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Catholicism in the Neonatal Context: Belief, Practice, Challenge, Hope

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Religion and Ethics in the Neonatal Intensive Care Unit

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Catholicism and the Neonatal Context

Chapter: Catholicism and the Neonatal Context

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On October 16, 2000, thirty-two weeks pregnant with twins, I sat in my office, preparing my lecture for the afternoon session of my undergraduate course entitled “Christian Ethics and Health Care.” I had taught this course every semester for six years. I was preparing my remarks on a chapter I had taught almost every semester, the first chapter of Margaret Morhmann’s short book, *Medicine as Ministry*.¹ Morhmann is a pediatric intensivist as well as a theologian-bioethicist who spent decades on faculty at the University of Virginia medical school, including an appointment in the Center for Biomedical Ethics and Humanities.

The first chapter of *Medicine as Ministry* is entitled “God Is One: The Temptations of Idolatry.” Here, Morhmann explores the relationship between a central claim of the monotheistic faiths—that God is One—and our choices, decisions, and actions in the clinical context. She lifts up the Shema of the Jewish tradition—“Hear O Israel, the Lord our God, the Lord is One!”—and the first commandment of the Judeo-Christian tradition: “I am the Lord your God who brought you out of the land of Egypt, out of the house of slavery; You shall have no other gods before me.”² She

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explores whether the current structures of medicine honor these claims, or whether they instead embody a deep idolatry—a worship of the false gods of medical technology or health or life or, perhaps, of the demiurge, death.³ In support of her challenge, she quotes Mother Teresa, elaborating on an observation the saint once made upon visiting a neonatal intensive care unit (NICU) in the United States:

Mother Teresa, for one, has called the neonatal intensive care units that populate American hospitals “obscene”; she could as easily have called them “blasphemous.”⁴

I took great pleasure in teaching this passage because undergraduates of all stripes generally love Mother Teresa. Consequently, they are quite taken aback to hear her criticize something that seems, on its face, to be so good—neonatal medicine. That afternoon, I was ready yet again to hit them with this challenge, to shake up their given conceptual frameworks, and to demonstrate how theology can destabilize taken-for-granted assumptions and open up new as-yet-unasked questions.

I never made it to class. Twenty-four hours later, I found myself sitting between two isolettes in the NICU of Kettering Medical Center—a hospital in the Seventh-day Adventist tradition—isolettes that housed my two newly born, two-month-premature babies. Like most parents of preemies, I had never expected my babies to arrive early. I had never expected to be whisked into the high-tech world of neonatal medicine, to sit on the sidelines while others monitored and managed a dizzying array of my children’s bodily functions and overall well-being, to be consulted on a daily basis as the *de jure* decision maker, rubber-stamping in my hormone-bathed mental state the daily recommendations of the truly outstanding neonatal care team.

But, unlike most parents of preemies, I sat amid this whirlwind not only as a mother but also as a Catholic moral theologian and medical ethicist. I had taught cases akin to many that populated the other isolettes around me. I knew well the principles that applied—both the principles of biomedical ethics and the principles of the Catholic moral tradition. And as I sat there day after day for almost a month, I found myself saying a number of times: “Mother Teresa says this is obscene. Margaret Mohrmann suggests it might be blasphemous.”

Needless to say, it was a rather surreal experience to be a Catholic theologian, a medical ethicist, *and* the mother of premature twins all in the same moment. It was akin to being both a vulnerable refugee in a strange country where one neither speaks the language nor knows the customs and being an anthropologist among the natives or an embedded journalist, all at the same time. My brain oscillated between the biologically driven compulsion to do everything so that my children would survive—all the while analyzing, observing, documenting, critiquing.

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After the children came home, the anthropologist was put on the backburner. There were more pressing things to deal with than the practical, theological, and ethical dynamics of the NICU. My reflections in this chapter mark the first time I have written about neonatal medicine since that unexpected immersion experience. In what follows, I leave most of my anthropological insights to the side. Yet, my NICU experience as a mother-theologian-scholar inevitably lies in the background whenever I approach these questions. And, while sharing many commonalities, this experience was not like that of all NICU parents: apart from being born at thirty-two weeks, my children were never really in any grave peril, at least as far as we knew. True, my son was not breathing and may not have had a heartbeat when he was born, but the excellent staff remedied that rather quickly. My daughter had a pneumothorax, but it resolved itself within 24 hours. The children were small but not tiny—1,640 and 1,950 grams, respectively—chubby babies by NICU standards. They mostly needed to learn how to eat and fatten up so that they could self-regulate their body temperatures. My daughter eventually needed an apnea monitor, but truth be told, it made those first months of parenting easier. They stayed at the hospital for roughly three weeks. And they have no developmental or other sorts of disabilities. They are healthy, athletic, smart, and flourishing. Thus, our experience was neither one of critical ethical dilemmas nor negative sequelae.

Catholicism and Neonatal Medicine: Contours and Complexities



In this chapter, I have been asked to focus on one very specific topic: Catholicism in the neonatal context. As the editors of this volume have noted, currently, there is little or no literature available within the discipline of biomedical ethics to assist neonatal caregivers in understanding how religious beliefs and values might influence parents' responses to the challenges posed by their newborn's care.⁵ Equally, there is little or no literature available within the disciplines of academic or pastoral theology addressing questions of neonatal medicine. My contribution here seeks to address the question: in what ways might the teachings and religious practices of the Roman Catholic tradition inform the ways in which parents and caregivers make treatment decisions about the high-risk newborn infant?

Let me begin by providing some background on Catholicism in the United States. For decades, Catholics have comprised approximately 22% of the US population, with approximately seventy million Catholics living in the United States today.⁶ This makes Roman Catholicism the largest single religious denomination in the United States. Although Catholic presence varies geographically, a sizeable proportion of the patient census in most hospitals will likely be Catholic. The growing edge of the Roman Catholic Church in the United States is the Hispanic or Latino Catholic population; as of February 2013, nearly half of Catholics in the United States younger than forty years were Hispanic (46%). This cohort is of childbearing age.

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Given ongoing issues of access to health care (even with the Affordable Care Act), compounded by immigration politics and the socioeconomics of race, many women in this cohort will continue to receive inadequate prenatal care, resulting in potentially higher rates of prematurity and other issues that will land them and their babies in the NICU.

Thus, a significant number of Catholics make their way through the doors of the NICU in the United States. On simply a percentage basis, roughly 125,000 premature babies born each year in the United States will have a Catholic parent. Yet, simply because a patient or family identifies with a particular religious tradition does not mean that the teachings, beliefs, and practices of that tradition necessarily influence their actions and decisions or influence the actions and decisions of all members of a tradition in the same way. There is a preponderance of Catholics in the United States, but the ways in which these seventy million people inhabit Catholicism certainly vary.

