria of futility, disproportionality and excessive burden of a treatment have been recognised, though applying them is often a sensitive issue.”<sup>25</sup>

Besides, British Catholics seem to lean towards the objective value of EV 65. For British/Europeans, their hermeneutical preference of prioritizing the objective aspect of extraordinary treatment over the subjective one stems from their conviction that the patient/family’s subjective value can only be interpreted within the limit of the social endorsement, and the society has tacitly commissioned physicians as the beneficent and impartial assessors for the sake of the common survival and thriving of the entire people. This is the kernel of the CBCEW’s statement: “all involved in these agonizing decisions have sought to act with integrity and for Charlie’s good as they see it.” Since the parental disagreement is also part of the process in which the British society decides for Charlie, all British people should respect it as their own when the British state/court decides.<sup>26</sup>

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<sup>24</sup> John Paul II, *Evangelium Vitae* [encyclical] Mar. 25, 1995. The Holy See.

<sup>25</sup> *Science & Ethics Vol. 2: Collection of Opinions*. Secretariat of the Commission of the Bishops’ Conferences of the European Community, COMECE Bioethics Reflection Group (Brussel, Belgium: COMECE, 2012).

<sup>26</sup> *Ibid.*

The characteristic difference between European and American *Catholic* bioethics is in tandem with that of European and American (secular) bioethics. As discussed above, the European culture, in general, refuses to see patient autonomy as independent from physician beneficence. And this European ethical-cultural mind is deeply reflected in the European theological thought. Many European theological bioethicists, both Protestant and Catholic, harshly criticize the American emphasis on individual/patient autonomy. The Spanish theological bioethicist, Pilar Nuñez Cubero says:

Without seeking to modify humanity as a whole, there are those who invoke a ‘principle of autonomy,’ to which they assign a supreme value, in the name of which they call for the freedom of the individual to choose the person they wish to become using new technologies, rejecting any limitation by whatever authority on achieving their desires. This ‘principle of autonomy,’ in the sense of the principle of self-determination, was put forward some thirty years ago by an American bioethics movement. Its authors acknowledged that it was poorly formulated. Anyway, it would be a massive contradiction to reject any social authority in a particular field and then call for the assertion of rights in the same field.<sup>27</sup>

Above is also the reason that, while the European Court refuses to intervene in the British ethical issues, the Italian Paglia calls for the parental concession to the state as they “must be helped to understand the unique difficulty of their situation.”<sup>28</sup>

On a further note, drawing the line between conservative and liberal Catholics to side respectively with Charlie’s parent and with British court is misleading. However, whether American or British Catholics’ view on Charlie’s case, in general, is “genuine Catholic” is theologically a valid issue, for the question is asking which culture’s lexical ranking of moral principles is closer to the Divine Truth. For the anti-metaphysical descriptivists like the bioethicists, Bernard Gert, Charles M. Culver, and K. Danner Clouser, the lexical ordering is determined by the public’s opinion emerging from a particular culture, thereby not posing any logical problem to their philosophical program.<sup>29</sup> However, in a religious system like Catholic bioethics, “who makes the final call for what treatment decision” should be made in accordance with the Metaphysical Truth. But neither the Magisterium nor *sensus fidei* nor *EV* are clear about where the Truth lies concerning the case. Within the Vatican, the Pontifical Academy and the Pope do not seem to agree with each other; outside the Vatican, British and American Catholics show different views; *EV 65* gives room for interpretation.<sup>30</sup> Accordingly, how the Church should understand Charlie’s case invites a rather extensive theological analysis for which we move to the next section.

### III. MCCORMICK-CLARK PROGRAM

#### A. McCormick's Two Guidelines of Quality of life

The theological program we will use here is a synthesized ethical device developed by the American Jesuit Bioethicist, Richard McCormick, a further revision of which is made by another American Jesuit Bioethicist, Peter A. Clark. Thus, this is an American and Catholic/Jesuit theological perspective. That being said, we do not presume to claim that the McCormick-Clark program is a culture-free or objective method of decision-making. However, we stress an analytic strength and in-depth quality that the program

<sup>27</sup> Pilar Nuñez Cubero, “On the Prospects for Human Enhancement by Technological Means” in *Human Enhancement: Scientific Ethical Theological Aspects from a European Perspective*, ed. Theo Boer and Richard Fischer (Strasbourg, France: The Church & Society Commission of the Conference of European Churches, Brussels, 2013): 240; Anestis Keselopoulos, “Drawing the Line and Expressing the Dilemma in Corrective or Plastic Surgery” in *Human Enhancement*, 184, 188

<sup>28</sup> “Vatican’s Academy for Life Issues Statement on Baby Charlie Gard.”

