Essay

Decision making in neonatal end-of-life scenarios in low-income settings¹

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The challenge of decision making in end-of-life scenarios is exacerbated when the patient is a newborn and in a low-income setting. The principle of proportionate care is a helpful guide but needs to be applied. The complex interplay of benefit, burden, and cost of various treatments all need to be considered. In patients with severe neonatal encephalopathy, prognosis can be hard to determine, and a team approach to decision making can help. In low-income settings, or where there are limited resources, the ideal care needs to be incarnated in the real context. Issues of social justice also arise as finite resources need to be used prudently.

Summary: Decisions regarding medical care become difficult when the patient is a seriously ill newborn baby. In the developing world, scarce medical facilities and minimal economic resources also limit possible treatment options. The Catholic Church offers practical ethical principles which can help the medical team and family to strive to do what is morally best in these difficult situations.

Keywords: Newborn, Neonatal encephalopathy, Decision making, Proportionate means, Social justice

¹Decision making in end-of-life scenarios can be difficult. When a loved one is sick and emotions are running high, families can be physically tired, and clinical outcomes are not always predictable. A helpful ethical principle for decision making at the end of life is that of proportionate means.

AVOIDING EXTREMES: THE PRINCIPLE OF PROPORTIONATE MEANS

In the *Ethical and Religious Directives for Catholic Health Care Services* we find:

A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate

means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community. (USCCB 2009, dirs. 56–57)

Using this principle, we hope to avoid two obvious extremes: on the one hand euthanasia² and on the other therapeutic obstinacy or futile care where instead of helping one simply prolongs the dying

process. One has to carefully navigate the good ship “patient care” between these two extremes. It is interesting to note that it is often “easier” to continue support, even if it prolongs the dying process and is actually “futile,” than to discontinue disproportionate means when death may be the result.

Aristotle’s so-called doctrine of the mean also may come in handy. He introduces it in his *Nicomachean Ethics*, and it has become a key tenet of virtue ethics. The doctrine of the mean avoids the extremes, called vices: one set of “vices” to avoid here are euthanasia on the one hand and over-aggressive or futile care on the other. The medical team and family instead seek to follow the virtuous middle path. This is not an arithmetical mean, but rather a carefully judged response to the concrete situation at hand. Considering the cost of treatment proposed, it may not mean to pay zero and withdraw all financial support, or to spend \$10,000 (which, if grossly excessive, may be a vice). The doctrine of the mean does not result in a proposal to spend \$5,000 (the arithmetical mean), but in a given context to spend \$1,000 and in another \$8,000. It leads one to make a reasoned judgment on the matter of how much to spend in the particular circumstances. Aristotle suggests that we should consider questions such as: is this the right time, about the right things, toward the right people, for the right end, and in the right way? (Aristotle 1953, bk. 2, chap. 6 [1106b]).

THE ROLE OF THE CONSCIENCE

Aristotle noted that vice can obscure our moral vision (Aristotle 1953, bk. 6, chap. 12 [1144a]).³ Vice could be understood at various levels:

- At the level of society, when legislators actively push for euthanasia legislation as is happening in Canada and various countries now;
- At the level of the hospital, which, seeking to maximize profits, too easily proposes treatments that may not be strictly medically necessary;
- At the level of the doctor, who, influenced by favors received from pharmaceutical companies, too readily prescribes their treatments/products;
- At the level of the family, who, experiencing emotions unbridled by reason, insist that “everything be done” even if the treatment would cause harm.

The locus of decision making, where the doctrine of the mean is worked out, extremes avoided, and the virtuous path sought, is the conscience. Catholic moral theology acknowledges the vital role our conscience plays in decision making. The *Catechism of the Catholic Church* notes:

Conscience is a judgment of reason whereby the human person recognizes the moral quality of a concrete act that he is going to perform, is in the process of performing, or has already completed. (Catechism 1997, no. 1778)

Conscience includes the perception of the principles of morality (synderesis); their application in the given circumstances by practical discernment of reasons and goods. (Catechism 1997, no. 1780)

A well-formed conscience can assist medical decision making. In my experience many doctors are unfamiliar with the principle of proportionate means and often experience hesitation and uncertainty when dealing with end-of-life decisions.