Immigrants and foreign visitors aside, American Catholics—just like most of the rest of the people who walk into the clinical setting—are often more deeply formed and informed by the traditions of US culture, their profession, and their socioeconomic class than by their faith tradition. For example, while civil divorce is generally considered a grave, morally illicit offense per Catholic teaching,⁷ divorce rates among Catholics are lower than other groups in the United States, but not by an overwhelming margin.⁸ Catholics cite lower rates of abortion than their Protestant counterparts in the United States, reflecting the Catholic Church's opposition to abortion, but again not by a large margin.⁹ Pew Research in 2013 found that roughly 50% of Catholics support both same-sex marriage and keeping abortion legal.¹⁰

Like many long-lived religious traditions, one finds a spectrum of adherence. Roughly 40% of Catholics attend Mass on a weekly basis; 17% go “seldom or never,” with the remaining 43% all over the map.¹¹ Various groups adhere strongly to one part of the tradition or another. There are the visibly evangelical Catholics who identify with the Church's teachings on marriage and life so much so that we used to be able to say they were “right of the Pope.” There are the social justice Catholics who are passionate about the Church's social justice tradition but have no time or patience for the Church's teachings on marriage and sexuality. There is a sizeable middle ground who are deeply faithful in practice and who do their best to hold both of these poles together. There are those who pray the rosary and believe in Marian apparitions; there are those who join the Maryknolls and do mission work in Central and South America. Then add the immigrant populations, where Catholic belief and practice have been interwoven for centuries with particular cultural traditions, and it gets very complex. Or, as we often say, Catholicism is a Big Tent.

Yet, Catholicism does present one decided advantage over many other religious traditions: Catholicism has developed an authoritative body of literature on key questions related to medicine and health care to which

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clinicians, the faithful, and others can turn for (relatively) clear guidance. In addition to a two-thousand-year tradition of saints, theologians, and developing wisdom, Catholics have a century's worth of papal encyclicals, apostolic exhortations, pastoral letters, and other documents issued by authoritative persons or bodies to which we can refer to try to clarify what the Church actually teaches on a given topic.

For the purposes of this chapter, I will draw largely from one very short document, *The Ethical and Religious Directives for Catholic Health Care Services*.¹² The *ERDs*, as they are often called, distill in pamphlet form basic convictions of the Catholic tradition and a set of directives or guidelines that provide the parameters for the ethical practice of medicine within Catholic healthcare institutions. The *ERDs* are designed to be a resource for all who work in Catholic health care as well as for patients and families who wish to make decisions consistent with their Catholic faith while situated in other-than-Catholic healthcare contexts.

Additionally, over the past two millennia, Catholicism has developed a rich and extensive set of liturgical traditions that are deeply inhabited by most Catholics. Sacramental practices, augmented by artifacts of material culture (such as images of Our Lady of Guadalupe for Latino/a Catholics or the Sacred Heart of Jesus for Catholics of European descent), are critical resources for many Catholics in times of illness, discernment, and death. When faced with a medical crisis, even Catholics who seldom attend Mass—or who may not have set foot in a church for decades—will instinctively turn to the sacraments and rites of the Church for comfort, for strength, for tradition, or for reasons unknown even to them.

Thus, demographically, “Catholicism” is not a monolithic entity but, rather, provides a complex and varied landscape; theologically and liturgically, Catholicism is a richly contoured tradition that provides a multiplicity of resources for patients, families, and caregivers to draw on. In the NICU, this complex and contoured religious tradition meets an equally multifaceted clinical reality. Neonatal cases vary widely. Charles Camosy, in his book, *Too Expensive to Treat? Finitude, Tragedy, and the Neonatal ICU*, helpfully groups neonatal patients into four categories:

- Full-term babies with acute illnesses
- Babies with congenital anomalies
- Babies with prematurity
- Babies with extreme prematurity

The types of issues encountered with neonatal patients may vary from category to category. While it would be most useful to examine how the Roman Catholic tradition might be applied to specific cases in the previous categories, in what follows, I will primarily provide an overview of the teachings and practices of the Roman Catholic tradition that are broadly applicable across categories. Ideally, readers of this volume could meet together with their pastoral care and ethics staff to explore how

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these teachings and practices might illuminate specific cases they have encountered in their own clinical contexts.

Roman Catholic Principles in the Neonatal Setting



For caregivers working with Catholic parents and decision makers in the neonatal setting, seven fundamental convictions or areas of teaching of the Roman Catholic tradition would be most relevant: (1) understandings of the moral and religious status of the premature infant or newborn; (2) teaching on patient decision making; (3) guidelines regarding withholding and withdrawing treatment; (4) developments with regard to medically assisted nutrition and hydration; (5) teaching on the care and treatment of conditions considered incompatible with life; (6) advocacy of palliative care; and (7) teaching on the care of dead bodies, including burial, autopsy, and organ donation.

The Dignity of the Human Person

Despite the variety of ways Catholics inhabit their tradition, it is safe to say that most Catholics are grasped by a deep, almost embodied commitment to the value of human life and the dignity of the human person.¹³ This conviction will be an operative factor in the discernment process of many Catholic parents. Especially with the papacy of John Paul II, this unwavering commitment to the dignity of the human person and the sanctity of human life gained a new visibility. For the *ERDs*, it is the foundational principle.

First, Catholic healthcare ministry is rooted in a commitment to promote and defend human dignity; this is the foundation of its concern to respect the sacredness of every human life from the moment of conception until death. The first right of the human person, the right to life, entails a right to the means for the proper development of life, such as adequate health care.¹⁴

Within Catholicism, there is a spectrum of adherence to this conviction. At one end are the vitalists, who insist on maintaining human biological life under any and all conditions, at any and all costs (a position not exclusive to Catholicism, by the way). As we will see later, the Catholic tradition is *not* vitalist, but there are self-identified Catholics who inhabit this position. At the other end of the spectrum are those, such as Catholics for Choice (formerly known as Catholics for Free Choice), who engage in advocacy efforts to advance access to safe and legal abortion services.¹⁵

Most Catholics inhabit a middle ground—they see human life as a holy thing, a unique image of God, and see each living person as having inherent dignity and worth regardless of social location, disability, age, health status, and so on. Importantly, the Catholic tradition does *not* define “personhood” as consisting in certain capacities or even potential for capacities, as is often the case in secular bioethics. From the moment

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of conception until “natural death,” each and every human being *is* considered to be a *person*, a creature of God, someone loved by God and therefore to be loved by us, regardless of their social utility, the costs of their care, how “disabled” they might be, or what potential for such disability there might be.¹⁶ In fact, there is a sense in the Catholic tradition that the more vulnerable a person is, the greater the obligation to treat them with respect and dignity.

Most parents—Catholic or not—understand their neonate to be not only a *baby* but also a *person*.¹⁷ This perspective will shape the ways in which they care for their infant as well as the decisions they make about treatment options. They will generally expect hospital staff to do the same, regardless of their baby’s condition. It is encouraging to see the evolution of language used with regard to neonatal patients, at least within the field of bioethics. No longer discussed under the heading of “handicapped newborns” or “defective neonates,” the language has shifted to “the high-risk neonatal patient.” This change in language signals a conceptual advance that sees the child not primarily as *defective* but, rather, hopefully, as a patient with inherent dignity and worth. In all interactions with neonatal patients and their families, the Catholic tradition would encourage all caregivers to envisage and treat neonates as unique persons of value and to support parents as they do the same.