<sup>29</sup> Bernard Gert, Charles M. Culver, and K. Danner Clouser, *Bioethics: A Systematic Approach* (Oxford: Oxford University Press, 2006).

<sup>30</sup> Note that *Sensus fidei* is an important measure for seeking where the Divine Truth lies in all matters. It is the sense of faith exercised by the faithful (the baptized members of the Catholic Church) as a whole which includes all priests and laity of the Catholic Church. *The Catechism of Catholic Church [CCC]* describes *sensus fidei* as “the supernatural appreciation of faith on the part of the whole people, when, from the bishops to the last of the faithful that manifests “a universal consent in matters of faith and morals. . . By this appreciation of the faith, aroused and sustained by the Spirit of truth, the People of God . . . unfaithfully adheres to this faith, penetrates it more deeply with right judgment, and applies it more fully in daily life.” (CCC, 92, 93.)



attempts to exhibit, as it suggests a normative understanding of “best interests for a patient” which evolves gradually into quality-of-life criterion by asking how treatment decisions should be made for disabled newborns. The device is a patient-centered, teleological assessment based on a normative understanding of what reasonable persons ought to choose in a particular situation for the never-competent patient, infant, as quality-of-life criterion is understood as a specification of his normative understanding of “best interests.” The structure and individual components that make up McCormick's moral criterion for decision-making are normative in the sense that 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.”<sup>31</sup> From this, McCormick believes that a normative understanding of “best interests” can be found because, “as social beings, our good, our flourishing (therefore, our best interests) is inextricably bound up with the well-being of others.”<sup>32</sup> The “best interests” category, he says, 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.”<sup>33</sup>

McCormick understands the “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: first, “those that allow us to do things well, easily, comfortably, and efficiently” and, second, “those that allow us to do them at all.”<sup>34</sup> The quality-of-life criterion is ethically significant for parents and healthcare 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.

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 establishes two guidelines. The first is *the guideline of the potential for human relationships* as developed for dealing with never-competent patients focused 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.”<sup>35</sup> 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.”<sup>36</sup> 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. This does not mean that once a decision has been made to forego or discontinue treatment, 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 of palliative care. Palliative care is aimed at controlling pain, relieving discomfort, and aiding dysfunction of various sorts.

McCormick claims this quality-of-life approach has its foundation in the traditional ordinary-extraordinary means distinction that was later clarified by Pius XII. McCormick quotes Pius XII as the Pope described the extraordinary as the case where “an obligation to use any means possible would be too burdensome for most men and would render the attainment of the higher, more

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<sup>31</sup> Richard McCormick, “The Rights of The Voiceless” in *How Brave A New World?: Dilemmas in Bioethics* (Washington, D.C.: Georgetown University Press, 1981), 99 -113; McCormick, “Review of ‘Selective Nontreatment of Handicapped Newborns by Robert Weir’” *Perspectives in Biology and Medicine* 29 (Winter 1986): 328

<sup>32</sup> McCormick, “The Rights of the Voiceless,” 99-113.

<sup>33</sup> It should be noted that when McCormick refers to benefits in his best-interest category, it is not restricted to medical benefits. Benefits also apply to social and familial benefits. This notion of “benefit” originates in Bioethicist Edmund Pellegrino's four components of best interests that McCormick has incorporated into his best-interest category. See Edmund Pellegrino, “Moral Choice, The Good of The Patient and The Patient's Good” in *Ethics and Critical Care Medicine*, ed. J. C. Moskop and L. Kopelman (Dordrecht, Netherlands: D. Reidel, 1985), 117-138.

<sup>34</sup> McCormick, “A Proposal For ‘Quality of Life’ Criteria for Sustaining Life,” *Hospital Progress* 56 (September 1975).