THE PARTICULAR CASE OF THE GRAVELY ILL NEWBORN

St Alphonsus Liguori, the Catholic patron saint of moral theology, wrote about the challenge of applying moral principles to particular cases. In one moment he explained the task of the confessor, stating that the confessor has the role of a doctor of the soul; to identify the spiritual sickness of the person and prescribe the treatment. “Who would deny that all cases have to be resolved with principles? But herein lies the difficulty: to apply to particular cases the principles appropriate to them” (Liguori 1755, no. 17).⁴ The doctor at the bedside is similarly faced with the challenging task of applying to a particular case, the relevant medical principles. How to apply the (general) principle of proportionate means to this patient (particular case) in front of me?

Perhaps the usual ethical and clinical context for the application of the principle of proportionate means is in elderly patients nearing the end of their lives (or acutely ill adults in grave condition). The situation is exacerbated when the patient is a newborn as we presume they would have more years of life ahead of them. It is one thing to apply the principle when the patient is 90 years old, but what if they are just 9 days old or 9 hours old? I would like to apply the principle of proportionate means to critically ill neonates in end-of-life scenarios. When specificity is needed by way of highlighting a point, I will refer to the condition of neonatal encephalopathy, a “major contributor to global childhood mortality and morbidity” (Wilkinson 2010, e451). Applying the principle of proportionate means I will consider the aspect of benefit, burden, and cost in determining whether to pursue a given line of treatment or not in a critically ill neonate.⁵

The clinical report on “Hypothermia and Neonatal Encephalopathy” from the American Academy of Pediatrics indicates the type of gold standard care an infant with hypoxic-ischemic encephalopathy can expect:

Medical centers offering hypothermia should be capable of providing comprehensive clinical care, including mechanical ventilation; physiologic (vital signs, temperature) and biochemical (blood gas) monitoring; neuroimaging, including MRI; seizure detection and monitoring with aEEG or EEG; neurologic consultation; and a system in place for monitoring longitudinal neurodevelopmental outcome. (American Academy of Pediatrics 2014, 1149)⁶

With such a gamut of treatments, how is one to assess “benefit” and “burden” in an infant of a few days old? Primarily one could consider the burden to the infant and also the burden to the family, and perhaps even to the society. With complex treatment paths, should one take each modality one by one, such as burden of ventilation, burden of hypothermia, and so on, and then do a kind of summation?⁷ Here the Church offers helpful advice on how to proceed, listing various elements of treatment planning and suggesting to evaluate

the type of treatment to be used, its degree of complexity or risk, its cost and the 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. (CDF 1980, part IV)

Usually a doctor in practice would consider the collective burden of the whole treatment package and, if funds are lacking, may be able to offer a tailored package

such that vital treatments can be sustained and subsidiary ones omitted.

Complex questions may include how to assess the “burden” of a future disability. The child may not be able to express a verbal opinion and the assessment would fall on the parents and carers.⁸ Many times this child, with concomitant disabilities, is considered a real blessing by their families. However there also exist unfortunate scenarios where the carers are left unsupported – with minimal assistance to help ease their heavy burden of care.

Cost and financial limitations

The consideration of cost becomes especially problematic in low-income countries where often the financial burden of health care falls largely on patients and their family.⁹ Some examples can help further situate a reader who is not familiar with the challenge of offering good neonatal care in a developing world context.

- In the Philippines, full supportive care and ventilation of a neonate costs approximately \$200 per *day* in a government hospital. This can pose a tremendous financial strain on families where the usual *monthly* wage is only US \$300.¹⁰
- Here in a government neonatal unit in the Philippines, there are many who qualify as “charity patients” – those who belong to a poor family and thus do not have to pay for the hospital stay, any operation costs or doctors’ fees. The family only has to pay for medicines and/or additional treatments such as surfactant. When the premature child needs surfactant (usually one vial would suffice, or at most two) the cost is 20,000 Philippine pesos (approximately \$400). If they cannot afford this, the child usually will spend longer on the ventilator or does not survive.
- When a child needs ventilation, it can be provided for free to a charity case. However, the parents still need to buy the necessary tubing to allow their child to be

connected to the ventilator. The tubing costs \$60 – \$80. Until they find this money, the family or relatives will have to handbag the baby. The hand bagging may last for a few hours to more than 24 hours, until the funds are found.

