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I am submitting herewith a dissertation written by L William Uhl entitled "Artificial Nutrition and Hydration for Infants with Life-Terminating Conditions: Rethinking the Catholic Position." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Philosophy.

John R. Hardwig, Major Professor

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**Artificial Nutrition and Hydration for
Infants with Life-Terminating Conditions:
Rethinking the Catholic Position**

A Dissertation
Presented for the
Doctor of Philosophy Degree
The University of Tennessee, Knoxville

L. William Uhl
December 2011

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Dedication

To Zachary and Teresa

In Memory of

Lee Shepski, Ph.D.
Assistant Professor of Philosophy
The University of Tennessee, Knoxville

Acknowledgments

I would like to thank John Hardwig for helping me keep my focus and complete this dissertation. I would also like to thank the other members of my committee—Glenn Graber, Richard Aquila, and Alfred Beasley—who graciously accommodated my schedule and helped me finish my program on time so that I could move on to my next Air Force assignment without delay. To Richard, I am particularly grateful for his having been my graduate student director and mentor for my history portfolio examination paper.

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Abstract

Infants with life-terminating conditions (ILTCs) are those whose conditions prevent them from living more than two years. When these infants have difficulty assimilating food and fluids orally, doctors can provide nutrition and hydration through artificial means. While artificial nutrition and hydration (ANH) can provide benefits, it can also result in complications leading to pain and/or distress in addition to that which an ILTC may already be experiencing from one or more underlying conditions.

Many medical experts maintain that withholding or withdrawing ANH can help a patient's body produce its own analgesics. I consider four categories of ILTCs: 1) infants who receive prognoses of two weeks or less; 2) infants who will live longer than two weeks but no more than two years and who are not suffering or in distress; 3) infants who are not dying, but are in distress from the use of ANH; and 4) infants who are not dying, but are in distress from their conditions and/or ANH. I argue that in addition to providing natural analgesics, withholding or withdrawing ANH is a form of comfort care that prevents the occurrence of further complications requiring additional medical treatments and keeps ILTCs content. Under certain circumstances, the withholding or withdrawing of ANH should be obligatory.

As it stands, the whole of Catholic teaching on ANH is inconsistent. Operating from the sanctity-of-life ethic, the Church teaches that ANH is an ordinary, therefore obligatory, form of care. But this position contradicts the view that any form of care presenting a grave burden to a patient and/or his family is extraordinary and therefore optional. In addition, by making ANH obligatory, the Catholic Church causes families to undergo heroic suffering (i.e., enduring more than what can be expected or asked of anyone), which the Church says is not required of everyone. I argue that rethinking the Catholic position on ANH will enable the Church to offer

practical moral guidance for families to comfort ILTCs, help ILTCs and their families avoid heroic suffering, and provide spiritual care families of ILTCs need, all while still respecting the sanctity of life of every person.

Preface

1 Considering the Use of Artificial Nutrition and Hydration

Should we use artificial nutrition and hydration (ANH) to feed and hydrate infants with life-terminating conditions (ILTCs)? ANH is normally provided as a temporary or “bridge” treatment for patients who cannot orally assimilate food and fluids. It is intended to be used until a patient is well enough to eat foods and drink liquids orally.

ANH is not peculiar to the twentieth century. Ancient Egyptians tried to feed patients using reeds and animal bladders. In the late eighteenth century, attempts to feed patients utilized “hollow whale bone covered with eel skin” (Greene). Attempts even occurred rectally (e.g., ancient Egyptians and the doctors treating President James Garfield after he was shot in 1881) (Greene).

Today, ANH can be provided in a number of different ways. Doctors can thread a nasogastric (NG) tube through the nose, down the esophagus, and into the stomach or duodenum. They can surgically insert a gastrostomy tube into the stomach, the duodenum, or further into the gastrointestinal tract. If necessary, doctors can feed and hydrate patients through a peripheral vein or a central vein near the heart. Each form of ANH has both its advantages and disadvantages. I shall provide a more detailed account of the various forms of ANH in chapter 1.

Sometimes, though, when an infant is not expected to live more than a year or two and has lost either his appetite or his ability to eat, families and doctors at least consider, if not follow through with, providing him with ANH. Providing ANH, however, does not always benefit the infant and/or the family caring for him. In fact, ANH can cause distress for the infant and suffering for the family. Sometimes it is best to withhold or withdraw ANH, but only under certain conditions.

2 Offering Help to Families of ILTCs

In 2010, Marie T. Hilliard,¹ the director of bioethics and public policy for The National Catholic Bioethics Center, published a pamphlet entitled *Caring for Each Other, Even Unto Death*. This pamphlet draws its information from the United States Conference of Catholic Bishops' (USCCB's) *Ethical and Religious Directives for Catholic Health Care Services* (ERDs), Wojtyla's *The Gospel of Life* and 2004 address, and the Congregation for the Doctrine of the Faith's (CDF's) "Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration." Since Hilliard's pamphlet is a USCCB-approved resource designed to help Catholic families make moral choices about the end of life for their loved ones, it is worth considering its discussion of ANH for dying patients.

The front panel of *Caring for Each Other, Even Unto Death* depicts a smiling religious sister helping a dying elderly woman drink from a cup. Inside the pamphlet is a picture of what appears to be an elderly husband at his dying wife's bedside. Like most Catholic resources on death and dying, this pamphlet focuses primarily on the care of dying elderly patients and of patients in a permanent vegetative state (PVS); it does not address caring for sick or dying infants. So Catholic families with ILTCs may find themselves without practical choices in their particular situations. We can probably assume that lessons learned in caring for the dying elderly can be applied to caring for dying ILTCs.

Looking at the pamphlet's front panel, we may be led to believe that the religious sister is helping the elderly woman drink all the water from her cup. Giving drink to the thirsty is an act of charity that the Church encourages all of her members to perform whenever the situation arises. But as we shall learn in chapter 1, a dying patient may only need a sip of water to keep

¹ Hilliard is a canon lawyer and a nurse.

his mouth moist, and nothing more. From a religious point of view, we may get the impression that we are supposed to help a dying patient finish whatever is in his cup or on his plate. From a medical point of view, however, by forcing (either intentionally or unintentionally) food and fluids, we may be delivering more harms than benefits to a dying patient.

Suppose, however, that the picture on the front panel depicted the religious sister feeding the elderly woman through an NG tube or a percutaneous endoscopic gastrostomy (PEG) tube. The scene may be disturbing to some people, especially if they are unfamiliar with ANH. The scene may also cause many people to say, “If that is the way I am going to be fed, I would rather die.” The risks and burdens of ANH are real, especially in conjunction with underlying conditions. While ANH is something that few, if any, people relish the thought of, it is important for everyone to learn that this has become a widely practiced, successful method of providing nutrition and hydration to patients who cannot assimilate food and fluids orally. And it may become just one of many treatments that families have to consider in caring for their ILTCs.

The fact that the elderly dying woman is sipping from a cup implies a number of things worth considering. As the sister is helping her with the cup, we notice the woman’s hand also holding it. From this picture we can infer 1) the woman is conscious, and has somehow indicated that she would like some water; 2) the woman can still perform certain functions such as drinking from a cup, although she needs help holding it steady; and 3) the woman probably has some kind of interpersonal connection with the sister (as indicated by the smile on the sister’s face).

While an ILTC may be similar to the elderly woman in virtue of the fact that both may be dying, there are a number of differences we need to keep in mind. First, while an ILTC may be

aware of stimuli, he is incapable of expressing himself in the same way the elderly woman may be able to. If she cannot ask for water verbally, she may be able to make gestures such as pointing to a pitcher of water or holding an imaginary cup to her lips. She can push a button to signal the nursing station that she needs assistance. An ILTC cannot do any of these things. It may be some time before someone notices his crying or other cues of distress (e.g., thrashing, etc.) during hospital rounds. If the elderly woman is conscious of her situation, she can indicate in some form or other that she wants something provided or withdrawn. If she is unable to do this for herself, other family members can give doctors and nurses permission to perform various treatments based on their knowledge of her preferences or prior wishes. But an ILTC is completely at others' mercy. In some instances, it is only when complications develop that doctors and parents realize that the infant is in pain and/or distress. And sometimes, the best interests of the family override the best interests of the ILTC. Sometimes it is in an ILTC's best interests to be allowed to die sooner rather than later. While it may not seem to be the case at the time, an ILTC's death may actually help relieve the family's suffering and allow them to move forward with their own lives and be a source of help and comfort for other families in similar circumstances.

3 Motivation and Purpose of This Dissertation

My dissertation will examine the debate over ANH for ILTCs from within the Roman Catholic tradition. Why am I taking this approach? I am a Catholic, and consequently, I think from within the Roman Catholic tradition. In 2002, my wife gave birth to our second son Zachary, who was born with trisomy 13, a fatal genetic condition. We learned of his condition a little more than two months before he was born. Because we wanted to remain in good standing with the Catholic Church (so as to be able to receive the sacraments), it was extremely important

for us to do only those things the Church permitted. Since Zachary lived for only six hours, feeding him was not an issue we needed to pursue. Had he lived longer, though, it would have been, and because of severe facial deformities, some form of ANH would have been necessary. In my research of the Catholic position on ANH, I have discovered that very little attention is given to infants within the debate over ANH.

Within the Catholic tradition, infants deserve as much protection as any other vulnerable persons such as the elderly, disabled, sick, or dying. For the purposes of this dissertation, I shall consider the question of providing ANH to ILTCs whose conditions will cause them to die before the age of two. ILTCs who die before the age of two will never be able to speak on their own behalf. Nor will they experience life as do healthy infants who live to later stages of childhood, adolescence, or adulthood. Since the Catholic Church considers ANH an obligatory form of care but clinical evidence suggests that it may be best to withhold or withdraw ANH from dying patients, Catholic families often find themselves facing a very difficult ethical dilemma in deciding what forms of care to provide to their infants. My goals are to resolve tensions within the Catholic tradition regarding ANH—especially in regard to ILTCs—and to offer suggestions as to how the Church can provide both spiritual care and practical moral guidance for her members.

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Chapter 1: ANH Not Always Beneficial for ILTCs

Some infants are born healthy and can assimilate food and fluids orally either by breastfeeding or bottle feeding. As they mature, they can eat solid foods as well. But some infants are born with conditions preventing them from assimilating food and fluids orally (e.g., duodenal atresia). Doctors can correct duodenal atresia with a relatively quick and simple surgical procedure to remove the blockage, after which an infant can begin to assimilate food and fluids orally. Still other infants who cannot assimilate food and fluids orally have more severe conditions that simple surgery cannot correct. While doctors are capable of more invasive forms of surgery, infants with life-terminating conditions (ILTCs) may be unsuitable candidates for these more invasive forms. Artificial nutrition and hydration (ANH) then becomes the only means of feeding and hydrating them.

Since my focus is on ILTCs who are not expected to live more than two years, we must ask some extremely difficult questions. First, if ILTCs are given prognoses of two weeks or less, must we feed and hydrate them through ANH? Second, if ILTCs are given prognoses of more than two weeks but less than two years, what should our position be on providing ANH to them? There are three groups of ILTCs we must consider in regard to the second question. Most ILTCs will eventually enter the dying process due to underlying conditions. But there are also some ILTCs who are not dying from underlying conditions but suffer distress from complications of the use of ANH. There are still other ILTCs who are not dying from their underlying conditions but suffer distress from complications of their conditions and/or ANH. Sometimes it is difficult, if not impossible, to tell the difference. Some of these complications can be life-threatening in and of themselves. I contend that if ILTCs are given prognoses of less than two weeks, it is in their best interests for us to withhold ANH from them completely. I also contend that if ILTCs

are given prognoses of more than two weeks but less than two years, it is in their best interests to withhold ANH from them once we can determine that they have entered the dying process. In cases where ILTCs are not dying but are in distress from the use of ANH, it is in their best interests to withdraw ANH and provide palliative care only. In cases where ILTCs are not dying but are in distress from their conditions and/or the use of ANH, I recommend that doctors first pinpoint the cause of the distress and then alleviate it. If either the underlying condition or complications from the use of ANH cause an ILTC to enter the dying process, doctors should withdraw ANH.

My position may seem to go against our instincts to provide food and fluids to our loved ones, especially infants. But many medical experts argue that withholding or withdrawing food and fluids, including ANH, may actually be in a dying patient's best interests. What I aim to show is that there are inconsistencies within the whole of Catholic teaching on ANH for sick and/or dying persons. While my position may not be consistent with the whole of Catholic teaching on this issue, it is consistent with at least part of it.