<sup>35</sup> McCormick, “To Save Or Let Die” in *How Brave A New World?: Dilemmas In Bioethics*, (Garden City, N.Y.: Doubleday, 1981), 345, 349, 350, 351

<sup>36</sup> McCormick, “The Best Interests of The Baby,” *Second Opinion* 2 (1986): 23-24

important good too difficult.”<sup>37</sup> 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 genuine respect for the person demands attention to the prospects held out by continued life.<sup>38</sup>

McCormick’s second guideline is the *guideline for 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.”<sup>39</sup> 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.<sup>40</sup> To 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 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 to deal with contemporary bioethical problem areas.<sup>41</sup>

The reason for this reformulation of the tradition is that over the centuries the theological distinction of “ordinary-extraordinary means” 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.”<sup>42</sup> Therefore, there is a need to reformulate the basic value of human life under new circumstances. McCormick reformulates the “ordinary-extraordinary means” distinction to mean the “benefit-burden evaluation.”<sup>43</sup> McCormick writes: “it is clear that the judgments of 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.”<sup>44</sup> 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.<sup>45</sup>

In sum, medical treatments are not morally mandatory if they are either gravely burdensome or useless for the patient. In McCormick, there should be a normative understanding of medical futility, which considers whether the agreed-on potential effect

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<sup>37</sup> Pius XII. “The Prolongation of Life,” *Acta Apostolicae Sedis* 49 (1957); Leonard J. Weber, *Who Shall Live?* (New York: Paulist Press, 1976), 69, 88-98

<sup>38</sup> Lisa Cahill, “On Richard McCormick: Reason and Faith In Post-Vatican II Catholic Ethics,” In *Theological Voices In Medical Ethics*, ed. Allen Verhey & Stephen Lammers (Grand Rapids, MI.: William B. Eerdmans Publishing Co., 1993)

<sup>39</sup> McCormick, “Technology and Morality: The Example of Medicine,” *New Theology Review* 2 (November 1989): 26

<sup>40</sup> McCormick, “A Proposal For ‘Quality of Life’ Criteria for Sustaining Life.”

<sup>41</sup> McCormick, “Technology and Morality.”

<sup>42</sup> McCormick, *The Critical Calling: Moral Dilemmas Since Vatican II* (Washington, D.C.: Georgetown University Press, 1989), 365.

<sup>43</sup> Paul Ramsey, *Ethics at The Edges of Life: Moral and Legal Intersections* (New Haven, CT.: Yale University Press, 1978), 35; Robert Veatch, *Death, Dying and The Biological Revolution* (New Haven, CT.: Yale University Press, 1976), 110-112; McCormick, “The Quality of Life, The Sanctity of Life” In *How Brave A New World?* (Garden City, N.Y.: Doubleday, 1981), 393-405.

<sup>44</sup> Richard McCormick and John Paris, “Saving Defective Infants” In *How Brave a New World?* (Garden City, N.Y.: Doubleday, 1981), 358, 359, 360.

<sup>45</sup> The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C., U.S. Printing Office, March 1983), 218-219; Congregation for the Doctrine of the Faith, “Declaration on Euthanasia,” *Origins* 10 (August 1980): 263

is of any value and benefit to the newborn, that is, in the newborn's "best interests" normatively understood.<sup>46</sup> For McCormick, 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.<sup>47</sup> However, this entails that 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."<sup>48</sup>

### B. McCormick-Clark's Program

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 the ethicists like 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 *four 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.
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.<sup>49</sup>

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 the attempts to provide outlines of the areas in which prudence should operate.<sup>50</sup>

The four criteria specified his quality-of-life criterion to help enlighten medical situations for the appropriate decision-makers. However, even specified by the concrete norms as such, his two guidelines of quality of life criterion cannot cover all circumstances and every possible situation for it requires 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)."<sup>51</sup> 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 healthcare professionals further in medical decision-making for handicapped newborns, five specific diagnostic treatment categories of handicapped newborns have been established by Bioethicist Peter Clark, one of the authors of

<sup>46</sup> Richard Sparks, *To Treat Or Not To Treat?: Bioethics And The Handicapped Newborn* (New York: Paulist Press, 1988), 110; Donald McCarthy, "Treating Defective Newborns: Who Judges Extraordinary Means?" *Hospital Progress* 62 (December 1981): 45-50; John Connery, "Prolongation of Life: A Duty And Its Limits," *Linacre Quarterly* 47 (May 1980): 151-165.