- For babies with hydrocephalus, ideally a CT (computerized tomography) scan would be performed post-delivery and a ventriculo-peritoneal (VP) shunt eventually placed to drain excess fluid from the ventricles of the brain. Here the parents will have to find the money for both the CT scan (around \$100) and the VP shunt (around \$300). Often it takes some two weeks or more before the CT scan is performed and many more weeks for surgery. While the parents look for funding, frequently, the baby will become sick.

In these and many other similar situations of scarcity, unable to afford the “gold standard” care, the family and attending medical team sadly, but realistically, may have to settle for silver or bronze.

Decisions and prognosis

Decisions based on foreseeable benefit are difficult because outcomes may be unpredictable: “The major problem that confronts those caring for infants who have hypoxic-ischemic encephalopathy is how to provide families with reliable information about outcome.... The difficulty lies in how long to pursue treatment in infants who may have a very poor prognosis” (Allan 2002, e108). It may be difficult in the period of initial injury to give clear information regarding prognosis but as “the neonatal illness progresses over the first few days, more information becomes available, and the accuracy of prediction of outcome of survivors improves” (Robertson and Perlman 2006, 279). Magnetic resonance imaging (MRI) is often used to provide prognostic information in severe

hypoxic-ischemic encephalopathy but its overall usefulness and reliability remains to be fully ascertained (Wilkinson 2010).

Where health resources are not readily available, it may not be possible to perform MRI scans or do an EEG to confirm brain activity or death. Here the medical team can rely only on a clinical judgment of brain death.¹¹ At times mechanical ventilation and full support may be continued in a brain-dead infant seemingly in direct contradiction to the principle of proportionate means. One reason for this is that the parents may not be able to accept immediately the death of their beloved newborn and the support is continued to allow a few more days to allow the parents more time to take in the situation and to grieve. In the Philippines it is common for one parent to be working overseas. More time may be needed to allow them to arrive before disconnecting the ventilator. The continued ventilation and support of a braindead baby may be judged “disproportionate,” but disproportionate treatments are optional, and some circumstances such as the aforementioned, may indicate their continuation for a short period of time.

Doctors also may feel uncomfortable when confronted with end-of-life dilemmas for a variety of reasons. Gloth observes that “without formal training, physicians can feel impotent in addressing the palliative needs of end-stage patients” (Gloth 2011, 75). Perhaps the training in medical school was lacking, or simply was more technical than ethical, such that the doctor later feels insecure and hesitant in addressing any moral conundrums.

At times the medical situation is not ideal: doctors may wish to prescribe a certain treatment according to their training or in line with the latest recommendations from developed world settings. A doctor can be inspired reading the latest guidelines on end-of-life issues from a highly specialized palliative care unit overseas, but in his setting he may have difficulty to put the guidelines

in practice. Here in the Philippines there are no palliative care units, only a palliative care service. Sometimes the ideal treatment is unavailable, or if it is available it might be unaffordable to the family. The doctor may face a dilemma of conscience knowing what he or she could do in an ideal situation but facing real-world limits. There is an obvious tension here between what the doctor would like to do and what he or she can actually do in practice.

This tension can weigh heavy on the doctor’s conscience but he or she can be reassured and encouraged to do the best in the given situation: the moral judgment regarding a particular medical case always needs to be incarnated in the actual context. As Pope Francis noted “There also exists a constant tension between ideas and realities. Realities simply are, whereas ideas are worked out. There has to be continuous dialogue between the two, lest ideas become detached from realities” (Francis 2013, no. 231).

Additionally, there may exist a grey zone in which the proper course of treatment is uncertain. In some situations treatment is clearly to be pursued, and in others, clearly wrong. In between there exists a grey zone. In these situations time may be helpful. The neonatal ICU could be offered for a fixed time, such as one week, to allow the progress of the child to be more carefully assessed. However, where limited resources exist, one may be forced to make premature medical decisions with greater uncertainty. In general families can be encouraged to do what they can.

Breaking the news

Various hospital groups, such as the Queensland Maternity and Neonatal Program, have clinical guidelines, which include advice that can be given to parents when discussing aspects of hypoxic-ischemic encephalopathy (Table 1; Queensland Department of Health 2016, 20):

Table 1 *Hypoxic-ischaemic encephalopathy*

Incidence	About 1–4 in 1000 newborn babies suffer from the effects of reduced blood flow or oxygen supply to their brain around the time of birth.
Consequences	<ul style="list-style-type: none"> • This can result in brain damage from direct injury and also from subsequent secondary changes within the brain. • These secondary changes are known to increase the amount of brain injury that occurs. Within 6 hours from injury there is a chance to lessen the secondary changes.
Prognosis	<ul style="list-style-type: none"> • Babies with mild brain injury often have a normal outcome. • Approximately 30 to 60 percent of those babies who survive after more severe damage to their brain may develop long-term disabilities. These disabilities include cerebral palsy and severe learning difficulties.