Patient Decision Making in Catholic Perspective

How do or ought religious beliefs factor into patient decision making from a Catholic perspective? Some, at times, wish to draw a dichotomy between “autonomy” and “heteronomy” in moral decision making. A Catholic perspective would challenge drawing this distinction too sharply. Contra Kant, all morality really is heteronomous. It is a rare (or perhaps nonexistent) moral principle or moral framework that a person can make up oneself. With few exceptions, we all adopt moral principles from “outside” ourselves. Consider the principle of utility, for example—John Stuart Mill coined this one, and most of us have imbibed it as an eternal truth from our culture. It often possesses a power over us that is difficult to resist. So it is with all moral principles. Especially because morality inherently has a social function, all morality is heteronomous. Thus, patient decision making across traditions is much more nuanced than either heteronomy or autonomy—and therefore more complicated and messy.

The *ERDs* understand the patient–physician relationship—and therefore the decision-making process—to be a collaborative endeavor. The Bishops open Part Three of the *ERDs*, entitled “The Professional-Patient Relationship,” with a rich account of this mutual collaboration:

A person in need of health care and the professional health care provider who accepts that person as a patient enter into a relationship that requires, among other things, mutual respect, trust, honesty, and appropriate confidentiality. The resulting free

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exchange of information must avoid manipulation, intimidation, or condescension. Such a relationship enables the patient to disclose personal information needed for effective care and permits the health care provider to use his or her professional competence most effectively to maintain or restore the patient's health. Neither the health care professional nor the patient acts independently of the other; both participate in the healing process.¹⁸

It is within this shared context that the Catholic tradition locates the centrality of voluntary, informed patient decision-making. As the *ERDs* note:

Free and informed consent requires that the person or the person's surrogate receive all reasonable information about the essential nature of the proposed treatment and its benefits; its risks, side-effects, consequences, and cost; and any reasonable and morally legitimate alternatives, including no treatment at all.

Each person or the person's surrogate should have access to medical and moral information and counseling so as to be able to form his or her conscience.¹⁹

What we hear here is that patients—or, in the neonatal context, patients' families—are charged with the task of making *informed* decisions. These decisions should be informed by a variety of sources. The medical facts and economic realities are first and foremost. In deciding whether to pursue a particular treatment, parents are enjoined to take into consideration "its benefits; its risks, side-effects, consequences, and cost." Health care professionals are enjoined to provide this information to parents in a way they can understand and in a nonbiased manner.

This empirical information enters into the ongoing process of formation of conscience. Conscience is considered almost sacrosanct within the Catholic tradition. It is that central human intellectual and moral faculty that interprets and reasons through particular situations in light of moral principles. In the words of the Second Vatican Council, "Conscience is the most secret core and sanctuary of a man. There he is alone with God, Whose voice echoes in his depths."²⁰ One's conscience must be formed well in order to function well. Ideally, conscience is formed on an ongoing basis by information, prayer, and consultation with others—family, friends, healthcare professionals, and clergy. Relevant information includes medical and economic information as well as familial and social commitments and Church teachings.

Thus, religious beliefs should enter into parental decision making in the neonatal context as one component of a careful process of reasoned discernment, or perhaps as an integrative framework that helps structure how the various components are related to each other. Such a decision-making process is far from formulaic. While communal and collaborative, the ultimate decision is finally the province of the patient or, in this case,

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the patient's parents. In this way, the Catholic respect for the dignity of the human person translates into a respect for conscience, productively integrating what might otherwise be construed as autonomy and heteronomy.²¹

Withholding and Withdrawing Treatment

Most Catholics are quite familiar with the Church's teaching on the dignity of the human person and conscience. Many, however, are not aware of the Church's teaching on withholding and withdrawing treatment; many others misunderstand it. Against those who take a vitalist position, Directive 28 makes clear that a viable treatment option may be "no treatment at all."

The Catholic tradition on withholding and withdrawing treatment is a clear, nuanced, well-established, five-hundred-year old position. It is summed up succinctly in the *ERDs*:

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.²²

These two Directives succinctly capture key convictions:

- Human life is a fundamental good—a gift, a holy thing! If it can be saved or prolonged using *reasonable* means, one has a moral obligation to do so.
- The locus of decision making is, again, the patient, or in the neonatal context, the parents.
- "Benefit," notably, is not defined; it is not limited to a "reasonable hope of extending biological life." What constitutes "benefit" is left to the judgment of the patient; the assessment of benefit must be *reasonable*, but the *Directives* make clear that benefit is determined relative to the medical condition and conscience of the patient.
- Likewise, "burden" is not defined. It must simply not be *excessive*, and reasons should be given for that judgment.
- Expense to the patient's family or community may legitimately be taken into account, even rendering an "ordinary" means "extraordinary."
- Human persons are finite; death is an inevitable reality for all.

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- And last, medical treatments may be declined or removed. Not all “means of preserving life” are morally obligatory.

Within this framework, those interventions that offer a reasonable hope of benefit *and* reasonable burden and cost are *always* obligatory. One should always pursue the good if one can, within reason. But note the conjunctions in the directives. One has no obligation to pursue treatments if one of the conditions does not obtain: if there is not a reasonable hope of benefit; *or* if the burdens would be excessive; *or* if the intervention would impose excessive expense on the family or community.

Benefit and burden have long been understood broadly in the Catholic tradition. A patient is permitted to take into account psychological, social, spiritual, familial, and financial dimensions of any treatment protocol. Pope Pius XII clarified two additional nuances in 1957, noting:

But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important goods too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty. . . . On the other hand, since these forms of treatment go beyond the ordinary means to which one is bound, it cannot be held that there is an obligation to use them nor, consequently, that one is bound to give the doctor permission to use them.²³

Per the Pontiff, a *medical means* is not ordinary or extraordinary in and of itself; that determination is based in part on the patient’s overall circumstances. And, in keeping with the Thomistic tradition of Catholicism, Pius identifies a hierarchy of goods, with the physical goods of health and even life being subordinated to—and “ordered to”—the pursuit of spiritual ends.

Human life is a great and wonderful good—sacred, sanctified, with inherent dignity. It is to be loved, respected, protected, and promoted. But it is *not an absolute*.²⁴ As natural death draws near, it is not obligatory to prolong biological life at all (or even significant) costs. As the Vatican noted in its 1980 *Declaration on Euthanasia*, refusal of disproportionate treatment “is not the equivalent of suicide” but rather “should be considered an acceptance of the human condition.”²⁵ This document affirms that patients may withhold or withdraw certain forms of medical treatment that “would only secure a precarious and burdensome prolongation of life.” The *Catechism of the Catholic Church* suggests that to fight death “at all costs” may in fact be morally problematic:

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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. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.²⁶

The *Catechism* here highlights one of the points of tension within the application of Catholic teaching on withholding and withdrawing treatment. For the teaching, as it developed over most of its five-hundred-year history, presumed the patient would be the one making the calculation about burdens and benefits relative to herself or himself. For most of this five-hundred-year history, there were few decisions to be made by families about patients. Over the past forty years—and particularly in the neonatal setting—this has changed dramatically. And this is where it becomes the most difficult. It is one thing for a patient to decline a course of treatment because it may impose excessive expense on his family; how can a surrogate make that same decision without devaluing the life of the neonate because he or she is disabled or expensive or inconvenient?