<sup>47</sup> 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; Glenn Griener, "The Physician's Authority To Withhold Futile Treatment," *Journal of Philosophy and Medicine* 20 (April 1995): 209.

<sup>48</sup> Richard McCormick and John Paris, "Saving Defective Infants"

<sup>49</sup> *Ibid.*

<sup>50</sup> *Ibid.*

<sup>51</sup> *Ibid.*

this paper. 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 mentioned earlier. McCormick has plotted the two extreme positions on this spectrum of handicapped newborns but has left the "conflictual middle" to be filled in by healthcare professionals and bioethicists.<sup>52</sup> 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. 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. We shall call the device "McCormick-Clark's Five Diagnostic Treatment Categories" the content of which is as follows:

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 relationship, 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.<sup>53</sup>

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."<sup>54</sup> The establishment of these five diagnostic treatment categories is an attempt to meet the challenge set before healthcare professionals and bioethicists to assist parents and medical professionals in making treatment decisions for handicapped newborns.

#### IV. MORAL VERDICT BY MCCORMICK-CLARK PROGRAM

In Charlie's case, the medical professionals have ascertained that Charlie has Infantile Onset Encephalomyopathic Mitochondrial DNA Depletion Syndrome (MDDS) also known as RRM2B Mutation of MDDS. This condition that begins in infancy affects multiple body systems. Charlie has severe brain damage, frequent seizures, progressive muscle wasting, and respiratory failure necessitating mechanical ventilation for survival. He is also blind, deaf and cannot swallow. There is no known cure for this condition. The prognosis is death in early infancy, as weakening of the intercostal muscles causes respiratory failure. At 11 months of age, the medical authorities treating Charlie at Great Ormond Street Hospital believe Charlie is suffering and his death is imminent. However, what added to the controversy is the experimental therapy offered by Dr. Michio Hirano's Nucleoside Bypass Therapy (NBT). "NBT works by providing an oral medication that contains the naturally occurring compounds that MDS patients cannot produce themselves. The pill which has to be taken daily provides patients with deoxythymidine monophosphate (dTMP) and deoxycytidine monophosphate (dCMP); as it requires continual treatment, the therapy cannot be considered a 'cure.' The treatment has already

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<sup>52</sup> McCormick, "To Save Or Let Die."

<sup>53</sup> Peter 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).

<sup>54</sup> McCormick, "The Best Interests of The Baby," *Second Opinion* 2 (1986).

been used to treat 18 MDS patients with some level of success, which is why it was considered carefully for Charlie's case."<sup>55</sup> The court in London rejected the experimental therapy because it had never been tested against RRM2B-related MDS in any animal, including mice. Typically, the treatment has been used against a different form of MDS that results from thymidine kinase 2 (TK2) deficiency and even in those cases, the patients were not as deeply affected as Charlie. After Dr. Hirano evaluated Charlie and an additional MRI was done, it was determined that the experimental treatment would no longer be effective, because the scan showed Charlie had suffered muscular atrophy and the damage was irreversible.<sup>56</sup>

Ethically, the use of this experimental therapy raises the question about under what conditions should parents allow children to receive experimental treatments. Some ethicists have questioned whether parents can give informed consent considering that the short- and long-term benefits/risks/consequences are often unknown. There is also a very fine line when the physician for the child is also the primary researcher. This can lead to potential conflicts of interest academically and financially. One could argue that, while the experimental treatment has a small possibility of helping Charlie directly, it could offer certain advantages for others in the future and benefits for society as whole. Clearly, there is no moral obligation to use an experimental treatment, but in this case one can question the role social media played in influencing the parents. In the end, the court ruled against the treatment because there is no evidence that the drug treatment has the ability to cross the blood-brain barrier.<sup>57</sup> Considering all these medical facts and applying the McCormick-Clark Category, it appears that Charlie would fit under Diagnostic Category Four.

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.