1.1 ANH: What It Is, Its Benefits, and Its Burdens

ANH becomes an option when an infant—or any person, for that matter—is incapable of assimilating food and fluids orally. Without proper nutrition and hydration, any infant will die. But an infant may refuse to eat altogether, spit out whatever is placed in his mouth, vomit what he has already ingested, or show other signs of distress such as choking, constipation, diarrhea, etc. It is important to consider the various forms in which ANH can be supplied, for each involves different risks and burdens.

1.1.1 Enteral Forms of ANH

The first type of ANH is referred to as enteral, or that which uses the digestive tract. ANH can be accomplished enterally by various methods: nasogastric tube, gastrostomy tube, or jejunostomy tube. I will briefly describe each of these devices, procedures for inserting them, benefits, and risks, as described by Myles N. Sheehan, S.J., in “Feeding Tubes: Sorting Out the Issues.”

Nasogastric (NG) tubes “are thin tubes inserted into the nostril, threaded into the nasopharynx, and then advanced down the esophagus into the stomach or, frequently, into the first portion of the duodenum” (18). NG tubes are relatively easy to insert and deliver necessary alimentation without surgery. As a means of feeding, however, they are not intended to be used longer than two weeks. NG tubes

can press against the delicate lining of the nostrils and pharynx and lead to ulceration. They can also interfere with drainage from the sinuses and lead to blockage and infection. Although they are sometimes used for a prolonged period of time, the risks of ulceration and infection make them a less-than-ideal choice. Some patients must be restrained so that, in a moment of confusion, they do not pull on the tube and dislodge it. (19)

A gastrostomy tube is “inserted directly into the stomach, either surgically or, more commonly, by placing an endoscope through the skin” (18). If an endoscope is used, the tube is referred to as a percutaneous endoscopic gastrostomy (PEG) tube. After insertion of the endoscope, doctors can see the lighted end of it through the skin. Once the endoscope is in the proper location, doctors can insert the PEG tube into the stomach or the duodenum. If necessary, doctors can place the tube further into the gastrointestinal tract in the same manner as a PEG

tube. When this is done, the tube is referred to as a jejunostomy (JPEG) tube (18). Gastrostomy tubes are an option if ANH is required for more than two weeks. “Surgically placed gastrostomy tubes are inserted when a person has had previous abdominal surgeries or when placing the tube endoscopically would be dangerous” (19).

PEG tube placement requires sedation, and an extremely ill patient or one with “serious breathing difficulties” can suffer rare “complications from drops in blood pressure or respiratory arrest during placement” (19). Other possible nonserious complications include “perforation of the gastrointestinal tract, infection of the abdominal cavity (. . . peritonitis), bleeding, and local infection at the site of the tube placement” (19). If a patient routinely suffers from “aspiration of stomach material into the lungs,” a jejunostomy tube is usually recommended (19). One drawback of jejunostomy tubes is that they require formulas that are different from and more expensive than PEG tubes. In addition, patients with jejunostomy tubes are more likely to suffer from diarrhea than patients with PEG tubes (19).

How a patient is fed with feeding tubes can also vary. “Tube feedings can be ordered as bolus feedings (where a relatively large amount is given over a short period of time several times a day) or through a continuous drip in which the solution is administered at a precise rate for eighteen or more hours a day” (19-20). The use of feeding tubes is not a trouble-free solution, however. “Bolus feedings can allow a person to be mobile when not being fed, but they do have a higher risk of aspiration. Drip feedings carry a lesser risk of massive aspiration but limit mobility and independence” (20). Newborn infants are not mobile, but family members must be careful not to interfere with drip-feed tubes when holding or providing other forms of care for their infants. In addition, “[d]iarrhea, transient pneumonia, restraints that keep a confused patient from pulling a tube out, severely restricted mobility, and occasional clogging by pill

fragments are day-to-day occurrences with feeding tubes. Feeding tubes are burdens, but the degree of burden varies from patient to patient” (20).

1.1.2 Parenteral Forms of ANH

Parenteral or intravenous feeding is the second type of ANH. Like enteral feeding, parenteral feeding can provide alimentation to a patient using different methods. The National Conference of Catholic Bishops’ (NCCB’s)² Committee for Pro-Life Activities describes various forms of parenteral feeding in “Nutrition and Hydration: Moral and Pastoral Reflections.” The first type of parenteral feeding is peripheral intravenous feeding, in which “a needle [is] inserted into a peripheral vein” (131). Benefits of peripheral intravenous feeding include the ability to “provide fluids and electrolytes as well as some nutrients; they can maintain fluid balance and prevent dehydration . . .” (131). One disadvantage of this method is that it “cannot provide adequate nutrition in the long term” (131).

The second type of parenteral feeding is central intravenous feeding, also referred to as “total parenteral feeding or hyperalimentation” (131). This method of alimentation involves “using a larger needle inserted into a central vein near the heart” (131). One benefit of total parenteral feeding is that it “can provide a more adequate nutritional balance” (131). At the same time, however, it can [pose] significant risks to the patient and may involve costs an order magnitude higher than other methods of tube feeding” (131). Total parenteral feeding “has become ‘a mainstay for helping critically ill patients to survive acute illnesses where the prognosis had previously been nearly hopeless,’ but its feasibility for life-long maintenance of patients without a functioning gastrointestinal tract has been questioned” (131).

² The National Conference of Catholic Bishops (NCCB) is now known as the United States Conference of Catholic Bishops (USCCB). While it may be found in print form, the reader may access “Nutrition and Hydration: Moral and Pastoral Reflections” [here](#).

1.1.3 A Review of the Burdens of Each Form of ANH

The ultimate benefit of any form of ANH is that it delivers nutrition and hydration that an ILTC needs to survive. But since the decision to withhold or withdraw ANH is dependent on the burdens, it may be helpful to summarize the burdens associated with each form of ANH.

I. Enteral:

A. Nasogastric (NG) tube:

1. Burdens:

- a. Not intended to be used for more than two weeks
- b. Easy to dislodge and may require patient restraint
- c. Ulceration
- d. Sinus blockage and infection
- e. Restraint is source of distress for patient

B. Percutaneous Enteral Gastrostomy (PEG) tube/Jejunostomy (JPEG) tube:

1. Burdens:

- a. Requires sedation
- b. Possibility of perforation of gastrointestinal tract
- c. Infection of abdominal cavity
- d. Bleeding
- e. Local infection at tube placement site
- f. JPEG is more expensive
- g. JPEG more likely to cause diarrhea
- h. Higher risk of aspiration with bolus feeding
- i. Limited mobility and independence with drip feeding

II. Parenteral:

A. Peripheral intravenous feeding:

1. Burdens:

- a. Cannot provide adequate nutrition in long term

B. Total parenteral feeding (hyperalimentation)

1. Burdens:

a. Significant risks to patient³

- (1) Cholestasis with possible resulting sepsis
- (2) Liver disease and hepatic failure
- (3) Irreversible liver failure after several months of use
- (4) Complications from use of line

(a) Thrombosis

(b) Vascular perforation

(c) Infection

((1)) Staphylococcus epidermidis (bacterial)

((2)) Staphylococcus aureus (bacterial)

((3)) Candida albicans (fungal)

((4)) Malassezia furfur (fungal)

- b. Much more expensive than other methods

- c. Long-term use questionable

³ The NCCB (now the USCCB) does not provide a list of what these significant risks may be. These risks may be found in *Neonatal-Perinatal Medicine: Diseases of the Fetus and Infant* 608-609.

These are only some of the burdens associated with ANH. Parents of ILTCs must also consider the burdens associated with their infants' underlying conditions, the burdens associated with treatments for those conditions, the burdens associated with complications resulting from treatments, etc. Likewise, parents must also consider the burdens associated with complications resulting from ANH. As we can see, families may be overwhelmed by all the decisions they must make about providing care for their ILTCs. Families need the expertise of doctors and nurses to help them make these decisions.

1.2 Diminishing Importance of Food and Fluids in the Dying Process

Because our society has, for the most part, become unfamiliar with the dying process, it may surprise many people to learn that when a patient begins the dying process, he no longer needs food and fluids as do people who are not dying. In our attempt to understand what happens to a patient's body during the dying process, we need to speak in clinical—not religious or moral—terms. Describing the dying process in clinical terms, the vast majority of medical experts concur that once the dying process begins, the patient's body no longer needs food and fluids. Administering food and fluids may in fact interfere with and prolong the dying process, and as a result, it does nothing more than create greater discomfort for the patient.

Complications can arise as a result of employing even the simplest form of ANH, an NG tube. According to Joyce Brennfleck Shannon, editor of the *Death and Dying Sourcebook*, an NG tube is the easiest of the various feeding tubes to insert, but it can cause a patient “pain and discomfort related to the forceful introduction of physical devices in the esophagus, needed sedation, and infections often resulting from the procedure” (135).

According to Dr. Ladislav Volicer, clinical director of the Geriatric Research, Education and Clinical Center (GRECC) at the E.N.R.M. Veterans Hospital in Bedford, Massachusetts, the

common practice at his facility is to “[convert Alzheimer] patients back to assisted feeding on arrival. ‘They can always eat to some degree,’ he says, ‘except during the actual dying process.’ Patients in the dying phase do not experience hunger and thirst. . .” (Shannon 135). Volicer also says, ‘What we are trying to do is switch the emphasis of care from high tech to high touch. . .’ ” (135).

Some ILTCs require ANH at the very beginning of their lives because they have conditions that prevent them from assimilating food and fluids orally. In this regard they are different from Alzheimer patients who eventually forget how to eat. But worth noting is the notion of “switching the emphasis of care from high tech to high touch.” ILTCs—as well as other patients—may benefit from the use of advanced technology in a hospital setting. But it is human presence—especially the sense of touch—that can help comfort an infant. In the neonatal intensive care unit (NICU) where Zachary would have been treated, there was a room with several rocking chairs in it, precisely so that families and/or nursing staff could rock these infants to comfort them. Rocking by itself will not cure an infant’s life-terminating condition(s), but the simple, gentle, steady act of rocking delivers benefits not only to the infant, but anyone caring for him.

What would prompt us to even consider withholding or withdrawing food and fluids from a person, especially in the dying process? Providing food and fluids is a basic form of care showing people that we love them. The body can produce its own painkillers. This phenomenon occurs, however, only when food and fluids are withheld during the dying process. In *Handbook for Mortals: Guidance for People Facing Serious Illness*, Drs. Joanne Lynn and Joan Harrold list a number of potential benefits of not using ANH when a patient is close to death. First, “less fluid in the lungs” makes it easier for a patient to breathe (131). Second, a patient needs less

suctioning—an unpleasant procedure—if there is “less fluid in the throat” (131). Third, a decrease in fluids results in “less pressure on tumors,” and this in itself will relieve some pain (131). Fourth, patients suffer “less risk of skin breakdown and bed sores” through “less frequent urination” (131). Fifth and finally, an “increase in the body’s natural pain-relieving hormones” results in “increased comfort and less pain” for the patient (131).

Since we ourselves are unfamiliar with the body’s ability to create its own painkillers in the dying process, we seek pharmaceutical remedies for others when it is really unnecessary. We need to educate ourselves more about what actually happens when people die. Darby Morhardt, a social worker from Northwestern University Alzheimer’s Disease Center, says,

Our modern culture tends to treat dying as unnatural. Our technology allows us to forestall death, yet cannot prevent it. Family members need to be informed—with great compassion, sensitivity, and patience—about the dying process and how natural and inevitable it truly is. The body is shutting down. The natural process of dying means that the body no longer wants or needs food or fluids. This is often viewed as unnatural by caregivers and even some health care professionals. However, we need to explore our own feelings and attitudes toward death and dying before we can help families through this transitional process, this time of loss and change. (Shannon 135)

Dying patients’ bodies are no longer functioning as a healthy person’s does. Often a person loses strength and the ability to fight infection. In many instances, pneumonia or a urinary tract infection (UTI)—conditions otherwise healthy people recover from with antibiotics⁴—ends up

⁴ While not the primary focus of my dissertation, it is worth noting that the Church considers antibiotics to be an ordinary form of medical care. Like ANH, the use of antibiotics can prolong

being the direct cause of a dying patient's death. Lynn and Harrold write, "Until this generation, everyone who died a natural death died without artificially supplied fluids. The stopping of eating and drinking has always been part of the last phase of a terminal condition. Only recently have people been afraid that not providing food and fluid through a tube would cause someone to 'starve to death' " (133). The patient's body is telling him in its own terms that the end is near. Since dying infants cannot express themselves in words, it is even more important for us to be able to read the signs of dying in their case so as to allow them to die in comfort.