Thus, in practice, in the neonatal setting, definitions of benefit and burden have necessarily narrowed somewhat. In all instances, the Catholic tradition holds, “those whose lives are diminished or weakened deserve special respect. Sick or handicapped persons should be helped to lead lives as normal as possible.”²⁷ Thus, if a medical intervention can help move a child toward a reasonable level of functioning—even with disability, expense, and ongoing medical support—that intervention may well be ordinary and obligatory. If a medical intervention promises little benefit in terms of advancing function *or* would impose an excessive burden *on the patient* or is proving *excessively* expensive to the family, then it may well be extraordinary and not required.

Such evaluations must be made by parents in collaborative consultation with the medical staff, family, friends, and perhaps even clergy based on the good of the patient and the patient’s best interests. But the good of the child and the good of the parents are deeply intertwined. We see this acknowledged, again, by Pius XII in his address cited earlier, where he comments on the morality of discontinuing resuscitation:

The rights and duties of the family [with regard to decision-making] depend in general upon the presumed will of the unconscious patient if he is of age and *sui juris*. Where the proper and independent duty of the family is concerned, they are usually bound only to the use of ordinary means Consequently, if it appears that the attempt at resuscitation constitutes in reality such a burden for the family that one cannot in all conscience impose it upon them, they can lawfully insist that the doctor should

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discontinue these attempts, and the doctor can lawfully comply. There is not involved here a case of direct disposal of the life of the patient, nor of euthanasia in any way: this would never be licit. Even when it causes the arrest of circulation, the interruption of attempts at resuscitation is never more than an indirect cause of the cessation of life, and one must apply in this case the principle of double effect and of “voluntarium in causa.”

While Catholic teaching on withholding and withdrawing treatment does not mandate extraordinary treatment, it also does not prohibit it. Parents may validly choose for their children what others may consider to be extraordinary treatments. While futile or vitalist interventions are discouraged by the Catholic tradition, caring for the disabled may be understood as a powerful form of witness. Families who choose to care for children with significant health issues ought to be supported by the communities in which they are located.

Medically Assisted Nutrition and Hydration

Few are not aware of the battles that have raged within the Catholic tradition over the past fifteen years around the question of medically assisted nutrition and hydration (MANH). For the most part, the argument has focused on patients in persistent vegetative state.²⁸ How might Church teaching on MANH apply to the neonatal context?

Until 2009, Catholic teaching on MANH generally followed the overall guidelines for withholding and withdrawing treatment outlined previously. But, subsequent to the Terri Schiavo case, and a brief address by Pope John Paul II to a conference on “Life Sustaining Treatments and the Vegetative State” held at the Vatican in 2004, the issue of MANH has become more contested. In this address, John Paul II stated:

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.²⁹

Some were concerned that in seeming to name a particular medical intervention as ordinary and proportionate in all situations, John Paul II was contradicting five hundred years of Catholic tradition. Yet, a more careful reading of the statement in context allays concerns. Importantly, the document applies only to patients in persistent vegetative states. To take this passage out of context and apply it to all patients would be a misinterpretation of the document.

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At issue is the normal care due to the sick; Catholic teaching is clear that one must never abandon care for a seriously ill or dying patient. In many cases, the initiation of MANH in patients in crisis is the standard of practice; it is a standard intervention in the neonatal setting, usually intended as a short-term intervention designed to bridge neonates to the point at which they can develop the sucking reflex and coordinate sucking and swallowing (approximately thirty-four weeks' gestational age). For some impaired newborns, however, MANH becomes permanent. For severely impaired newborns, or those whose medical issues become critical before thirty-four weeks, questions may be raised about discontinuing tube feeding.

Directive 58 of the *ERDs* provides the parameters for addressing such situations. As the Bishops note:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.³⁰

The Directive sets the question within the fundamental context, namely, that (in the words of the *Catechism*), “those whose lives are diminished or weakened deserve special respect. Sick or handicapped persons should be helped to lead lives as normal as possible.”³¹ In most situations, the administration of nutrition and hydration—either through traditional means or medically assisted—provides reasonable benefit with reasonable burden; in most situations it is *ordinary* and therefore obligatory. But circumstances can change. The same intervention that initially was ordinary may, because of the changing situation of the patient, become “morally optional” or extraordinary. If MANH—alone or in conjunction with other interventions—becomes, in the estimation of the parents, excessively burdensome for the patient, or if the usual battery of medical interventions does little more than impede death, MANH may become morally optional.

Fundamentally, the main question is: what is the purpose or aim of the withdrawal of MANH or any other intervention? Is the treatment being removed because it is not effective or because it is imposing an excessive burden on the patient? Or is it being removed in order that the patient

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will die? At issue here is the intention and the real goal or end. The Catholic tradition retains a commitment to the distinction between allowing death to come versus deciding for death (a.k.a., euthanasia, assisted suicide). Euthanasia, as defined by the Catholic tradition, is “an action or an omission which of itself or by *intention causes death, in order that all suffering may in this way be eliminated.*”³² In other words, it is legitimate to withdraw treatment if there is a problem with the treatment (insufficient benefit, excessive burden); it is not legitimate to withdraw treatment because there is a problem with the patient (impairment or suffering). It is legitimate not to fight death at all costs; it is not legitimate to bring death forward.

At work here are two aspects of the Catholic tradition often obscured by our culture. The first is that the Catholic moral tradition is more one of *character* than of *consequences*. The Catholic moral tradition has for centuries forwarded a virtue ethic, an ethic that evaluates actions based not only on their outcomes or consequences on others or in the world but equally based on their effect on the character of the agent. Premised on a complex account of human moral psychology, all actions are understood to have a reciprocal effect on the person who commits them. All actions we commit are understood to shape us—our wills, our dispositions, our bodies, the interpretive lens through which we view the world—in particular directions, toward or away from certain fundamental goods. In doing so, each action trains us more easily to commit similar actions in the future. The more I commit a particular action, the more it becomes a habit.

This character or virtue framework informs Catholic teaching on end-of-life care. A key question is: how will a particular end-of-life action affect the character of the decision maker? Acts of euthanasia, where an agent actively pursues or brings forward death (an end that diminishes human flourishing), are understood to habituate that person to more easily carry out further acts of killing. They habituate and reinforce certain character traits—efficiency, expediency, control—that may be at odds with fundamental Christian virtues. Allowing a patient to die, when death is imminent, however, is understood to aim toward a different goal and inculcate a different set of virtues. To accept death’s imminence is not to aim toward or to seek death; it is, rather, to simply acknowledge an inescapable part of reality. To allow death to come often requires actions that inculcate the virtues of patience (death often will not be hurried or work on our own timetable), of charity (the gift of self offered by being present to the patient through attention and caregiving), of hospitality (welcoming the patient despite his or her anomalies or impairments), or of prudence (as one constantly evaluates care options in the face of the patient’s demise).