In this category, since the potential for human relationships is present, McCormick's second guideline of his quality-of-life criterion (that is, the benefit-burden evaluation) would be applied to determine whether Charlie ought to be treated or not. 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. Examining Charlie's condition with all his comorbidities, it appears that he is in the dying process. Any aggressive treatment would be medically futile. 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 Charlie 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. Charlie is in a terminal state and further aggressive treatments will only prolong the dying process. Both social and familial factors, especially being in the United Kingdom with their universal health care system, ought to play a proportionate role in determining the benefit/burden evaluation.

Again, when Charlie has the potential for human relationships but after initiating treatment, it becomes apparent that the treatment is medically futile, his parents in consultation with healthcare professionals are not morally obliged to continue medical treatment. That is, 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 outweigh the benefits to the infant. Therefore, in the "best interests" of Charlie, and all concerned, the parents in consultation with healthcare professionals have the moral obligation to forgo or withdraw treatment for their child in these circumstances. As reasonable people,

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<sup>55</sup> Francis Addison, "Charlie Gard and Mitochondrial DNA Depletion Syndrome." *Front Line Genomics* (July 10, 2017): 1, 4-7, <http://www.frontlinegenomics.com/news/13145/charlie-gard-mitochondrial-dna-depletion-syndrome>.

<sup>56</sup> "Arturito Estopinan – Boy Inspiring Charlie Gard's Parents." *Tkscures.com*. Accessed Mar. 3, 2018, <http://www.tk2cures.com/in-the-news/feature-world/>

<sup>57</sup> Addison, "Charlie Gard and Mitochondrial DNA Depletion Syndrome."



Charlie's parents should be considered most knowledgeable about the family situation in which Charlie will be raised in the light of financial, emotional, and social factors. Also, the parents can weigh and balance the religious and cultural values that inform their decision-making. GOSH physicians and other researchers have specialized medical knowledge and clinical expertise that can assist the parents in the decision-making process. They have a level of objectivity that parents may lack because of the overwhelming emotional stress of the situation. Together, parents and healthcare professionals can determine what are the appropriate needs of the baby, to assess these needs, and to determine whether medical treatment is in the infant's best interests "integrally and adequately considered."

## V. CONCLUSION

McCormick-Clark program affirms the view of the general American public and American Catholics. The parents should have the final call, not the doctors. However, the reason for that is, as it has been so far stressed, not that an individual autonomy should be the king of all moral principles as American culture dictates it, but that parents, unless proven irrational, are situated in the position to act in the best interests of their infants which includes knowledge about the family environment into which the baby will be raised in the light of financial, emotional, and social factors, and also of the family's religious and cultural ethos. In other words, the parental views represent not only subjective as well as objective values, though not medically objective values, in the best interests of their infants. Accordingly, in the McCormick-Clark program, the moral status of parents as their infants' surrogate decision-makers cuts across the subjective and objective domains in decision-making process.

On the other hand, the McCormick-Clark program affirms the ruling of the British High Court that the parents should have decided not to pursue the futile experimental treatment but let the baby die in peace, and shares the Vatican's concern that the parents "must be helped to understand the unique difficulty of their situation and not be left to face their painful decisions alone. If the relationship between doctor and patient (or parents as in Charlie's case) is interfered with, everything becomes more difficult and legal action becomes a last resort, with the accompanying risk of ideological or political manipulation, which is always to be avoided, or of media sensationalism, which can be sadly superficial."<sup>58</sup> In other words, those surrounding the parents which include GOSH physicians, independent specialists, bioethicists, must help them free from the media's confusing coverage and the manipulation of political interest groups and come to understand that Charlie is in the dying process. Nevertheless, we emphasize again that the decisions should come from the parents.

This is fundamentally an American program borne out of the Roman Catholic/Jesuit theological tradition. Thus, it is not our claim that the proposed McCormick-Clark thesis is a culture-free or objective method of decision-making because it is philosophically absurd for any proposed methods to allegedly achieve those qualities. However, we stress an analytic strength and in-depth quality that the program attempts to exhibit in its *effort of normatizing* the criteria of pediatric decision-making beyond the culture-laden ethical discussions, which our readers may appreciate.

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<sup>58</sup> Vatican Radio. "Vatican's Academy for Life Issues Statement on Baby Charlie Gard."

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