Consider how Mary K. Kazanowski, a registered nurse and professor at Saint Anselm College in Manchester, New Hampshire, describes in "Symptom Management in Palliative Care" the benefits of withholding fluids:

. . . [D]ehydration in individuals at the end of life is considered a normal physiologic process that occurs to prepare the body for death. Reduced desire and intake of food and fluids is also a normal physiologic process near death. Although decrease (sic) intake and consequent dehydration may be associated with weakness, fatigue and thirst, it is not considered an uncomfortable condition for the patient that merits reversal. Furthermore, dehydration may actually have some beneficial effects in terms of symptom palliation (Zerwekh, 1983; Musgrave, 1990). Zerwekh (1983) contended that intake cessation leads to a reduced fluid load which serves to reduce urinary output, nausea and vomiting,

a dying patient's life to the point where he recovers from an infection, only to contract it again or bear the pain of some other condition(s) or complication(s). Coupled with ANH, antibiotics can begin a vicious cycle of being fed, suffering complications (e.g., pneumonia from fluid in the lungs or a UTI), being treated with antibiotics, and possibly suffering further complications (either from antibiotics, underlying condition[s] or both). I believe no patient should be placed in such a predicament.

pulmonary congestion, and edema. Printz (1992) described a possible endogenous benefit of intake cessation citing the effects of ketosis and increased levels of endorphins on the central nervous system in rats. Increased endorphins in humans may lead to a heightened state of well-being. (351-352)

When we think of dehydration as a negative condition only, we deny ourselves the possibility of viewing it as a benefit for a dying patient. Likewise, if we view hydration as a positive condition only, we may be providing more harms than benefits to a dying patient. Kazanowski describes the following negative side-effects of providing ANH:

Forcing fluids or food on a person who has no or little appetite risks causing nausea, vomiting, and aspiration. Insertion and maintenance of intravenous catheters or nasogastric/feeding tubes is often painful for patients. Fluids from intravenous infusions or nasogastric tube feedings can increase respiratory secretions, which in turn increases pulmonary congestion, cough, and sensations of dyspnea. Administration of intravenous fluids will also increase urinary output, increasing the occurrence of incontinence or need for Foley catheters. Intravenous fluids will also increase total body water, which could result in an increase in fluid retention in the form of edema, ascites, or pleural effusions. Intravenous and nasogastric fluids would also increase gastric secretions, which could contribute to nausea and vomiting. (352)

Marianne LaPorte Matzo, a registered nurse, professor of nursing at New Hampshire Community Technical College in Manchester, New Hampshire, and editor of *Palliative Care Nursing: Quality Care to the End of Life*, recommends the following actions when caring for dying patients:

The person may have a decrease in appetite and thirst, wanting little to no food or fluid. The body will naturally begin to conserve energy that would be expended on these tasks. Do not try to force food or drink into the person. To use guilt or manipulation only makes the person more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing inside the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe. . . . Glycerin swabs may help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort. (497)

Sometimes, medical personnel who are determined to save the lives of terminally ill infants use guilt or manipulation to get parents to consent to ANH when it may be unnecessary.

Kazanowski urges nurses to discuss advantages and disadvantages of terminal dehydration with families, “and allow families time to absorb the information” (352). If family members cannot bring themselves to consent to withholding or withdrawing food and fluids but insist on continuing with ANH, nurses should ensure that over-hydration does not occur (352-353).

1.3 Comforting ILTCs with Forms of Care other than ANH

It may help to narrow our focus within the debate over ANH for ILTCs by beginning with forms of care that 1) everyone agrees we should provide to ILTCs until they die; 2) do not present complications that cause distress; and 3) do not make decisions about their moral nature (i.e., ordinary or extraordinary) difficult.

As the human body shuts down, it needs less of the things we consider necessary for good health: food, fluids, exercise, etc. Since we are talking about infants, most of the things that matter to adults and older children (e.g., work, school, sports, hobbies, friends, etc.) have no

relevance for ILTCs. But there are three things that every person benefits from, regardless of his age or condition: warmth, cleanliness, and human presence.

As the body begins to shut down, it is unable to regulate its own temperature. An obvious sign of discomfort from cold is shivering. An infant will, if able, cry to alert us that he is in distress. Keeping any patient warm can be as simple as turning up the thermostat, adding additional layers of clothing, or placing additional blankets over the patient. Keeping a terminal infant warm will not prolong the dying process. So the simple act of providing warmth can help not only the infant, but also family members (to include young children) and friends by making them feel as though they are doing something useful, even when the infant is dying.

Another need that every single person has—but terminal infants especially—is cleanliness. While soiled diapers are not in themselves a life-threatening condition, they make an infant uncomfortable, and, left untreated, lead to other discomforts such as diaper rash. Cleanliness is especially important for infants because their immune systems are not fully developed, and it is easier for them to pick up infections of one sort or another. If an infant has undergone surgery—to include placement of a feeding tube—medical personnel and family members must routinely check to ensure complications (e.g., bleeding, infection, etc.) have not arisen. Like providing warmth, cleaning can help anyone involved feel useful.

Satisfying an infant's physical needs such as warmth and cleanliness also satisfies another need: human presence. Providing cleanliness requires human presence. But there is more to human presence than just placing blankets over the infant or changing his linens. Moreover, human presence entails more than checking an infant's charts and vital signs, administering feedings, and inspecting medical devices such as tubes, monitors, etc.

An ILTC cannot communicate in the same manner as an older patient who still has the ability to speak or give nonverbal cues to caregivers. Crying, thrashing, or some other indication of distress may be all ILTCs are capable of in terms of communicating their need for something. But unlike an older person who can tell his caregivers that he does not want any more food or fluids, an ILTC being fed by ANH cannot tell his caregivers that he does not want any more food or fluids. Caregivers must be extremely vigilant of indications that the ILTC is receiving more food or fluids than his body needs: edema, aspiration, infection, etc. Some of these complications can be life-threatening in and of themselves.

Another difference between dying elderly patients and dying ILTCs is that some dying elderly patients can enjoy interpersonal relationships on different levels with family, friends, doctors, and other caregivers. We do not expect these things of dying ILTCs, but they may somehow know that the presence of their mothers, fathers, and/or other family members means comfort. Family, friends, doctors, and caregivers can provide human presence by providing the sound of a human voice as they share their own memories and stories, as well as by holding, rocking, caressing, singing to him, etc. Though an ILTC cannot articulate his gratitude the way older children or adults can, caregivers should feel reassured that if the ILTC is comfortable, they must be doing something right, that is, providing loving care that the ILTC needs right here and now. Warmth, cleanliness, and human presence are all, I maintain, morally ordinary (i.e., obligatory) forms of care for an ILTC. Attempts to provide more aggressive treatments may actually interfere with these forms of care which are always morally required.

1.4 Conditions Making Decisions about ANH Difficult

We consider infants—especially ILTCs—to be some of the most vulnerable persons among us. The vulnerable deserve our care and protection. Infants also represent our future.

They give us hope and reasons to look forward to the future. But in the case of ILTCs, their future may end just minutes, hours, days, weeks, months, or a couple of years from now. As a hospital chaplain told my wife and me just a few weeks before Zachary was born, Zachary's birth was going to be bittersweet: just as soon as we would be welcoming him into the world, we would have to begin planning for the moment he would be leaving it. Especially for first-time parents, there is also the frightening question of how they are going to care for their infant once they bring him home from the hospital. For the parents of ILTCs, the terrifying question is how they are going to care for their infants and keep them comfortable until the time they die.

Keeping in mind that death for anyone deprived of all food and fluids occurs within approximately fifteen days, I wish to consider four groups of ILTCs when it comes to withholding or withdrawing ANH as a means of providing comfort care. In chapter 4, I present my recommendations and arguments for doing so.

1.4.1 Infants Who Receive Prognoses of Two Weeks or Less

The first group consists of those ILTCs who receive prognoses of two weeks or less. Conditions that often result in death within two weeks after birth are trisomy 18, trisomy 13, and trisomy 9. About trisomy 18, Kenneth Lyon Jones, professor of pediatrics, chief of the Division of Dysmorphology and Teratology, and author of *Smith's Recognizable Patterns of Human Malformation*, writes, "Fifty percent die within the first week and many of the remaining die in the next 12 months. Median survival time is 14.5 days. . . . Once the diagnosis has been established, limitation of extraordinary medical means for prolongation of life should be seriously considered" (14).

About trisomy 13, Jones writes,

The median survival for children with this disorder is 7 days. Ninety-one percent died within the first year. . . . Because of the high infant mortality, surgical or orthopedic corrective procedures should be withheld in early infancy to await the outcome of the first few months. Furthermore, because of the severe brain defect, limitation of extraordinary medical means to prolong the life of individuals with this syndrome should be seriously considered. (19)

Infants with trisomy 13 often also have several abnormalities including those affecting the central nervous system, heart, and kidneys. Like his comments about infants with trisomy 18, Jones says, “. . . [I]t is important to emphasize that each case must be taken on an individual basis. The individual circumstances of each child as well as the personal feelings of the parents must be acknowledged” (19).

The majority of infants with trisomy 9 “die during the early postnatal period” (26). There are “[c]ongenital heart defects in approximately two thirds of cases” (26). In addition, infants with trisomy 9 may have abnormalities affecting the gastrointestinal system, kidneys, and bladder (26).

For our purposes, we may consider these infants already in the dying process from the moment they are born. Of course, there will be infants who live longer than expected. In very rare cases, infants with trisomy 18 live much longer than one year. “There are at least ten reports of affected children older than 10 years of age” (14). “Only one adult [with trisomy 13], 33 years of age, has been reported” (19). But obviously only a few children defy the odds; the vast majority of children with trisomy 18, trisomy 13, or trisomy 9 will die well before their first birthday.

*1.4.2 Infants Who Will Live Longer than Two Weeks but No More than Two Years but Who Are Not Suffering or in Distress*⁵

The second group consists of those ILTCs who will live longer than two weeks but no more than two years but who are not suffering from the condition that will eventually cause their death. There are a number of conditions that may cause infants to die before they reach their second birthday: triploidy syndrome, duplication 3q syndrome, deletion 4q syndrome, duplication 10q syndrome, and Wiedemann-Rautenstrauch syndrome.

Describing triploidy syndrome, Jones writes, “All cases of full triploidy either have been stillborn or have died in the early neonatal period, with 5 months being the longest recorded survival” (28). Infants with triploidy syndrome often have congenital heart defects, brain anomalies, and renal anomalies (28).

Over one third of infants with duplication 3q syndrome die before the twelfth month. A majority of these infants have cardiac defects, and/or renal or urinary tract anomalies (34).

For infants with deletion 4q syndrome, “[f]ifty percent of patients with a terminal deletion . . . died before 15 months of age of cardiopulmonary difficulties including asphyxia, apnea, and congestive heart failure” (38). At least one fifth of these infants have gastrointestinal defects (38).

⁵ ILTCs raising some of the most difficult ethical problems regarding treatment are those born with anencephaly, a condition which leaves them permanently unconscious and unable to feel pain (due to the absence of the forebrain and the cerebrum). Anencephaly is occasional in certain syndromes such as acrocallosal syndrome, hydroethalus syndrome, and Meckel-Dieker syndrome (Jones 868). The majority of anencephalic infants die within the first year, but there are reported cases of anencephalic infants living for many years. Since my focus is on ILTCs who can and do experience pain and/or distress, I exclude anencephalic infants from my discussion.

Almost one half of infants with duplication 10q syndrome “died within the first year of life, usually from congenital heart defects and other malformations” (49). Renal malformations are another abnormality associated with duplication 10q syndrome (49).

For infants with Wiedemann-Rautenstrauch syndrome, “the life expectancy of affected patients is approximately 7 months” (150). Infants may have congenital heart defects. “Feeding difficulties and respiratory infections occur frequently” (150).