Thus, actions and decisions in the neonatal context ought (from a Catholic perspective) to be evaluated in part relative to the effects of those actions on the character of medical staff and parents. The Catholic tradition also challenges those in the neonatal context to evaluate the lens through

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which they perceive imperiled patients. It pushes back against what has often been perceived as a subtle but advancing cultural lens that values efficiency, economics, and control over the lives of human persons. This mindset is at times referred to as the “culture of death.” Pope John Paul II in his 1995 encyclical *Evangelium Vitae* describes this mindset as:

. . . a veritable structure of sin. This reality is characterized by the emergence of a culture which denies solidarity and in many cases takes the form of a veritable “culture of death.” This culture is actively fostered by powerful cultural, economic and political currents which encourage an idea of society excessively concerned with efficiency. Looking at the situation from this point of view, it is possible to speak in a certain sense of a war of the powerful against the weak: a life which would require greater acceptance, love and care is considered useless, or held to be an intolerable burden, and is therefore rejected in one way or another. A person who, because of illness, handicap or, more simply, just by existing, compromises the well-being or life-style of those who are more favoured tends to be looked upon as an enemy to be resisted or eliminated. In this way a kind of “conspiracy against life” is unleashed.³³

While it is true that the taking of life not yet born or in its final stages is sometimes marked by a mistaken sense of altruism and human compassion, it cannot be denied that such a culture of death, taken as a whole, betrays an individualistic concept of freedom, which ends up by becoming the freedom of “the strong” against the weak, who have no choice but to submit.³⁴

For John Paul II, the culture of death is a subtle force, driven by powerful yet often invisible economic factors and masked by “a mistaken sense of compassion,” which justifies eliminating persons with illness and disabilities. Persons with disability complicate society’s drive toward ever-greater efficiency, productivity, and economic growth. Yet, within a Catholic perspective, *our* personhood—the personhood of the strong—calls us toward a greater solidarity with those who are vulnerable, poor, weak, and in need. As the *ERDs* note,

Catholic health care should distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of our society and makes them particularly vulnerable to discrimination. . . . In particular, the person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons.³⁵

Neonatal medicine is one of the first instances of this solidarity in the lives of most high-risk infants.

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Persons or Conditions? Conditions “Incompatible with Life”

Catholic teaching and theologians have rarely addressed questions of infants with conditions deemed “incompatible with life,” presuming that the principles outlined earlier are sufficient. However, questions surrounding the treatment of anencephalic fetuses have been disputed within the Catholic tradition for at least the past thirty years.³⁶ The main areas of disagreement have primarily concerned prenatal interventions—namely, is it morally licit to terminate a pregnancy once a diagnosis of anencephaly is made?

The US Catholic Bishops weighed in definitively on this question in 1996 with their statement, “Moral Principles Concerning Infants with Anencephaly.”³⁷ Reaffirming the dignity and personhood of anencephalic fetuses, they concluded that:

It is clear that before “viability” it is never permitted to terminate the gestation of an anencephalic child as the *means* of avoiding psychological or physical risks to the mother. Nor is such termination permitted after “viability” if early delivery endangers the child’s life due to complications of prematurity. . . . Only if the complications of the pregnancy result in a life-threatening pathology of the mother, may the treatment of this pathology be permitted even at a risk to the child, and then only if the child’s death is not a means to treating the mother.

Yet, the Bishops are not vitalists. They do not argue that, postpartum, all efforts to extend the biological life of anencephalic infants ought to be employed. Rather, they affirm the practice of solidarity as noted previously:

The anencephalic child during his or her probably brief life after birth should be given the comfort and palliative care appropriate to all the dying. This failing life need not be further troubled by using extraordinary means to prolong it. It is most commendable for parents to wish to donate the organs of an anencephalic child for transplants that may assist other children, but this may never be permitted before the donor child is certainly dead.

This reasoning would apply to other infants with congenital conditions that are generally fatal within the first month of life, such as Meckel-Gruber syndrome, various chromosomal abnormalities, Potter syndrome, and Trisomies 13 and 18. For conditions such as Tay-Sachs disease, in which symptom onset is later, reasonable medical treatment would be indicated, following Directives 57 and 58.

Palliative Care

Catholic teaching on conditions “incompatible with life” signals the importance of palliative care in the neonatal context. Palliative care in the neonatal or perinatal setting remains a growing edge of this important

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movement within medicine. Ideally, palliative medicine should become a norm in the neonatal context, insofar as new developments in palliative medicine reject the former distinction between “doing everything” for the patient and “doing nothing but pain management” (hospice). Palliative medicine, as it is now understood, has expanded beyond only end-of-life care to the holistic treatment of all patients with life-threatening or chronic diseases.³⁸

The World Health Organization (WHO) definition of palliative care captures its many dimensions.³⁹ Recently, the WHO has further articulated what palliative medicine means specifically in the care of children, noting:

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO’s definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.⁴⁰

Thus, consistent with the broader field, palliative care in the neonatal context should be provided to all neonatal patients; it does not signal that the patient is necessarily terminal and entails equally care for the patient’s family.

Out of concerns about euthanasia and the culture of death, some within the Catholic tradition have been slow to accept the validity of palliative care in general.⁴¹ Yet, many Catholic hospitals have been leading the way in implementing palliative care, given its deep resonance with the best of the Catholic tradition,⁴² and Catholic magisterial writings have recently affirmed the importance of palliative care. As the *Catechism* notes:

Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and

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tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged.⁴³

Similarly, the work of Pope-Emeritus Benedict XVI highlights the convergence between the WHO definition of palliative care and the Catholic tradition. Benedict names palliative care as “a right belonging to every human being, one which we must all be committed to defend.”⁴⁴ He sees it as providing “integral care, offering the sick the human assistance and spiritual accompaniment they need.”⁴⁵ And he understands palliative care as a medical practice inextricably tied to spiritual accompaniment.⁴⁶

Catholic parents facing the shock of the NICU may be unfamiliar with the practice of neonatal palliative care. They should be counseled that it is deeply consistent with the Catholic tradition.