The Royal Children's Hospital in Victoria, Australia, has produced a handbook called *Caring Decisions* to assist parents facing end-of-life decisions for their child (Wilkinson et al. n.d.). In front of the decision to "Do not attempt resuscitation" (DNAR) the parents may ask, "Will I be a bad parent if I agree to a DNAR order for my child?" The response in *Caring Decisions* is "No. If life support is not helpful, or will do more harm than good, the best and most loving decision is to make sure that a child is kept comfortable" (Wilkinson et al. n.d., 12).

Feelings of guilt

Feelings of guilt are commonly observed in families with a sick newborn. Some feel they did something wrong or that they should be doing more. This can lead to insistence on providing over-aggressive, disproportionate means.

Doctors should try to understand the dilemma of the family but avoid being bullied also. The authors of *Caring Decisions* note, "Sometimes when doctors talk to families about life support treatment, parents reply that they want 'everything done.' It is natural to feel this way. The doctors and nurses will do everything they can to help your child. But some treatments are not helpful. It is really important that doctors avoid doing things that would harm your child" (Wilkinson et al. n.d., 13). When treatment needs to be discontinued, the family should be supported through the process, and helped to understand that the most caring decision might be to "let their loved one go." They can be comforted in this difficult moment by the objective teaching of the Church: "Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment. Here one does not will to cause death; one's inability to impede it is merely accepted" (Catechism 1997, no. 2278).

Feelings of guilt may also be found among doctors. At times doctors themselves can be confused and unclear of the difference between withdrawing disproportionate treatment and euthanasia. In *Evangelium vitae*, Pope John Paul II explained

Euthanasia must be distinguished from the decision to forego so-called "aggressive medical treatment," in other words, medical procedures that 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.... 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. (John Paul 1995, no. 65) ¹²

It can also help if delicate topics are addressed with time, not waiting for catastrophic moments to begin the sensitive dialogue, but foreseeing and actively anticipating the need. In this way parents, and relatives, have time to assimilate the gravity of the situation. Multi-disciplinary dialogues, in the form of case conferences, are helpful, where the family can meet and discuss their child's care with representatives of the various teams involved, including doctors, nurses, speech therapy, physiotherapy, and the like. The presence of a person from the hospital bioethics committee and a religious representative such as a priest may also be indicated. At times, difficult decisions can be confronted more readily through a team approach.

Preferential option for the poor and social justice

One important principle from Catholic social teaching is the so-called "preferential option for the poor." Pope John Paul II described it as "an option, or a special form of primacy in the exercise of Christian charity, to which the whole tradition of the Church bears witness" (John Paul II 1987, no. 42). This challenges us to give a preferential consideration to the poor and those "without medical care" (John Paul II 1987, no. 42). Pope Francis in *Amoris laetitia*, his recent exhortation on love in the family, also calls our attention to those who suffer because of a lack of access to "adequate health care" (Francis 2016, no. 44). Living out this preferential option for the poor, many doctors here in the Philippines admirably attempt to raise funds to help pay for the medicines and hospital bills of their

poor patients. They offer not only part of their "spare time" to do this (up to half a day's work for certain patients) but even a part of their own salary in the search for everything from donor breast milk, diapers, examinations, tests, even up to life saving equipment.

The Catholic bishops of the Philippines remind us of the social aspect of justice in health care. In number 1039 of the *Catechism for Filipino Catholics* we hear, "However, when there is no real hope for the patient's genuine benefit, there is no moral obligation to prolong life artificially by the use of various drugs and machines. In fact, using *extraordinary means* to keep comatose or terminally ill patients artificially alive seems clearly to lack objective moral validity, especially in a society where the majority of the population do not enjoy even adequate elementary health care" (Catechism for Filipino Catholics 1997, no. 1039). In the setting of a government hospital here in the Philippines, many patients are provided care by the hospital's social services. In needlessly pursuing disproportionate means, families may not only be draining their own limited resources, but that of the hospital as well – which resources could instead be used to benefit other charity patients in need. Charles C. Camosy nicely summarizes the interplay of responsibilities telling us that all persons "have a right to a proportionate amount of the community's resources – and a duty to refrain from using a disproportionate amount" (Camosy 2010, 92).