1.4.3 Infants Who Are Not Dying, but Are in Distress from the Use of ANH

The third group consists of those ILTCs who have not yet entered the dying process, but are in distress from complications resulting from the use of ANH. For example, infants with deletion 3p syndrome often have cardiac defects and renal anomalies. Because these infants cannot suck well, feeding often requires an NG tube. “Persistent central and obstructive apnea is common with frequent pneumonia. Gastroesophageal reflux and profound failure to thrive often occur” (32). Reported cases include one infant who died of cardiac arrest after 3 days and another who died of aspiration pneumonia at 3 months (32).

1.4.4 Infants Who Are Not Dying, but Are in Distress from Their Conditions and/or ANH

The fourth and final group consists of those ILTCs who have not yet entered the dying process, but are in distress from complications resulting from their conditions, and possibly also the use of ANH. It may be difficult in some instances to determine whether an ILTC in this fourth group is in distress from complications resulting from an underlying condition and/or from the use of ANH. Examples of conditions include Smith-Lemli-Opitz syndrome, Noonan syndrome, Costello syndrome, Opitz G/BBB syndrome, and Marshall-Smith syndrome.

Half of infants with Smith-Lemli-Opitz syndrome have cardiac defects. In addition, these infants may have renal abnormalities. Occasional abnormalities include diaphragmatic hernia.

Consider the problems associated with trying to feed these infants:

Feeding difficulty and vomiting have been frequent problems in early infancy. Oral tactile defensiveness and failure to progress to textured food is common resulting in the need for nasogastric tube feeding in 50%. Gastroesophageal reflux is common because of small stomach, intestinal dysmotility, and milk or soy protein allergy. Of those who survive, 20% die during the first year. Death appeared to be related to pneumonia in most of them, one of whom had a hemorrhagic necrotizing pneumonia with varicella, suggesting an impaired immune response. (114-115)

Infants born with Noonan syndrome have a number of abnormalities of the heart, including hypertrophic cardiomyopathy (124). Jones notes, "Poor feeding and symptoms of gastrointestinal dysfunction (vomiting, constipation, abdominal pain, and distention) often lead to failure to thrive and require nasogastric tube feeding. . . . Twenty percent with cardiomyopathy die in the first 2 years of life. Onset of the myelomonocytic leukemia has been in the first 2 months of life" (124).

More than half of infants with Costello syndrome have hypertrophic cardiomyopathy (128). "Polyhydramnios occurs and swallowing difficulties leading to failure to thrive frequently necessitate gavage feedings in the neonatal period. . . . The cardiomyopathy can be associated with dysrhythmias and sudden death" (128).

Opitz G/BBB syndrome leads to problems of the larynx, trachea, and esophagus. "Swallowing problems with recurrent aspiration, stridulous respirations, intermittent pulmonary

difficulty, wheezing, and a weak, hoarse cry should raise concern about a potentially lethal laryngoesophageal defect. In those individuals, mortality is high unless vigorous efforts are made to repair the defect and protect the lungs with gastrostomy or jejunostomy” (140).

A majority of infants with Marshall-Smith syndrome “die by 20 months with pneumonia, atelectasis, aspiration, or pulmonary hypertension. . . . Aggressive management of respiratory difficulties is extremely important with respect to ultimate prognosis” (172).

Remember that I consider an ILTC to be an infant who will die before the age of two. That would make the twenty percent of infants with Noonan, more than half of infants with Costello syndrome, and a majority of infants with Marshall-Smith syndrome who die within their first two years ILTCs. Of all the infants with any of these syndromes, not knowing for certain which of these infants are ILTCs according to my criteria is what makes prognoses and treatment decisions—especially the decision to withhold or withdraw ANH—so difficult.

The conditions I have described in this section are by no means the only congenital conditions that infants may have. My aim here is to show that any number of conditions can present serious challenges to parents providing care for their infants. Many of these infants have both severe internal and external anomalies.

It is easy to see why caring for these infants poses a tremendous challenge to doctors and families.

Withholding or withdrawing ANH provides a number of benefits for ILTCs, regardless of the category to which they may belong. First, an ILTC’s body is able to produce its own analgesics once all food and fluids are withheld or withdrawn. Second, the complete suspension of food and fluids eliminates the possibility of complications that could result from providing ANH. Third, without ANH, an ILTC’s body can begin the process of naturally shutting itself

down without interference. Fourth, while death may occur sooner rather than later when ANH is withheld or withdrawn, it is in the ILTC's best interests to be released from all pain and/or distress that his condition(s) and/or ANH may cause, especially since he derives no benefit from suffering (something I shall address in chapter 3). I provide a much more detailed account of the benefits and the conditions under which ANH should be withheld or withdrawn for ILTCs in all four categories in chapter 4.

1.5 An Objection to My Proposal

From a strictly medical point of view, an objective weighing of benefits and burdens associated with conditions and treatments may make the decision to withhold or withdraw ANH somewhat easier. But even from a medical point of view, doctors do not categorically advocate withholding or withdrawing ANH from ILTCs simply because they have birth defects or because the provision of ANH may pose risks. For instance, most medical professionals do not agree with the decision to withhold food and fluids from a trisomy 21 infant since doctors can now rather easily and quickly correct duodenal atresia. And some infants need ANH only as a bridge treatment, after which they can assimilate food and fluids orally. Short-term use of ANH does not prevent many of these infants from maturing to lead healthy, fulfilling lives.

From a religious point of view (specifically that of the Roman Catholic Church), decisions based on such calculations are not always morally permitted. Karol Wojtyla (more famously known as Pope John Paul II) was adamant in his defense of all human life. I shall address his position in detail in chapter 2, but for now, I present the claim he makes in his 2004 address, "Care for Patients in a 'Permanent' Vegetative State": ". . . [T]he 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. . .” (205). This statement follows the command he gives in his 1995 encyclical, *The Gospel of Life*: “[R]espect, protect, love and serve life, every human life” (11 [5]).⁶ “Every human life” includes all ILTCs, many of whom I have just described.

Wojtyla would object to my proposal claiming that it is my intention to eliminate weak and vulnerable persons. My proposal to eliminate such persons, he would argue, promotes the culture of death, which he is attempting to defeat. My response to this objection is that I respect ILTCs as persons and am very much concerned about their welfare (hence my call for comforting them). At the same time, I acknowledge that their health is compromised to the point where even the most aggressive treatments will not save them from death before the age of two.

Let us review the four groups of ILTCs I have addressed in my proposal:

1. Infants who receive prognoses of two weeks or less
2. Infants who will live longer than two weeks but no more than two years but who are not suffering or in distress
3. Infants who are not dying, but are in distress from the use of ANH
4. Infants who are not dying, but are in distress from their conditions and/or ANH

Regardless of the category, Wojtyla would say that unless an ILTC is imminently dying, (i.e., in his final hours), doctors must administer ANH, unless it proves useless and/or produces more burdens than benefits. So he would call my recommendations a promotion of euthanasia on the grounds that it is my intention to hasten an ILTC’s death, possibly out of convenience for the family.

⁶ When citing *The Gospel of Life*, I shall use both page numbers and section numbers (in brackets) for greater clarity. Should the reader wish to examine [*The Gospel of Life*](#) on the Internet, section numbers will prove to be more helpful.

As I shall argue in the next chapter, we must weigh the benefits and burdens of ANH as they affect not only the ILTC, but also his family and the community at large. As we begin to compare Wojtyla's statements about ANH within the Catholic tradition, we shall see that he may have made too broad a statement regarding the obligation to provide ANH, without the possibility of withholding or withdrawing under certain circumstances. In addition, there are inconsistencies between his position and the position of Catholic Church on the whole issue of providing care for the sick and/or dying. Such inconsistencies make it impossible to abide by Catholic teaching as a whole in this regard. In the next two chapters, I shall argue for why I believe Wojtyla's position is inconsistent with part of the Church's teaching on providing care for the sick and/or dying. In doing so, I shall pave the way for why I believe that my proposal is more consistent with what I believe to be the correct position on providing care for the sick and/or dying.

Chapter 2: Introducing *The Gospel of Life* and “The Prolongation of Life”

This chapter introduces the ethical pronouncements made by two recent Popes, Pius XII and John Paul II (whom I shall refer to as “Pacelli” and “Wojtyla,” respectively).⁷ Why am I focusing on these two individuals’ positions? Obviously, papal pronouncements carry great weight within the Church. Also, as we shall see, the central issue regarding artificial nutrition and hydration (ANH) is whether it is an ordinary (and therefore obligatory) or extraordinary (and therefore optional) means of care. Pacelli attempts to explain under what circumstances various forms of artificial life support may become extraordinary, while Wojtyla explicitly states that ANH is an ordinary means of care. Pacelli’s and Wojtyla’s positions have framed the contemporary debate within the Catholic tradition. I shall address the contemporary debate in greater detail in chapter 4.

Commentators since the sixteenth century have debated whether certain forms of medical care, including food and fluids taken orally, are to be considered ordinary or extraordinary. Even something as simple and natural as water can become extraordinary under certain circumstances. Throughout the twentieth century, significant breakthroughs in medicine and science, including artificial respiration, allowed doctors to save people who would have died without medical intervention. The debate over whether ANH constitutes an ordinary form of care or a medical treatment has played a significant role in blurring even further the distinction between ordinary and extraordinary means. In light of what medical and technological breakthroughs mean for patients, families, and the community at large, we need to reconsider what we mean by “ordinary” and “extraordinary,” which I do at the end of this chapter.

⁷ Eugenio Cardinal Pacelli became Pope Pius XII upon his election to the papacy in 1939. His pontificate lasted until 1958. Karol Cardinal Wojtyla became Pope John Paul II upon his election to the papacy in 1978. His pontificate lasted until 2005.

Prolonging life by artificial means was (and continues to be) not without its troubles, however. Doctors continue to encounter families who oppose their professional opinions and decisions over whether or not to save patients from death using artificial means. Upon request, Pacelli offered guidance to a group of anesthesiologists and other doctors asking questions about artificial respiration in a 1957 speech entitled “The Prolongation of Life.” Since Pacelli died in 1958 but it was not until 1979 that the first successful instance of ANH⁸ as we know it today occurred, it is impossible to know what he would have said specifically about ANH (Fritz). Since then, most commentators discussing end-of-life issues involving artificial life support refer to Pacelli in the hope of drawing parallels to artificial respiration. Wojtyla is no exception. In his 1995 encyclical *The Gospel of Life*, Wojtyla challenges the world to transform itself from being a “culture of death” to a “culture of life.” Aware that some people resort to ending patients’ lives by withholding or withdrawing food and fluids, Wojtyla states in a 2004 speech entitled “Care for Patients in a ‘Permanent’ Vegetative State” that “the administration of water and food, even when provided by artificial means,” is an ordinary, thus obligatory form of care, and not an extraordinary medical act (205). This statement, when compared with Pacelli’s statements, fuels the ANH debate.

2.1 Wojtyla’s *The Gospel of Life*

My starting point for the debate over ANH for infants with life-terminating conditions (ILTCs) is Wojtyla’s encyclical, *Evangelium Vitae* [*The Gospel of Life*], in which he challenges us to become the “culture of life.” But what does he mean by this phrase? He does not explicitly

⁸ The first successful occurrence of modern ANH occurred on 12 June 1979 at University Hospitals of Cleveland, when Dr. Michael Gauderer, a pediatrician, and Dr. Jeffery Ponsky, an endoscopist, saved a ten-week-old infant’s life by inserting a percutaneous endoscopic gastrostomy (PEG) tube.

define it, but we can surmise that it is the antithesis of what he labels the “culture of death.” In developing what he means by that phrase, Wojtyla lists threats that have existed and caused suffering since ancient times, such as “poverty, hunger, endemic diseases, violence and war” (6 [3]). Quoting the Vatican II⁹ document *Gaudium et Spes* to express his alarm at the current situation of the world, Wojtyla lists numerous human actions which cause human suffering:

Whatever is opposed to life itself, such as any type of murder, genocide, abortion, euthanasia, or wilful (sic) self-destruction, whatever violates the integrity of the human person, such as mutilation, torments inflicted on body or mind, attempts to coerce the will itself; whatever insults human dignity, such as subhuman living conditions, arbitrary imprisonment, deportation, slavery, prostitution, the selling of women and children; as well as disgraceful working conditions, where people are treated as mere instruments of gain rather than as free and responsible persons; all these things and others like them are infamies indeed. They poison human society, and they do more harm to those who practice them than to those who suffer from the injury. (7 [3])

Restricting our discussion to ILTCs, there are many ways in which they can suffer harm. They can be abandoned or neglected. Even though they cannot comprehend abusive words, they can acknowledge resentment and go into distress from it if their parents or siblings harbor grudges against them (e.g., “How come you were born this way?” “Do you realize what I must do for

⁹ Pope John XXIII convened the ecumenical council known as Vatican II in 1962 but died the following year. His successor, Pope Paul VI, allowed Vatican II to continue until it reached its conclusion in December of 1965. Bishops attending the council (including Wojtyla himself) produced several documents, including those discussing the role of the Catholic Church in the modern world, liturgical reform, etc. The reader may access the documents of Vatican II on the Internet [here](#).

you now?” “You have ruined my life.”). We cannot hold infants responsible for the conditions they have at birth. But we can hold family members responsible for neglecting or abusing these infants in any way. Especially for Catholics who believe in Jesus’ statement that whatever they do or fail to do to others, they do or fail to do to Jesus (*New American Bible*, Matt. 25.40, 45), the care they provide or fail to provide affects their standing with the Church and society at large, and, to some extent, their eternal salvation. This is what Wojtyla may be implying in the comment that these violations “do more harm to those who practice them.”