Care for the Dead: Burial, Autopsies, and Organ Donation

A brief word about Catholic teaching regarding care for the dead is worth including here. As noted previously, the protection and promotion of the dignity of neonatal patients is central to the Catholic tradition. At all times, the bodies of such patients—perinatal, living, dying, or dead—should be treated with the respect accorded all human persons. Roman Catholic canon law recommends that the remains of deceased persons be buried, although cremation is not prohibited.⁴⁷ The *Catechism* teaches that the bodies of the dead must be treated with respect and charity, noting the burial of the dead as one of the corporal works of mercy.⁴⁸ Such respectful treatment extends to fetal remains, whether the result of intentional abortion, miscarriage, or some other form of premature fetal demise. As Catholic ethicist Ron Hamel makes clear, fetal remains should never be considered or treated merely as medical waste.⁴⁹ In addition, as he notes:

Also of great importance is the pastoral care of the parents who have experienced a tragic loss. As part of this care, parents should normally be the ones to arrange for the disposition of the remains of their fetus. If, for some reason, the parents are not able to do this, the hospital should then arrange for disposition, carefully informing the family of the hospital’s procedures and ensuring that the family is comfortable with them.⁵⁰

Hamel also provides a model policy on how to deal with fetal demise due to miscarriage or stillbirth.⁵¹

A related question is that of autopsy. Especially in complex neonatal cases, an autopsy may be warranted to determine an actual cause of death, or a particular infant may help advance the scientific understanding of her or his specific condition. Again, autopsies, respectfully done, are consistent with Catholic teaching. As the *Catechism* states: “Autopsies can be morally permitted for legal inquests or scientific research.”⁵²

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Equally, organ donation and transplantation are supported by Catholic teaching. This is noted in both the *Catechism* (§2301) and the *ERDs*:

Catholic health care institutions should encourage and provide the means whereby those who wish to do so may arrange for the donation of their organs and bodily tissue, for ethically legitimate purposes, so that they may be used for donation and research after death.

Such organs should not be removed until it has been medically determined that the patient has died. In order to prevent any conflict of interest, the physician who determines death should not be a member of the transplant team.

The use of tissue or organs from an infant may be permitted after death has been determined and with the informed consent of the parents or guardians.⁵³

Thus, although autopsies and organ donation may not be the norm in most neonatal contexts, the Catholic tradition finds both to be acceptable practices as long as parental consent is obtained and the deceased infant is treated with the respect accorded a person with dignity.

Catholic Practices and Neonatal Care



While the teachings of the Catholic tradition shape many Catholic patients and families as they face medical crises, it is the case that, frequently, many Catholics are not familiar with the intricacies and nuances of Catholic teaching. Most Catholics, however, even—and sometimes, especially—lapsed Catholics are deeply familiar with the sacraments and sacramental practices of the Catholic tradition. These practices, often learned at a young age and learned in embodied and community-based ways over a lifetime, can have a more powerful effect on Catholic patients and families. How parents proceed with regard to medical decisions surrounding their infant children may, in the end, not be a matter so much of *what* is to be done medically but *how* it is done—not so much a matter of *what* decision is made but *how* they and their children are treated by the hospital and staff.

Practices and gestures that recognize parents and children as valued, relational beings are critical. And the ability for families to incorporate religious practices into the care of their imperiled children should be encouraged. Not only is this a matter of good patient care, but also allowing families to embed their children and the issues raised in their care in a larger framework shaped by ritual and sacrament may facilitate decision-making processes. In the final sections of this chapter, I would like to briefly discuss four key Catholic practices relevant to the neonatal context: baptism, anointing of the sick, prayers and blessings, and practices surrounding bereavement and funerals.

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Baptism

The Catholic tradition endorses general good practice: that parents' understanding of their neonates as their children, as members of their family, as small *persons* with dignity requiring love and care should be recognized and nurtured at all times by healthcare staff. As with full-term healthy babies, parents should at all times and places be supported in their requests to see and hold and be present with their baby and should be offered opportunities to create identities and memories, even in the NICU. The bodies of babies—living or dead—should be treated with respect at all times.

More specifically, the Catholic tradition provides specific resources to families that if done well can help parents form their consciences. Baptism, for example, is an appropriate practice for all live-born babies, regardless of age, birth weight, or medical condition. Baptism affirms the sanctity and dignity of the infant—inviting the child into full membership in the Church regardless of illness or disability. But it also affirms the reality of death—for in baptism, Christians are baptized into the death of Christ. Granted, this is not usually emphasized during most baptismal ceremonies, but when performed well, the rite should equally emphasize reality and hope and should provide a spiritual and conceptual framework for the possibility that their child may be overmastered by their condition. When a priest or deacon is not available, anyone (even a nonbaptized person) may baptize with the consent of the parents.⁵⁴

The issue of baptism for children who are stillborn or have died is a sensitive one. Canonically, the Catholic Church prohibits the baptism of those who have already died. For parents who wish baptism for their deceased child, a sensitive medical and pastoral staff should craft a middle ground event that encompasses all parties—including, perhaps, but not limited to, renewal of baptismal promises for the parents, the blessing and commendation of the child, and the blessing and commendation of the healthcare staff.

Anointing of the Sick

The Sacrament of the Anointing of the Sick is another potential practice with application to the neonatal context. Thoroughly revised after the Second Vatican Council forty years ago, the new understanding of the Sacrament of Anointing of the Sick (formerly Extreme Unction, which was reserved only for the dying) sees the rite as one *for the sick*. It entails anointing with blessed oil and laying on of hands together with prayers for healing and strength. In many ways, the practice of the Sacrament is in flux. Again, the Canon Law of the Church limits the Sacrament of Anointing to those baptized Catholics, gravely ill, who have “reached the age of reason,” which is generally interpreted to be around six or seven years old. Other traditions akin to Roman Catholicism—including Orthodox Christianity and Eastern Catholic rites—do not have this limitation. And in pastoral practice, priests will often perform the

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Sacrament for sick children and their families. In instances where a priest will not anoint a child, there are many prayers that can be drawn from the rite (formally entitled *Pastoral Care of the Sick*), and more general ceremonies of prayer and blessing for the child, family, and caregivers can be developed.⁵⁵

Like baptism, the Sacrament of the Sick practiced in the neonatal context should help family discernment by not shying away from the realities of grave illness and the real possibility of death while also reminding parents and caregivers that grace will surround their child both in death and in life. Both baptism and anointing also value, in important ways, the bodies of neonates, affirming the goodness of their bodies, even with pain, disability, and multiple medical interventions.

Prayers and Blessings

At all times, making space for ongoing prayer and blessings in the NICU, for and with the babies and families, is deeply consistent with the Catholic tradition. Rosaries, prayer cards, pictures of Our Lady of Guadalupe—the myriad aspects of material, religious culture—can be deeply sustaining to parents navigating the often frightening, uncomfortable, and intimidating environment of the NICU. These are especially important for parents from immigrant or ethnic communities for whom the US hospital may be particularly foreign and frightening. The rite of the *Pastoral Care for the Sick* includes a number of prayers and blessings for the sick, including a Blessing for Sick Children, which can be used by anyone at any time a blessing seems called for.⁵⁶

Bereavement and Funerals

Attending to bereavement and mourning for parents who experience the death of a child in the neonatal context is extremely important. Many studies report that parents who experience perinatal death—late-term pregnancy loss, stillbirth, or infant death within the first month—find themselves bereft of many of the usual material social supports that normally would be provided to individuals in the case of a “real” birth or death.⁵⁷ Portraits of the ways that healthcare professional behave in instances of perinatal death are often quite unflattering.

In cases of perinatal death, the treatment of parents, the babies’ bodies, and the parent-child bond should be attended to very intentionally. Again, parents should be supported in their requests to hold their dead child. Babies should not be taken to the mortuary until the parents are ready. Parents should be supported in their wish to take the baby home with them and to arrange for funeral services.