Overview of scenarios

It is not possible to present the varied and multiform clinical situations one may encounter in a child with hypoxic-ischemic encephalopathy. However, before we wrap up our discussion, it may be beneficial to present some paradigmatic

scenarios amidst a myriad of clinical possibilities. The following situations are by no means exhaustive but may be helpful as reference points. For each scenario a brief course of action is suggested.

- The child is treatable and the family can afford the treatment. Here the choice is obvious to offer the treatment so that the child can recover.
- The family has a limited budget so treatment should be tailored to match their resources. The situation here is more difficult, and needs to take into account the prognosis, resources available, and the possibility of obtaining additional resources. Spiritual and ethical guidance, for example from a priest, may be particularly helpful in this situation to both guide the family to an ethical decision and lessen any guilt they may feel from being unable to afford the highest level of care.¹³
- Severe brain injury with uncertain prognosis – here a limited time trial of treatment can be offered. When the moment of decision arrives one option may be to withdraw treatment (considered disproportionate) knowing the child's death will ensue.¹⁴ At times it can be hard for the medical staff to confront the possibility of death (or even future serious disability) of a neonate and difficult to discuss these issues with the family members: "One difficulty a physician may face is broaching the topic of discontinuing care with the patient's family – in a sensitive manner that will not cause undue feelings of helplessness, anger or even indifference from the family."¹⁵ Clinicians need to communicate the relevant information in a way that is open, honest, truthful, thoughtful, and compassionate.
- The child may recover but afterward have a severe cognitive and physical deficit. In low-income settings, the family can really struggle to care for such a child. Often supportive services such as physiotherapy or speech therapy may be sadly lacking or usually non-existent if the patient lives at any distance from the major hospitals. The

saving grace in the Philippines is that families are often large and inter-generational, living under the same roof. At times the care is done by a sibling, relative, or even a neighbor, offering some respite to the primary carer.

- The parents may insist on treatment that the medical team considers disproportionate. The doctor may be constrained by limited resources and feel it wholly inappropriate to pursue over-aggressive care in such a futile situation. Where a strong and irreconcilable difference of opinion exists between the family and the medical team, and the situation cannot be resolved, transfer to an alternative hospital may have to be considered. However, this may be "a wholly unsatisfactory resolution since the ethical dilemma is not 'solved' by moving it to another location" (Linacre Institute 2007, 261).

CONCLUSION

At times decision making in medicine is challenging and complex, especially when the patient is newborn and the decision may mean life or death. The principle of proportionate means is helpful but it needs to be applied. In low-income settings not all prognostic data may be readily available. Doctors have to strive nobly to do their best in limited situations. Having to keep in mind an ideal but live in the real world can be a source of tension in the carers. Extremes should be avoided, and doctors should not be coerced into providing treatments that harm or prolong the burden. Where resources are limited, issues of social justice should be taken seriously.