But even if a good family provides loving care for their infant, they may still worry that they have not done enough, or have done something that causes unintentional harm (e.g., allowing doctors to perform a procedure that delivers more harm than benefit to the infant). Even if they only feel guilt but are not actually guilty of sin, they can suffer indefinitely and unnecessarily. That is why the debate over ANH for ILTCs is so important: the Church needs to provide not only spiritual care for her members, but also practical moral guidance¹⁰ when families of ILTCs find themselves having to make end-of-life choices without a clear understanding of what is and is not morally permissible.

¹⁰ By “spiritual guidance” I mean prayer, counseling, or anything else that provides spiritual benefits for a person’s soul. By “practical moral guidance” I mean providing a person with practical alternatives that the Church considers morally permissible. For example, suppose a couple asks their pastor about what the Church teaches on withholding or withdrawing ANH. If the priest merely responds, “You cannot do either, but I will pray for you,” he has not provided practical moral guidance. The priest offers practical moral guidance by helping the couple understand the Church’s teaching on end-of-life issues (e.g., palliative care), contacting on their behalf support groups or parishioners who work in the medical profession, etc. The purpose of this dissertation is to demonstrate how my proposal to withhold or withdraw ANH when an ILTC has entered the dying process can actually become a practical alternative to offer Catholic families.

Regarding the harmful actions listed above, Wojtyla laments the fact that some of these practices seem to be expanding, not diminishing, in the modern world:

At the same time a new cultural climate is developing and taking hold, which gives crimes against life a *new and—if possible—even more sinister character*, giving rise to further grave concern: broad sectors of public opinion justify certain crimes against life in the name of the rights of individual freedom, and on this basis they claim not only exemption from punishment but even authorization by the State, so that these things can be done with total freedom and indeed with the free assistance of health-care systems. (7-8 [4])

Wojtyla then gives his account of how the culture of death emerges:

In fact, while the climate of widespread moral uncertainty can in some way be explained by the multiplicity and gravity of today's social problems, and these can sometimes mitigate the subjective responsibility of individuals, it is no less true that we are confronted by an even larger reality, which can be described 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 (sic) 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. (22 [12])

So the culture of death appears to be marked by various attitudes and actions of denial, intolerance, and rejection. To combat these problems requires acceptance, love, and care. And this is Wojtyla’s challenge to us to become a culture of life: “*respect, protect, love and serve life, every human life!*” (11 [5]). He further states where we must stand in this conflict between the culture of life and the culture of death:

This situation, with its lights and shadows, ought to make us all fully aware that we are facing an enormous and dramatic clash between good and evil, death and life, the “culture of death” and the “culture of life”. We find ourselves not only “faced with” but necessarily “in the midst of” this conflict: we are all involved and we all share in it, with the inescapable responsibility of *choosing to be unconditionally pro-life*. (50 [28])

But as we shall see, being “unconditionally pro-life” does not mean—at least, within the Catholic tradition—prolonging it by whatever means possible until the body is completely unable to survive despite assistance from various forms of artificial life support. To do absolutely everything possible to avoid death—no matter the cost—is a type of idolatry that Richard A. McCormick, S.J., in “To Save or Let Die,” calls “medical vitalism” (30). When we talk about being pro-life, we must not only be able to accept the fact that dying and death are parts of the cycle of life, but also be able to allow individuals to die—as difficult as it may be—when it is in their best interests to do so. One of the things that makes the deaths of ILTCs difficult is that just as soon as they enter the world, their parents must plan for them to leave it.

So how do we apply Wojtyla's command to respect, protect, love, and serve every infant with life-terminating conditions? A very important question to consider is, can we respect, protect, love, and serve an ILTC by allowing him to die by withholding or withdrawing ANH once he has begun the dying process? My dissertation will be a response to this question.

Within *The Gospel of Life*, Wojtyla makes several references to children who are at risk of being harmed:

- . . . [T]he point has been reached where the most basic care, even nourishment, is denied to babies born with serious handicaps or illnesses. (26 [14])
- As well as for reasons of a misguided pity at the sight of the patient's suffering, euthanasia is sometimes justified by the utilitarian motive of avoiding costs which bring no return and which weigh heavily on society. Thus it is proposed to eliminate malformed babies. . . . (27 [15])
- In the materialistic perspective . . . *interpersonal relations are seriously impoverished*. The first to be harmed are women, children, the sick or suffering, and the elderly. (42 [33])
- Human life finds itself most vulnerable when it enters the world and when it leaves the realm of time to embark upon eternity. The word of God frequently repeats the call to show care and respect, above all where life is undermined by sickness and old age. (78 [44])
- “. . . [Y]ou shall not put a child to death by abortion nor kill it once it is born. . . .” (97 [54]; Wojtyla quoting *Didache*; ellipses in orig.)
- “Nothing and no one can in any way permit the killing of an innocent human being, whether a fetus or an embryo, an infant or an adult, an old person, or one

suffering from an incurable disease, or a person who is dying.” (102 [57];

Wojtyla quoting *Declaration on Euthanasia*¹¹)

- The Second Vatican Council defines . . . infanticide . . . as an “unspeakable crime”. (103 [58]; Wojtyla quoting *Gaudium et Spes*)

From these quotations, it first appears that Wojtyla wants every infant to survive no matter the cost to that infant or to others. It is possible, though, that when Wojtyla mentions “babies born with serious handicaps or illnesses”, he may not have conceived instances in which ILTCs have significantly compromised gastrointestinal systems, or how serious some complications become when certain ILTCs are fed. But notice in the fourth quotation that Wojtyla acknowledges that there is a proper time for earthly life to come to an end. Some infants’ conditions are such that no matter what is done for them, they will not survive. Notice also that ILTCs can be labeled as “sick,” “disabled,” “terminally ill,” “dying,” or “weak.” If we withhold food and fluids from a healthy infant or fail to treat a minor medical condition that turns into a life-terminating condition for him, we can be said to have killed him. But in certain instances, we may withhold or withdraw medical treatments that seem to provide no benefit to an ILTC. From the numerous examples of life-terminating conditions I presented in chapter 1, many infants have compromised gastrointestinal systems. In these instances, we are said to have allowed an ILTC to die, which is morally permissible. There seems to be a very fine line here, then, between killing and allowing to die. This distinction seems to be even more blurred when we consider ANH for ILTCs.

¹¹ The reader may access the Congregation for the Doctrine of the Faith’s (CDF’s) *Declaration on Euthanasia* (1980) on the Internet [here](#).

Recall that Wojtyla says, “. . . [T]he most basic care, even nourishment is denied to babies born with serious handicaps or illnesses” (26 [14]). What should we consider to be basic care? Let us first begin by listing common things that most people have access to: water, food, clothing, and shelter. Now obviously there will be instances where we must consider infants born into abject poverty all around the world. When certain treatments are unavailable to them, these treatments become extraordinary and therefore optional. I cover the notion of ordinary and extraordinary means in the next section. But for the present, let us determine what it is about certain things that make them basic or ordinary. Ordinary things such as food, water, clothing, and shelter are necessary for a person’s overall well-being and survival (provided, of course, that they are accessible). Without them—especially food and water—life becomes miserable and/or unsustainable. Newborns need to be swaddled, as their systems are not fully developed after birth. Shelter is also especially important for infants. Not only do infants need protection from the elements, but also from communicable diseases and infection.

So far I have mentioned only physical things that count as basic care for infants. But there are nonphysical things that can also be considered basic care and should not be overlooked: human presence, love, compassion, etc. Anyone can do the following things to an infant: hold, rock, speak, sing, read, play with, etc. We usually want to do these things especially if the infant is healthy and beautiful. But what if the baby is sick or deformed in some way? People—especially nonfamily members—tend to have an aversion to anyone or anything that is somehow sick and/or deformed. But there may be another reason why an infant may not receive all the attention he needs: medical devices (e.g., incubators), tubes, wires, etc. may prevent people from being able to hold or even touch him. The attempt to provide ANH may interfere with meeting the nonphysical needs of an infant.

In *The Gospel of Life*, Wojtyla sets the stage for the dilemma by claiming normal care for sick persons should not be interrupted (117 [65]).¹² But the fact that Wojtyla does not explicitly mention ANH may leave some wondering whether he views ANH as normal care. In the 2004 address given to participants in the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” Wojtyla explicitly states his position on ANH:

The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery.

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 proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

(“Care” 205)

In making these comments, Wojtyla recalls what he says in *The Gospel of Life*. What he thought about ANH might have been clear in his own mind all along, but it probably occurred to him that others might not have held the same position. Keep also in mind that Wojtyla made these

¹² Wojtyla here refers to the CDF’s *Declaration on Euthanasia*.

comments a year before Terri Schiavo¹³ died. After her case reignited the ANH debate, the Vatican found itself having to reclarify its position and provide additional commentary in 2007 (two years after Wojtyla's death) as several bishops in the United States repeatedly found themselves facing these questions from their faithful. I shall address these considerations in chapter 4.

Before concluding my discussion of Wojtyla's position, I raise the question as to whether it is permissible to provide all forms of basic care to an infant except ANH once we can determine that he has entered the dying phase. Although not all ILTCs are in the dying phase, the Church permits the withdrawal of ANH in a dying patient's final hours. Moreover, as we have seen in chapter 1, an infant may not need food and fluids once he enters the dying phase; continued nutrition and/or hydration may cause an infant distress by preventing the body from shutting itself down. But a dying infant still needs warmth, cleanliness, and human presence. We can provide many forms of basic care. But do we need to continue to provide *all* forms of basic care? And which forms of basic care are most important if the provision of one form (e.g., ANH) interferes with another (e.g., human presence)?

2.2 Pacelli's "The Prolongation of Life"

I have briefly mentioned the notion of ordinary and extraordinary means of medical care. Most Catholic commentators who debate the use of advanced medical care invoke the difference between the two. Like most contemporary commentators who address the Catholic Church's position on the care of the sick and the dying, Wojtyla himself refers to Pacelli's speech, "The

¹³ Terri Schiavo was a patient in a permanent vegetative state (PVS) beginning in 1990 until her death in 2005. A critical consideration in her case was the fact that although she was being cared for in a Florida hospice, she was not in fact dying. Her death resulted from the court-ordered removal of her feeding tube, not an underlying condition.

Prolongation of Life,”¹⁴ so it is surprising to discover basic tensions between his position and Pacelli’s.

Pacelli delivered “The Prolongation of Life” in 1957 to a group of doctors regarding the topic of resuscitation, primarily as it pertains to anesthesiologists. Pacelli did not invent the distinction between ordinary and extraordinary means of medical care; the distinction goes back several centuries. I shall address this distinction in detail in the next few pages. The current debate over ANH for dying patients appears to hinge on this distinction. We shall see the conflict that arises if we claim—as Wojtyla does—that ANH is always to be considered an ordinary means of care. For now, however, I merely wish to introduce Pacelli’s discussion of prolonging life by artificial means.

The twentieth century witnessed advances in medicine and science—both in scope and in number—unlike any other period in history. But with many of these advances came ethical dilemmas never needing attention before. Pacelli was entering his last year of life when he delivered his speech in 1957. Had he lived longer, he might have addressed other ethical dilemmas regarding medicine and science as they arose. But since he did not, other commentators have attempted to draw parallels with his discussion of artificial respiration. But as I shall show, difficulties encountered with artificial respiration are not completely identical to difficulties encountered with ANH.