Pastoral ministers will find many resources in the Order of Christian Funerals, particularly Part II, “Funeral Rites for Children.”⁵⁸ Some rites can be celebrated in the hospital or in the family home even if the child’s body is not present—including “Prayers after Death,” “Gathering in the Presence of the Body,” or “Order for Blessing of Parents after a

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Miscarriage.” Particularly suited to stillbirths and infants who have died soon after birth is the “Rite of Final Commendation for an Infant.”⁵⁹ It can be celebrated in the hospital with or without the presence of the child and can be adapted to suit the particular needs of the family.

The public, communal character of Catholic liturgical rites is best respected when family, friends, and hospital staff are invited to participate both in rituals performed in the hospital and those performed in parishes. Such public acknowledgment can help address complications of perinatal grieving. The importance of the presence of members of the healthcare team at these events cannot be overstated.

Conclusion



The Catholic tradition provides a rich array of convictions, tradition, and practices that have formed parents who will walk into hospital NICUs and that can help them make informed decisions about treatment options for their children. Catholics will inhabit this tradition differently—there is no question about that. Many Catholics do not know their own tradition very well, or some may misinterpret it. And although the Roman Catholic tradition provides a relatively clear framework for reasoning about utilizing or withholding treatment, the application of that framework to specific cases is always more of an art than a science—even for those who know the tradition well.

In the end, although so much more could be said, I hope this chapter has conveyed that Catholicism is a tradition with a deep commitment to each and every person, regardless of disability; that it is a tradition that values the exercise of reason within the context of faith and spirituality; and that through prayer and sacramental practice, it seeks to create and sustain communities of persons in body, mind, and spirit—communities that encompass not only infants and their parents but also the wider circle of healthcare providers and caregivers who find themselves thrown together—often by surprise, often by tragedy—in the neonatal context.

Notes:

1. Margaret E. Mohrmann, *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope* (Cleveland, OH: Pilgrim, 1995).
2. Exodus 20:2-3 and Deuteronomy 5:6-7.
3. See William F. May, *The Physician's Covenant: Images of the Healer in Medical Ethics*, 2nd edition (Louisville, KY: Westminster John Knox, 2000), 30-35.
4. Mohrmann, 13.
5. Only two books have been published by Roman Catholic authors on neonatal medicine: Richard C. Sparks, *To Treat or Not to Treat: Bioethics and the Handicapped Newborn* (Mahwah, NJ: Paulist, 1988); and Charles

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C. Camosy, *Too Expensive to Treat? Finitude, Tragedy and the Neonatal ICU* (Grand Rapids, MI: Wm B. Eerdmans, 2010). The number of articles on neonatal medicine listed in the Catholic Periodical and Literature Index—the main research database for Catholic publications—over the past forty years can be counted on one hand.

6. Michael Lipka, “A Closer Look at Catholic America,” Pew Research Center (September 15, 2015), accessed June 20, 2016, <http://www.pewresearch.org/fact-tank/2015/09/14/a-closer-look-at-catholic-america/>.

7. *The Catechism of the Catholic Church* (Mass Market Paperback, 1995), §§2383–85. *The Catechism of the Catholic Church* can be found on the Vatican website at: http://www.vatican.va/archive/ENG0015/_INDEX.HTM.

8. “‘Catholics stand out with only 28% of the ever-married having divorced at some point’ [compared with] . . . the 40% divorce rate for those with no religious affiliation, 39% for Protestants and 35% for those of other religious faiths. Overall, 26% of all American adults have divorced, whereas 20% of Catholics have done so.” Wayne Laugesen, “Divorce Statistics Indicate Catholic Couples Are Less Likely to Break Up,” *National Catholic Register* (November 14, 2013), accessed June 20, 2016, <http://www.ncregister.com/daily-news/divorce-statistics-indicate-catholic-couples-are-less-likely-to-break-up/>.

9. According to one source, “37% of women obtaining abortions identify themselves as Protestant, and 28% identify themselves as Catholic.” “U.S. Abortion Statistics,” *Abort73.com* (June 21, 2013), accessed June 20, 2016, http://www.abort73.com/abortion_facts/us_abortion_statistics/.

10. Michael Lipka, “Majority of U.S. Catholics’ Opinions Run Counter to Church on Contraception, Homosexuality,” *Pew Research Center* (September 19, 2013), accessed June 20, 2016, <http://www.pewresearch.org/fact-tank/2013/09/19/majority-of-u-s-catholics-opinions-run-counter-to-church-on-contraception-homosexuality/>.

11. Pew Research Center, “U.S. Catholics View Pope Francis as a Change for the Better,” (March 6, 2014), accessed June 20, 2016, <http://www.pewforum.org/2014/03/06/catholics-view-pope-francis-as-a-change-for-the-better/>.

12. US Conference of Catholic Bishops, *The Ethical and Religious Directives for Catholic Health Care Services*, 6th edition, 2018. Henceforth abbreviated *ERDs*.

13. The notion of the dignity of the human person has been a staple of the Roman Catholic tradition throughout the twentieth century and has become increasingly central to Roman Catholic moral thought since the Second Vatican Council forward. It has also become a central concept in secular bioethics. In both traditions, it is more often simply asserted

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rather than defined, often precipitating confusion and masking the source of disagreements. In the Catholic tradition, the term is used to indicate that each human person—from a zygote to a person in a coma or with dementia at the end of life—is a being of inestimable value and transcendent, incomparable worth. Insofar as each human person bears the image of God, all human beings are to be inviolable. Regardless of capacities or health status, they are loved unconditionally and completely by God and are therefore to be loved unconditionally and completely by us. The concept applies not only in bioethics but also across the spectrum—social ethics, economic ethics, and so on.

For more on dignity in Catholic bioethics, see the encyclicals of John Paul II, *Evangelium Vitae*, nos. 2 and 96; Benedict XVI, *Dignitatis Personae*, no. 7; Francis, *Evangelii Gaudium*, no. 178; and Benedict XVI, *Caritas in Veritate*, no. 45. For a more extensive discussion of the topic within Roman Catholic bioethics, see, for just two examples, B. Andrew Lustig, “The Image of God and Human Dignity: A Complex Conversation,” *Christian Bioethics* 23, no. 3 (December 2017): 317–34; and Edmund D. Pellegrino and Adam Schulman, *Human Dignity and Bioethics* (Notre Dame, IN: University of Notre Dame Press, 2009). For insight into the secular conversation, see, e.g., Leon Kass, *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics* (New York: Encounter Books, 2002).

14. *ERDs*, p. 10. The dignity of the human person is mentioned twenty-one times in the thirty-eight pamphlet-sized pages of the *ERDs*, beginning in the Preamble and informing every subsection except the section on the formation of partnerships between hospitals and health systems (though it is presumed there as well).