NOTES

1. A shorter version of this paper was delivered by the author at the 3rd international convention of the Philippine

- Society of Newborn Medicine, "Cutting Edge Neonatology: Applications in the Developing World," February 1–3, 2017, in Manila, Philippines.
2. The Groningen Protocol, reported in the *New England Journal of Medicine*, chillingly states the various conditions required to actively end the life of a suffering newborn. While such a protocol would clearly contravene the doctor's principle of "do no [further] harm," the authors do recognize that "discussions regarding the initiation and continuation of treatment in newborns with serious medical conditions are one of the most difficult aspects of pediatric practice" (Verhagen and Sauer 2005, 959). Presenting the position paper of the American College of Pediatricians, Vizcarrondo roundly critiques the Groningen Protocol stating, "Taking the suffering person's life is not the solution to the pain and suffering that are part of the dying process. The taking of innocent life is never a moral act. Neonatal euthanasia is not ethically permissible" (Vizcarrondo 2014, 392).
 3. Thomson translates Aristotle here as "Now the supreme good appears such only to the good man, for vice gives a twist to our minds, making us hold false opinions about the principles of ethics" (Aristotle, trans. By Thomson 1953, 167–8).
 4. My translation, from the Italian text "Chi nega che tutti i casi si hanno da risolvere coi principi? Ma qui sta la difficoltà: in applicare a' casi particolari i principi che loro convengono."
 5. I have found the mnemonic "BBC" helpful to explain the main criteria of the principle of proportionate means when speaking to doctors and healthcare workers.
 6. A plethora of literature exists in pediatric journals on the use of therapeutic hypothermia for hypoxic-ischemic encephalopathy. For low-income settings, the work of Shankaran (such as Pauliah et al. 2013), Galvao (Galvao et al. 2013), and Montaldo (Montaldo et al. 2015) is helpful. One challenge faced by doctors in poor countries is that to institute therapeutic hypothermia, prior blood-gas analysis is essential. However, blood-gas analysis machines are often scarce in low-income settings. In cases of neonatal hypoxic-ischemic encephalopathy, the gold standard care in a U.S. context for severely affected infants might consist of "mechanical ventilation, anticonvulsants, antibiotics, corticosteroids and pressor medications for blood pressure support, and IV fluids. Hypothermia for 72 hours (whole body cooling to ~93 degrees Fahrenheit) is now standard of care in the United States. In the U.S., knowing the extent of brain damage and prognosticating about the associated outcomes require having access to MRI scanners to delineate the extent and severity of the brain damage. Sometimes the severely affected never recover the ability to be normal and need treatments like tracheostomy and gastric tube placement." Dr Tom Bender, Division of Medicine Neonatal-Perinatal Medicine, Department of Pediatrics, Saint Louis University School of Medicine, St. Louis, Missouri, USA. Email correspondence with author, January 12, 2016.
 7. O'Rourke asks "Are two criteria used when evaluating medical therapy, or are benefit and burden to be combined?" (O'Rourke 2005, 547). Perhaps in low-income settings we have to ask "Are three criteria used when evaluating medical therapy, or are benefit, burden and cost to be combined?"
 8. Marcussen notes that the quality of life of a newborn is not easy to assess. He writes "Judgments of well-being in cases of selective nontreatment are often made on the basis of how parents measure what their sense of well-being would be in that circumstance, based on their development and past experiences. The development of the child would be a completely separate and different experience, and the child's experience of overall well-being would likely be different than that of the parents, should their parents ever find themselves in similar circumstances." (Marcussen 2014, 3). This may also be of relevance in regard to the challenge of trying to assess future burdens.
 9. The problem of cost is not often considered in many moral or theological reflections, especially when the reflection is done in a first-world setting. In low-income settings, and especially when

the state funded healthcare system is inadequate, people do not even go to the hospital in the first place. If they do go, their treatment is usually sub-optimal as they are unable to afford medical items, such as a one-unit blood transfusion, which in the first world can be taken for granted.

10. In the private hospital setting in Manila, ventilation and full support of a sick neonate is \$1000 per day. For an insightful video about the effects of poverty on neonatal health care as well as a beautiful testimony of how a Catholic doctor can respond, see the account of Dr Enrique M. Ostrea Jr., M.D., Professor of Pediatrics, Wayne State University, at <http://www.youtube.com/watch?v=uugTQ0wZWJA>.
11. There are no unified criteria worldwide for brain death (Wahlster et al. 2015).
12. In low-income settings, families may run out of funds and have to discontinue the life sustaining treatment of their child. Occasional reports exist of attending doctors being hesitant to withdraw the endotracheal (ET) tube as they fear litigation and that they are “committing euthanasia.” Instead they ask the family to withdraw the ET tube. This practice is to be strongly discouraged and doctors should assume responsibility for their patients.
13. Unfortunately, a priest with knowledge of end-of-life moral issues in the pediatric setting is not always available. In some countries, there are Catholic moral bodies that offer a telephone service for ethical consultation. It would be a genuine act of Christian charity if they could also make their services more accessible to those working in low-income settings.
14. O’Rourke notes, “In order to justify forgoing life support, the burden must be judged to be excessive. Determining an excessive burden is often a difficult process. All medical care is a burden in one sense. But an excessive burden makes striving for the continuation of life, or an important good of life, a moral impossibility - or at least very difficult” (O’Rourke 2005, 545–6).
15. Dr. Mackie Quiazon, a former pediatric resident at a government hospital in

Manila. Email correspondence with author, March 1, 2016.

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