The fact that we can keep patients alive longer than we were able to in the past raises a very important question as to whether it is always in the best interests of a patient to keep him alive. That is the problem Pacelli attempts to address. Pacelli specifically addresses the notion

¹⁴ [“The Prolongation of Life”](#) (published only in Spanish at the Vatican’s website) can also be found in *Artificial Nutrition and Hydration and the Permanently Unconscious Patient: The Catholic Debate* 91-97.

of resuscitation, which he describes as “. . . the technique which makes possible the remedying of certain occurrences which seriously threaten human life, especially asphyxia, which formerly, when modern anesthetizing equipment was not yet available, would stop the heartbeat and bring about death in a few minutes” (91). He considers a variety of patients: “. . . persons who have suffered head wounds, . . . persons who have undergone brain surgery or . . . those who have suffered trauma of the brain through anoxia and remain in a state of deep unconsciousness. . .” (92). While Pacelli does not specifically address ILTCs, from the types of patients he does consider, we can assume that at least some of these newborns would warrant his consideration. In the 1950s, little could be done for such infants, but doctors can do much more to save their lives today.

Consider Pacelli’s discussion of how an anesthesiologist artificially resuscitates a patient:

It happens at times—as in . . . cases of accidents and illnesses, the treatment of which offers reasonable hope of success—that the anesthesiologist can improve the general condition of patients who suffer from a serious lesion of the brain and whose situation at first might seem desperate. He restores breathing either through manual intervention or with the help of special instruments, clears the breathing passages, and provides for the artificial feeding of the patient.

Thanks to this treatment, and especially through the administration of oxygen by means of artificial respiration, a failing blood circulation picks up again and the appearance of the patient improves, sometimes very quickly, to such an extent that the anesthesiologist himself, or any other doctor who, trusting his experience, would have given up all hope, maintains a slight hope that spontaneous breathing will be restored. (92)

But not every attempt at resuscitation is successful. Sometimes a patient's condition is so serious that it is artificial life support (e.g., a respirator) that is keeping a patient "alive." Pacelli raises the following concern:

In most cases this situation¹⁵ arises, not at the beginning of respiration attempts, but when the patient's condition, after a slight improvement at first, remains stationary and it becomes clear that only automatic artificial respiration is keeping him alive. The question then arises if one must, or if one can,¹⁶ continue the resuscitation process despite the fact that the soul may already have left the body.

The solution to this problem, already difficult in itself, becomes even more difficult when the family—themselves Catholic perhaps—insist that the doctor in charge, especially the anesthesiologist, remove the artificial respiration apparatus in order to allow the patient, who is already virtually dead, to pass away in peace.

(92-93)

A very important phrase to consider here is "the soul may already have left the body." No one—not even the Pope himself—can determine the moment at which a soul leaves a body. If a person has already died, we can say that his soul has left his body, but we cannot mark the moment of the soul's departure from the body as we can the moment of death. The problem in using modern medical equipment is that it may be machines, rather than the person himself, that give the appearances of life. While monitors can track vital signs such as body temperature, respiration, and blood pressure, they cannot track the status of the person's soul. Why is this so important? If we can determine that a person is already dead, we can remove everything from

¹⁵ Pacelli refers to a brain lesion so serious that the patient will most likely die despite the use of artificial life support.

¹⁶ Pacelli uses "can" to mean "morally permissible," not "actually capable."

him that was keeping him alive, including whatever form of ANH was employed.¹⁷ If we cannot determine this fact, then, according to Church tradition, ordinary means of life support must remain in place. If we consider ANH ordinary care as Wojtyla does, then it must remain in place.

Pacelli alludes to basic principles that will help him arrive at answers to various questions of using artificial life support:

Natural reason and Christian morals say that man (and whoever is entrusted with the task of taking care of his fellowman) has the right and the duty in case of serious illness to take the necessary treatment for the preservation of life and health. This duty that one has toward himself, toward God, toward the human community, and in most cases toward certain determined persons, derives from well ordered (sic) charity, from submission to the Creator, from social justice and even from strict justice, as well as from devotion toward one's family. (94)

Granted, not everyone is Christian. Especially for people who do not believe in God, "submission to the Creator" seems inapplicable. But even if a person does not believe in God, he can still have a sense of duty towards his family, community, or any other individual or group based on the demands of love, devotion, and justice. Pacelli does not specify what he means by "certain determined persons," but I believe we can interpret this phrase to mean specific individuals in our midst, such as family members, friends, or someone we care enough about to take care of. There may even be instances when we do not truly care for someone (e.g., a parent or grandparent with whom our relationship is strained for one reason or another), but have a

¹⁷ In "The Artificial Prolongation of Life," The Pontifical Academy of Sciences states, "Death occurs when: a) The spontaneous cardiac and respiratory functions have definitively ceased; or 2) If an irreversible cessation of every brain function is verified" (107).

responsibility to take care of him nonetheless. Or it may be the case where a person feels he cannot risk growing attached to an infant with a serious condition.

For example, years ago we had a next-door neighbor whose son was born prematurely. Since his son's lungs were underdeveloped, he needed an extended stay in the neonatal intensive care unit (NICU). A few days after his son's birth, we asked our neighbor whether he had been to the hospital yet that day to see his son. His reply was something to the effect of, "I do not want to get too close to him, in case something happens to him." The father was fulfilling certain duties toward his son by giving the doctors permission to treat him. It might very well have been the case that he had difficulty in accepting the possibility that his son could have died and was guarding his emotions, but the matter-of-fact manner in which he expressed his emotional detachment shocked everyone who was part of the conversation. As it so happened, his son survived and was unaffected by his condition.

Continuing his discussion of basic principles, Pacelli refers to what we often refer to as "ordinary" and "extraordinary means" of medical care:

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 good 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. (94)

Most, if not all, contemporary Catholic commentators cite the above passage in their arguments, as the distinction between ordinary and extraordinary means of medical care occupies center stage in the Catholic debate over end-of-life issues. This distinction can also be applied to issues not involving the end of life.¹⁸ There are many points to address, and I shall each one in turn.

The first point regards the definitions of ordinary and extraordinary means of medical care. If Pacelli means by “ordinary” those “means that do not involve any grave burden for oneself or another,” we can assume that he would define “extraordinary means” as those means that do involve any grave burden for oneself or another. The next logical question, then, is, what constitutes a grave burden? Pacelli does not give specific examples, but provides a general list of factors to take into consideration: “circumstances of persons, places, times, and culture.”

In the Catholic tradition, “ordinary” refers to that which is morally obligatory, not necessarily technically simple. Likewise, “extraordinary” refers to that which is morally optional, not necessarily technically elaborate. For example, in “End-of-Life Care Revisited,” Daniel Sulmasy, O.F.M., a doctor and Franciscan friar, recounts the argument made by Cardinal John De Lugo in the seventeenth century regarding whether a person being burned at the stake was obliged to douse himself with water to prolong his life (190). In the event that there was only enough water to douse oneself but not extinguish the fire, dousing oneself would do nothing more than prolong the agony of burning. Therefore, according to Lugo, the victim was not

¹⁸ Some conditions do not threaten an infant’s life but are incurable. As an infant, Olivia Rusk, now a teenager, developed alopecia areata, a condition in which defective white blood cells attack hair follicles, thus causing baldness. Other than completely losing her hair, Rusk does not seem to suffer any other symptoms. In the attempt to make her look “normal,” her parents had her fitted for a wig to hide her baldness. Years ago, Rusk decided to remove the wig because it was hot outside, and has not worn one since (Adams, “One Smooth Kid” 7). Decisions based on considerations of benefits and burdens related to cost, comfort, etc. of something like a wig strictly for cosmetic purposes are still decisions about what people consider to be ordinary (obligatory) or extraordinary (optional).

obliged to pour water on himself. Something as simple as water, then—at least in this case—could be considered extraordinary, not ordinary.

On the other hand, returning to the example of our next-door neighbor's son, the use of an incubator, monitors, etc. involved technically sophisticated equipment. But there was reasonable hope of the son's survival. In addition, since the mother was in the military and gave birth at a U.S. Army hospital, the family did not have to cover the cost of their son's treatment. So in this instance, technically elaborate equipment was ordinary. From these two examples, then, we can say that it is impossible to label something as ordinary simply because it is simple or found in nature, or extraordinary simply because it is somehow more complex or manmade.

Like an artificial respirator that delivers air—something we consider natural—ANH presents a challenge in that it delivers something natural (e.g., food and fluids) to a patient through artificial means (e.g., a tube or an intravenous [IV] line) and requires medical competence for placement. To appreciate all the considerations a family of an ILTC must make in this regard, it may be easiest to compare an ILTC born into a well-to-do family with one born into an underprivileged family.

Suppose these two ILTCs are in need of ANH; without it, both will die. Is each family obliged to have their child undergo the procedure? Since Pacelli says that *any* grave burden is enough to consider a form of treatment extraordinary, we need to find only one. As we have seen in chapter 1, certain forms of ANH (e.g., a nasogastric [NG] tube, the easiest to insert) are not meant for long-term use due to foreseen complications and patient discomfort. It is because of one or more underlying conditions that ANH is required in the first place. So ANH may be just one of either a few or several treatments that doctors need to discuss with families. Suppose that the procedure that gives the infants their only hope of survival is open heart surgery. Let us

also suppose that the well-to-do infant is too weak to undergo surgery; it is highly likely that he will die either on the operating table and away from his family, or from a complication resulting from surgery. At the same time, the underprivileged infant is strong enough to undergo surgery, but his family cannot afford the procedure. Open heart surgery, then, would be extraordinary and therefore optional for the well-to-do infant based on the likelihood of his dying during surgery. The same judgment would apply to the case involving the underprivileged infant based on his family's inability to pay for it. Even though forgoing surgery would result in both infants' deaths, their families would be able to continue providing ordinary forms of care, especially human presence, up to and including their infants' final moments. On the other hand, if either one of these infants is choking to death and the remedy is as simple as dislodging some object with a finger, then such a procedure is ordinary and therefore obligatory.

Second, the word "persons" is vague, so we must ask the question of whether Pacelli is taking into account the patient only, his family, and/or others beyond the family. I believe that his focus not only includes but also extends beyond the patient. As I mentioned in my example, we are dealing with both a well-to-do and an underprivileged family. The well-to-do family may have excellent medical coverage on their insurance policy, perhaps even enough money to cover the financial costs that insurance does not. The underprivileged family, we can assume, has minimal to no insurance, and not enough money to cover the cost of a doctor's visit, let alone a procedure like open heart surgery.

Notice, I have just been discussing a family's finances. What if a family is unable from an emotional or psychological standpoint to watch their infant undergo invasive surgery? The word "cost" typically refers to finances, but there are physical, intellectual, emotional, psychological, social, and/or spiritual costs associated with providing care for a loved one. We

cannot assume that ILTCs are born into families where every other family member is perfectly healthy. One or both parents may be physically debilitated. Families of ILTCs can be overwhelmed by all kinds of worries and concerns, and, coupled with an incomplete understanding of their infants' condition(s), families may not comprehend all that a doctor is explaining or suggesting to them. They may find themselves unable to make even simple choices, let alone choices that mean the difference between life and death. It may very well be the case that other incidents in the family's life have left one or both of the parents emotionally or psychologically scarred, and taking care of an ILTC is too overwhelming. Caring for anyone with a terminal condition often isolates a family from society. Hobbies, activities, friends, and groups often become much less of a priority, even though these things or people may be what family members providing care to an ILTC need most of all for their own well-being. We cannot overlook the importance of the ILTC's or the family's spiritual well-being, either, as this is a good that Pacelli (and the Church, for that matter) holds superior to any temporal good such as life or health. I shall address the notion of spiritual goods in chapter 5.

Third, places can make medical means ordinary or extraordinary. A family living in a metropolitan area may very well have access to an excellent healthcare facility, while a family living somewhere else may have to travel a considerable distance to arrive at a hospital that cannot provide cutting-edge procedures or state-of-the-art technology and equipment. But even if a family lives in a metropolitan area, their infant may have a condition that requires the family to travel extensively to a hospital specializing in treatments for that particular condition. And even if a family can afford to travel there, chances are more than likely that treatment for the condition will require the child to remain there. Are the parents then obligated to relocate and find new employment, or live out of a hotel room while they wait for the child to recover?