15. See Catholics for Choice website, accessed June 20, 2016, <http://www.catholicsforchoice.org/abortion/>.

16. Some Catholic theologians have based their argument for the personhood of embryos and fetuses on their inherent *potential* to exercise certain capacities. Other theologians have argued that embryos do not become persons until implantation prevents twinning, thus establishing an *individual*. For the most comprehensive overview of these positions, see Michael R. Panicola, “Three Views on the Preimplantation Embryo,” *National Catholic Bioethics Quarterly* 2, no. 1 (Spring 2002): 69–97. The positions outlined by Panicola are not well known by Catholic lay persons and are not the official position of the Catholic Church.

17. At issue in one of the seminal cases in neonatal medicine and ethics—the Baby Doe case—was a perception by the medical staff that Baby Doe was not treated respectfully, as a person with dignity. Denied surgical treatment and nutrition and hydration due to his Down syndrome, Baby Doe was largely moved to the side and allowed to die. See Allen Verhey, “The Death of Infant Doe: Jesus and the Neonates,” in *On Moral Medicine: Theological Perspectives on Medical Ethics*, 3rd edition, ed. M. Therese

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Lysaught and Joseph Kotva (Grand Rapids, MI: Wm B. Eerdmans, 2012), 796–800.

18. *ERDs*, p. 18.

19. *ERDs*, Directives 27 and 28.

20. *Gaudium et Spes*, The Pastoral Constitution on the Church in the Modern World, number 16; see also the *Catechism of the Catholic Church*, §1776–1802.

21. Importantly, the discussion of conscience within the *Catechism of the Catholic Church* is located under the larger subheading of “The Dignity of the Human Person.”

22. *ERDs*, Directives 56 and 57.

23. Pius XII, “Address to an International Congress of Anesthesiologists,” November 24, 1957.

24. As the *ERDs* state: “We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome” (p. 29).

25. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 1980.

26. *Catechism*, §2278.

27. *Catechism*, §2276.

28. See Ronald Hamel and James Walters, *Artificial Nutrition and Hydration and the Permanently Unconscious Patient: The Catholic Debate* (Washington, DC: Georgetown University Press, 2007); and Christopher Tollefsen, ed. *Artificial Nutrition and Hydration: The New Catholic Debate* (Dordrecht: Springer, 2010).

29. “Address of John Paul II to the Participants in the International Congress on ‘Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” 2004.

30. *ERDs*, Directive 58.

31. *Catechism*, §2276.

32. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 1980, Part II.

33. John Paul II, *Evangelium Vitae*, 1995, §12.

34. *Ibid.*, §19.

35. *ERDs*, Directive 3.

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36. See James F. Drane, "Anencephaly and the Interruption of Pregnancy: Policy Proposals for HECs," *HEC Forum* 4, no. 2 (1992): 103-19; James L. Walsh and Moira M. McQueen, "The Morality of Induced Delivery of the Anencephalic Fetus prior to Viability," *Kennedy Institute of Ethics Journal* 3, no. 4 (1993): 357-69; Kevin O'Rourke and Jean deBlois, "Induced Delivery of Anencephalic Fetuses: A Response to James L. Walsh and Moira M. McQueen," *Kennedy Institute of Ethics Journal* 4, no. 1 (1994): 47-53; and Kevin O'Rourke, "Ethical Opinions in Regard to the Question of Early Delivery of Anencephalic Infants," *Linacre Quarterly* 63, no. 3 (1996): 55-59.

37. National Conference of Catholic Bishops, Doctrine Committee, "Moral Principles Concerning Infants with Anencephaly," *Origins* 26, no. 17 (October 10, 1996).

38. See, e.g., Ira Byock, *The Best Care Possible: A Physician's Quest to Transform Care through the End of Life* (New York: Avery, 2013).

39. For those not familiar with the WHO definition, it states: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients' illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." See: <http://www.who.int/cancer/palliative/definition/en/>.

40. Ibid.

41. See, e.g., Romanus Cessario, O.P., "Catholic Considerations on Palliative Care," *National Catholic Bioethics Quarterly* (Winter 2006): 639-50; and Suzanne Gross, F.S.E., and Marie T. Hilliard, R.N., "Palliative Care, Pain Management, and Human Suffering," in *Catholic Health Care Ethics: A Manual for Practitioners*, ed. Edward J. Furton with Peter J. Cataldo and Albert S. Moraczewski, O.P. (Philadelphia: National Catholic Bioethics Center, 2009), 193-97.

42. See, e.g., Ronald Hamel, "Palliative Care Needs a Culture to Sustain It," *Health Progress* (January-February 2011): 70-72; Tina Picchi,

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"Palliative Care: A Hallmark of Catholic Mission," *Health Progress* (January–February 2011): 11; and "How Four Systems Approach Palliative Care," *Health Progress* (January–February 2011): 27–37.

43. *Catechism*, §2279.

44. Benedict XVI, "For the Fifteenth World Day of the Sick," December 8, 2006.

45. *Ibid.*

46. Benedict XVI, "Meeting with the Authorities and the Diplomatic Corps [Austria]," September 7, 2007. Or, as he stated in his address to healthcare workers in November 2007: "Indeed, recourse to the use of palliative care when necessary is correct, which, even though it cannot heal, can relieve the pain caused by illness. Alongside the indispensable clinical treatment, however, it is always necessary to show a concrete capacity to love, because the sick need understanding, comfort and constant encouragement and accompaniment" (Benedict XVI, "Address of His Holiness Benedict XVI to the 22nd International Congress of the Pontifical Council for Health Pastoral Care," November 17, 2007).

47. *Code of Canon Law*, Book IV, Part II, Title III, Canon 1176, §3.

48. *Catechism*, §2300.

49. Ron Hamel, "Some Guidance on Disposition of Fetal Remains," *Health Care Ethics USA* (Spring 2008): 8–9.

50. *Ibid.*, 9.

51. *Ibid.*, 10.

52. *Catechism*, §2301.

53. *ERDs*, Directives 63–65.

54. As it states in *The Catechism of the Catholic Church*, §1256: "The ordinary ministers of Baptism are the bishop and priest and, in the Latin Church, also the deacon. In case of necessity, anyone, even a non-baptized person, with the required intention, can baptize, by using the Trinitarian baptismal formula. The intention required is to will to do what the Church does when she baptizes. The Church finds the reason for this possibility in the universal saving will of God and the necessity of Baptism for salvation."

55. *Pastoral Care of the Sick: Rites of Anointing and Viaticum* (Collegeville, MN: Liturgical Press, 1983).

56. Examples of these prayers and blessings can be found on the website of the US Conference of Catholic Bishops, "Order for the Blessing of the Sick," accessed June 20, 2016, <http://www.usccb.org/prayer-and-worship/>

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sacraments-and-sacramentals/sacramentals-blessings/persons/order-for-the-blessing-of-the-sick.cfm.

57. Claudia Malacrida, "Complicating Mourning: The Social Economy of Perinatal Death," *Qualitative Health Research* 9, no. 4 (July 1999): 504-19.

58. *Order of Christian Funerals with Cremation Rite* (Totowa, NJ: Catholic Book Publishing, 1990).

59. *Ibid.*, §§337-42.