Situations like these can make certain treatments extraordinary. But the question remains, if a hospital can provide ANH but not the lifesaving procedure an ILTC needs to survive, must the hospital provide ANH? As we have seen in chapter 1, the answer is not as obvious as we might think, especially when ANH creates complications in addition to the ones the ITLC may already have.

When we consider places as a determining factor, we often think only in terms of the distance between a patient's home and the hospital. But we must also consider factors such as weather, road construction, etc. For example, recent tornados across the United States completely destroyed certain towns, and massive quantities of debris made many roads impassable. In some areas, health facilities were completely destroyed, and in other areas, families could not find a good road to travel on (if they still had vehicles to travel in, that is). A new health facility may replace one that was destroyed, and at some point in time, a once-impassable road will once again become usable. Perhaps a family's vehicle is now inoperable (or even missing), but someone else may offer to drive the infant to the hospital in his vehicle. But for the time being, these setbacks are real and can be deciding factors affecting the outcome of whether an infant lives or dies. As we can see, certain circumstances—even temporary ones—can change a factor's status from being ordinary to extraordinary or vice versa.

The fourth point to consider in the distinction between the ordinary and the extraordinary is the notion of "time" or "times." Like "persons," "times" is vague. We can take "times" to mean the times we live in. One hundred years ago, infants unable to assimilate food and fluids orally died. It is impossible for doctors to provide treatments that do not exist. In *The Will to*

Live: Clear Answers on End of Life Issues, Archbishop Jose H. Gomez of Los Angeles¹⁹ says, “. . . As science progresses, various methods that were previously considered medically extraordinary have become medically ordinary” (36). But as we all know, impoverished areas throughout the world do not benefit from the latest advancements such as ANH; primitive medicine may be all that some families have access to.

We can also take “time” to mean the time it takes to produce a desired benefit. A treatment’s status as ordinary or extraordinary depends on the fortuitous combination of interdependent variables such as location, the time needed for a treatment to take effect, etc. For example, inserting a percutaneous endoscopic gastrostomy (PEG) tube is a rather simple and quick procedure, but it may take a family a very long time to travel to a place where competent doctors can perform the operation. For instance, a family may get their infant to the proper facility for emergency treatment of an underlying fatal condition, only to discover that the only doctor competent to perform the procedure is unavailable. Certain procedures are so advanced now that doctors who are not qualified to perform them cannot simply take the place of a specialist. A change in any of these variables, then, can make a treatment normally considered ordinary extraordinary.

Fifth, a patient’s culture can make certain medical treatments extraordinary. The example often given is the prohibition on blood transfusions for Jehovah’s Witnesses. They believe that were they to receive transfused blood, they would suffer eternal punishment. A person’s faith is only one aspect comprising his culture. A patient’s culture is also made up of and influenced by his family, his friends, organizations to which he belongs, his ethnicity, etc.

¹⁹ At the time his book was published in 2006, Gomez was the Archbishop of San Antonio, Texas.

Illness and dying are stressful enough, but creating added anxiety over cultural issues does nothing to comfort the patient or his family. Infants may be oblivious to arguments over their care, but they can perceive stress when they are being held, which in turn causes them distress. While using cultural reasons to determine whether ANH is ordinary or extraordinary is more subjective than using objective reasons (e.g., financial costs), cultural circumstances are real, important, and worthy of consideration.

The sixth and final consideration concerns duties a family has towards not only the infant, but also themselves, other family members, and the community at large. An infant obviously has no responsibilities or duties, regardless of his health. But families have countless duties and responsibilities: parents must care for each other, their children, and other relatives. Family members need to maintain good relationships with friends, bosses, coworkers, etc. When parents bring a healthy newborn infant home from the hospital, their roles and responsibilities increase, in addition to the ones they already have. But caring for ILTCs requires even greater effort to meet all obligations imposed by family, work, etc. Parents may find themselves making routine trips to the doctor and/or the hospital. They may also find themselves feeling overwhelmed by trying to locate specialists, support groups, accurate information about such conditions, what care will involve, etc.

A primary duty for the breadwinner is to return to work so he or she can continue to support the family. Especially for families with ILTCs, it is often impossible to fulfill all duties. What if both parents were working to support the family, but now one must stay home to provide round-the-clock care? For the parent who continues to work, will his or her mind be focused on the job, or on the difficulties at home? If job performance suffers, that parent may find himself or herself out of work. Children who are already living in the home may also find themselves

having to sacrifice any number of things: extracurricular activities, jobs, or even college (if caring for the infant wipes out the family's savings). Parents would then have to deal with emotional issues such as resentment, disappointment, grief, etc. And they must find a way to help each person deal with the circumstances.

What duties or responsibilities would those caring for ILTCs have towards the community at large? It is easy to forget that when any family member is in medical distress, there are others in the community who are also suffering at the same time and may have a greater need for more medical attention. It would be a disservice to the community if a family demanded their doctor to treat their infant every single time the infant developed some kind of symptom. The time a doctor takes to see one infant is time that he cannot give to another patient. Likewise, there may be a shortage of medical supplies such as injections, units of blood, etc. There are also real limitations when it comes to transporting infants to hospitals, either by ambulance or, in some cases, helicopter. A real dilemma arises when doctors use scarce resources on an infant who is not expected to live to the detriment of other infants who are. It is unfortunate that not all infants can be saved from death. As difficult as it may be, families need to recognize that at some point, care for their infant should include the very basics they themselves can provide (e.g., warmth, cleanliness, and human presence), thus freeing up medical personnel and resources for the benefit of others.

Having considered the ways in which something can become ordinary or extraordinary, I now turn my attention toward three specific questions that Pacelli aims to address in his speech. The first question is as follows:

1. Does the anesthesiologist have the right, or is he bound, in all cases of deep unconsciousness, even in those that are considered to be completely hopeless in

the opinion of the competent doctor, to use modern artificial respiration apparatus even against the will of the family? (95)

Pacelli responds by saying, “In ordinary cases . . . the anesthesiologist has the right to act in this manner, but he is not bound to do so, unless this becomes the only way of fulfilling another certain moral duty” (95). These “certain moral duties” refer to a person’s preparing his soul for eternity (e.g., receiving final sacraments such as Viaticum [Holy Communion], Penance, or Anointing of the Sick [normally entailing both Penance and Holy Communion]). Another moral duty may be ensuring one’s last will and testament is in proper order. Last wills and testaments are normally considered legal matters, but there is also a moral dimension in ensuring one’s family is provided for after one’s death. Yet another moral duty may entail making final goodbyes to family members and friends so that they (as well as the dying person, if able) can forgive past grievances and provide closure.

Pacelli maintains that a doctor cannot take any action without the patient’s consent, as the patient has primary rights when it comes to healthcare. Again, Pacelli seems to be discussing adults who at one point in time were capable of making decisions about their own healthcare but because of accident, illness, etc. are not now. In the case of newborns, the primary rights belong to them, but they are completely dependent upon their parents for healthcare decisions. In the case of ILTCs, the chances of their surviving to an age where 1) they can understand what is happening to them; and 2) they are able to give informed consent are very small, if they exist at all. So their families must make every decision regarding their care. “Where the proper and independent duty of the family is concerned, they are usually bound to the use of ordinary means” (Pacelli 96). As we have seen from my discussion of circumstances, determining what is ordinary is more complex than many people imagine.

Given many forms of medical treatment that may be used to save a person's life, many people raise the question of whether withholding or withdrawing artificial life support constitutes killing a person. For when a person is taken off artificial life support, death occurs shortly thereafter. Pacelli says the following:

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 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*" ['indirect cause']. (96)

When a patient is placed on artificial life support, it can be difficult to determine whether natural bodily functions or the apparatus is keeping the patient alive. Before the advent of artificial life support, patients in these situations would have died because their bodies were no longer functioning properly. It is precisely because their bodies are not functioning properly that patients are placed on life support in the first place. The real question here is that of intention: what is the motive behind withholding or withdrawing life support? If one determines that the patient cannot recover without creating additional burdens (e.g., financial hardship, prolonged pain and suffering, emotional toll on family, etc.), one can, according to Pacelli, in good conscience, decide to withdraw artificial life support. It would be immoral, however, if one decides that it would be better to withdraw artificial life support to maximize one's inheritance or

avoid providing simple care. Once again, Pacelli does not address the nutrition and hydration of ILTCs, but we can assume that the considerations will be similar to those regarding resuscitation.

Let us now turn to the second question that Pacelli addresses:

2. We have, therefore, already answered the second question in essence: “Can the doctor remove the artificial respiration apparatus before the blood circulation has come to a complete stop? Can he do this, at least, when the patient has already received Extreme Unction? Is this Extreme Unction valid when it is administered at the moment when circulation ceases, or even after?” (96)

Responding to the first and second parts of the question, Pacelli says that removing the means of artificial life support is morally permissible. In order for the person to receive Extreme Unction, artificial life support should be continued until he has received the sacrament. Afterwards, artificial life support may be removed. Pacelli says that it is impossible to determine whether Extreme Unction is valid once circulation stops or shortly thereafter (96).

Responding to the third part of the question, Pacelli says that it is possible for doctors to keep particular organs alive even after circulation has completely ceased. If doctors are of the opinion that the patient’s soul has left his body, Extreme Unction cannot be given, since only living persons can receive sacraments. But if doctors are doubtful that this separation has occurred, the patient should receive Extreme Unction. Pacelli says, “But applying her usual rules: ‘The sacraments are for men’ and ‘In case of extreme necessity one tries extreme measures,’ the Church allows the sacrament to be administered conditionally in respect to the sacramental sign’ ” (96).

Determining when a person dies is important in the Catholic faith because there is an opportunity—only before death—for a dying Catholic to receive what is known as Extreme

Unction, Last Rites, or Viaticum. In this situation, the dying Catholic can receive the sacraments of Penance (i.e., make a final confession), Anointing of the Sick (for healing),²⁰ and Holy Communion in preparation for death (i.e., Viaticum). But when it comes to infants, the only sacrament they truly need is Baptism in order to be absolved of Original Sin.²¹ Since an infant has not reached the age of reason (for the Church, typically around the age of seven), there is no further sin that needs to be confessed and forgiven. And since Holy Communion is typically not administered until a child reaches the age of reason, the child's salvation is not jeopardized if he has not yet received Holy Communion.

The validity of the sacraments is a major point of concern within Pacelli's speech, but it is not a concern here. What Pacelli's answer highlights, though, is the question of what we must do when biological life continues in some manner, while the qualities that make an individual a person seem to have disappeared. The sacraments, as they are instrumental in providing grace upon which a person's salvation depends, are a form of spiritual care. As Pacelli explains, as long as there is hope in receiving grace from the sacraments, the sacraments should be administered.

²⁰ In the Anointing of the Sick, the person prays for both physical and spiritual healing. The primary emphasis is on spiritual healing, even if physical healing does not occur. "This assistance from the Lord by the power of his Spirit is meant to lead the sick person to healing of the soul, but also of the body if such is God's will" (*Catechism of the Catholic Church* n. 1520).

²¹ Even today, there is a looming, agonizing question as to what happens to infants who die without Baptism. The *Catechism of the Catholic Church* states: "As regards *children who have died without Baptism*, the Church can only entrust them to the mercy of God, as she does in her funeral rites for them. Indeed, the great mercy of God who desires that all men should be saved, and Jesus' tenderness toward children which caused him to say: 'Let the children come to me, do not hinder them,' allow us to hope that there is a way of salvation for children who have died without Baptism. All the more urgent is the Church's call not to prevent little children coming to Christ through the gift of holy Baptism" (n. 1261).

There are a few key phrases in Pacelli's response warranting further attention. The first—"separation of the soul from the body, even if particular organs go on functioning"—raises concerns about what we must do with individuals whose bodies continue to show even minimal signs of biological life. Probably the best example that is relevant here would be that of babies born with anencephaly,²² a condition which leaves them permanently unconscious and unable to feel pain (due to the absence of the forebrain and the cerebrum). Most anencephalic babies die within the first year. What may make these cases difficult is that the baby looks like a person, but will never act as a person. Because nothing can be done to correct the condition, most, if not all, people would agree that aggressive medical treatments would not be necessary because they would not improve the baby's condition. In other words, the gains (or really, lack thereof) would be disproportionate to the level of effort required—not pain on the infant's part—to keep him alive.

A key question regarding anencephalic infants would be whether they need to be fed and hydrated, or whether it is better for them not to receive alimentation so that their deaths will occur sooner rather than later. (I mean "need to be fed and hydrated" in a moral sense, i.e., someone needs to feed and hydrate them. From simply a biological standpoint, all living things need to be fed and hydrated, or else they will die.) With the consideration of food and hydration also come considerations of other basic forms of care (e.g., blankets, vaccinations, etc.) Perhaps it is because an anencephalic baby looks like a human person that we think we have the obligation to provide basic care for him. Even though an anencephalic baby cannot feel pain, we

²² I acknowledge that caring for of anencephalic infants raises ethical challenges for parents and doctors. In chapter 1, I mentioned that infants with anencephaly would fall under the category of infants who are not yet dying but who are also not suffering. See footnote 5 in section 1.4.2.

would probably be abhorred at the thought of dropping (either accidentally or intentionally) the baby on the ground.

The second phrase worth considering is “in extreme necessity one tries extreme measures.” Again, Pacelli here is speaking about administering the sacraments very close to the moment of death. If there is a chance at all for a dying patient to receive final grace for the benefit of salvation, Pacelli says it is best to administer the sacraments. But we must be careful not to extend this rule to all instances of medical treatment where a person is on some type of artificial life support. To do so would run counter to Pacelli’s earlier guidance about withholding or withdrawing extraordinary measures when they prove to be too burdensome.

The third and final question pertains to when a person is dead. Pacelli presents the question as follows:

3. “When the blood circulation and the life of a patient who is deeply unconscious because of a central paralysis are maintained only through artificial respiration, and no improvement is noted after a few days, at what time does the Catholic Church consider the patient ‘dead,’ or when must he be declared dead according to natural law (questions ‘*de facto*’ and ‘*de jure*’)?”

(Has death already occurred after grave trauma of the brain, which has provoked deep unconsciousness and central breathing paralysis, the fatal consequences of which have nevertheless been retarded by artificial respiration? Or does it occur, according to the present opinion of doctors, only when there is complete arrest of circulation despite prolonged artificial respiration?) (97)

Of the three questions, Pacelli provides the shortest response here. He says that we cannot deduce an answer to this question from religious or moral principles (97). He admits that many cases cause serious doubt:

But considerations of a general nature allow us to believe that human life continues for as long as its vital functions—distinguished from the simple life of organs—manifest themselves spontaneously or even with the help of artificial processes. A great number of these cases are the object of insoluble doubt, and must be dealt with according to the presumptions of law and of fact of which we have spoken. (97)

What constitutes human life—“vital functions” of the whole person or “the simple life of organs?” In “The Artificial Prolongation of Life,” the Pontifical Academy of Sciences reports that “. . . it has been found that when the entire brain has suffered irreversible damage (cerebral death), all possibility of sensitive and cognitive life is definitively ruled out, while a brief vegetative survival can be maintained by artificial prolongation of respiration and circulation” (107). The cases involving Karen Ann Quinlan and Terri Schiavo (both entering the permanent vegetative state [PVS] in their twenties) astounded the medical community.²³ They both remained in a PVS for several years; sustaining the simple life of their organs was accomplished through ANH. Before they became PVS patients, they were able to function as competent adults.

²³ Doctors used an artificial respirator to keep Karen Ann Quinlan alive for more than a year. Once they were allowed to remove it, she “lived” another ten years (Pence, *Classic Cases in Medical Ethics* 3-5, 7, 22). Terri Schiavo remained in a PVS for fifteen years. While she did receive various forms of therapy over the years, it was ANH—not other forms of artificial life support such as a respirator—that kept her “alive” (Echiavarria).

Now consider cases involving ILTCs. No infant is capable of the higher functions that older children or adults (in good health, that is) are capable of. If these ILTCs die by the age of two, it may remain a mystery as to what level of functioning they would have possessed were they to live beyond the age of two. If simple organs are not functioning in unison to help a person function as a human being, what moral obligations do we have toward them in terms of providing artificial life support? If we cannot ascertain that the ILTC is already dead, then operating on the assumption he is still alive, we must—according to Church tradition—provide ordinary means of life support. If we consider ANH ordinary means of life support as Wojtyla does, then we must provide this as well. But as we have just seen, ANH is not always an ordinary means, at least not if Pacelli’s statements are accepted. As we have seen in chapter 1, ANH is not trouble-free; it can create additional medical problems for a patient. These new problems raise the question of whether we must treat these as well. A vicious cycle of providing ANH and treating subsequent complications may then begin. It is my aim to avoid this vicious cycle altogether.

2.3 Status of ANH: Ordinary Care or Medical Act?

If Wojtyla had said that ANH constituted a medical act, we could regard certain cases involving ANH for ILTCs extraordinary and therefore optional under Pacelli’s considerations of the “circumstances of persons, places, time and culture.” But Wojtyla did not; instead he said, “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*” (“Care” 205). But I—as do others—question the status of ANH. It appears to be more a medical act than an ordinary form of care. It is because of these opposing positions that the

debate over ANH continues. Reconsidering the status of ANH is one step toward resolving the debate over ANH for ILTCs.

Sulmasy provides a robust investigation of several issues within the debate over the status of ANH, especially the controversial claim: “The use of feeding tubes is an act of basic human caring, and is not a medical act” (195).

Sulmasy cites several examples of feeding as a basic form of care: a mother’s feeding her child and the miracles of the multiplication of the loaves and fishes as found in the Scriptures. “And it is clear that the emotional significance of feeding tubes, and their symbolism, make the decision to withhold or withdraw feeding tubes particularly stressful for family members, even compared with the stress of forgoing other treatments” (195).

Let us consider the following argument distilled from Sulmasy’s treatment of the subject:

1. An act that requires a qualified doctor to perform it is a medical act.
2. Insertion of a PEG tube²⁴ requires a qualified doctor to perform it.
3. Therefore, insertion of a PEG tube is a medical act.
4. An act that does not require a qualified doctor to perform it is not a medical act, but “nonmedical, obligatory, ordinary care” (195).
5. Feeding a patient through a PEG tube requires training, but the person trained to feed a patient does not necessarily have to be a qualified doctor.
6. Therefore, feeding a patient through a PEG tube is nonmedical, obligatory, ordinary care.

²⁴ Although Sulmasy argues using a PEG tube as an example, any form of ANH requires qualified doctors to implant it to prevent life-threatening complications.

What we must resolve is the inconsistency between (3) and (6), that is, the insertion of a device such as a PEG tube and the subsequent use of it. Sulmasy writes,

First, logically, this would imply that withholding a PEG tube would be morally permissible, since its *insertion* is a medical act, whereas discontinuing its use once it is in place would be prohibited, since its *use* is *not* a medical act. This would be the first instance of a Catholic teaching that there is a morally relevant distinction between withholding and withdrawing care. The tradition has always consistently held that the same criteria apply to withholding as apply to withdrawing life-sustaining treatments. (195)

A second problem with the argument as it stands occurs when we compare PVS patients (the individuals under discussion in Sulmasy's article) to anyone else suffering from a chronic illness. If we regard the discontinuation of ANH as morally impermissible based on respect for the PVS patient's dignity,²⁵ then discontinuing ANH for any other patient is morally impermissible as well. Sulmasy writes, "This, of course, would have the absurd conclusion that no one dying of a chronic illness could have a feeding tube withdrawn" (196). Notice that he says "dying of a chronic illness." This is distinguishable from dying from a lack of food and fluids. Without this clear distinction, it is understandable how families can unintentionally cause their infants additional pain and/or distress by providing ANH, when their real intention is to comfort them. There are ways to comfort dying infants other than providing food and fluids. I elaborated on these other ways in section 1.3.

²⁵ The notion of dignity falls under the discussion of the sanctity of life, which I shall address in chapter 3.

According to Sulmasy, resolving the argument requires drawing the “proper parallel” (197). His examples involve a patient on an artificial respirator and a patient being fed by a feeding tube. In both cases, artificial means are being used to replace functions the patients do not possess: breathing and swallowing,²⁶ respectively (197). It is not as if we are telling these patients, “I do not permit you to have air,” or “I do not permit you to have food and fluids.” What we are saying is that they cannot, without artificial assistance, breathe or eat on their own. Sulmasy writes,

Taking the oxygen out of the air that a dying person is breathing is killing and is always wrong. Failing to provide food is allowing to die. Doing so is sometimes wrong and sometimes morally permissible. It is wrong not to feed a baby who can eat. It is not wrong to refrain from force-feeding someone dying of cancer who has lost his appetite. (197)

We must be careful with terms and phrases such as “failing” and “allowing to die.” As Sulmasy demonstrates, there are instances when we should provide food (e.g., the baby who can eat) and times when we should refrain from feeding a person (e.g., a patient dying of cancer). There is, however, a world of difference in the meanings of these following statements:

1. The baby died because the parents failed to provide food to him.
2. The baby died because the parents tried to feed him but failed.
3. Though the baby needed medical attention, the parents allowed him to die.

²⁶ To be clear, we must note that some ILTCs are able to swallow. It may be a condition such as duodenal atresia, esophageal atresia, or esophageal fistula that prevents ILTCs from assimilating food and fluids orally. So for the sake of argument, let us take “swallow” to mean “unable to adequately process food and fluids when taken orally.” This example clearly shows how, in certain regards, PVS patients are different from ILTCs. This is why there needs to be more debate over ANH for ILTCs.

4. Because medical intervention could not save the baby, the parents allowed him to die.

So Sulmasy's statement, "Failing to provide food is allowing to die," can be construed as an act of omission, or passive euthanasia. Without further clarification, someone taking Wojtyla's position could misconstrue this statement and claim that Sulmasy is advocating a practice condemned by the Church.

To draw another distinction, cancer patients can differ from ILTCs insofar as some cancer patients may have the ability to tell us they are not hungry, eating makes them sick, etc. ILTCs, on the other hand, cannot verbally tell us that they do not want food. Just as we would not want someone to feed us to the point where we have negative reactions (e.g., vomiting, reflux, bloating, diarrhea, etc.), we should not feed ILTCs to the point where they experience pain and/or distress.

Concluding his comparison between artificial respiration and ANH, Sulmasy writes,

The analogous medico-moral issues concern the interventions aimed at assisting persons who have lost these functions [of breathing and swallowing]. If that is so, then just as there are reasonable limits to the obligation one has to replace the lost function of breathing via a ventilator machine or an Ambu²⁷ bag, there are limits to the obligation one has to replace a lost ability to swallow with a pump machine or a syringe. So there seems to be no principled way to define a medical act in such a way that feeding tubes are classified as "nonmedical" while other treatment modalities that are initiated and prescribed by physicians remain classified as "medical." (197)

²⁷ "Ambu is the trademarked name of a self-reinflating bag used in resuscitation" (Sulmasy 197).

Sulmasy is concerned about the Church's becoming involved in the debate over what counts as medical or nonmedical. He asks, "Is the answer to the medical/nonmedical question of such import that the church (sic) must define which acts are, when performed by medical personnel, in fact not medical?" (198). In addition, he says that "[t]he tradition has never considered the question of whether something was 'medical' to be a criterion for distinguishing ordinary from extraordinary means of care" (198). He refers to "commonplace acts, such as traveling to a healthier climate, eating certain kinds of foods, or even eating itself have all been considered, in the proper circumstances, 'extraordinary means' under traditional analysis" (198). The Church's becoming involved now as to the medical/nonmedical debate would seem, at least in Sulmasy's opinion, a step towards "alter[ing] the tradition and mak[ing] this a decisive factor in distinguishing ordinary from extraordinary means of care" (198).

Why is Sulmasy's analysis important in the ANH debate? He states that questions regarding end-of-life care "require serious examination in advance of any formal dogmatic resolution of these hotly disputed questions" (198). We see a marked distinction between Pacelli's and Wojtyla's remarks. Pacelli gives credence to various circumstances and admits that some cases will be most difficult, if not impossible, to resolve without much anguish. Wojtyla, on the other hand, tries singlehandedly to close the debate on ANH by proclaiming that it "always represents a natural means of preserving life, not a medical act" in his 2004 address. While this is not an infallible²⁸ teaching, the fact that he gave a public address and reaffirmed

²⁸ It is important to understand what constitutes an infallible statement by a pope. First, the matter under discussion must pertain to faith and morals. Second, a pope must declare that the statement he is making is infallible (that is, he must invoke the doctrine of infallibility). Third, the pope must be speaking *ex cathedra*, that is, speaking physically from the Chair of St. Peter himself when issuing such a statement. If these conditions are not met, then the statement is not infallible. To date, only two infallible statements have been promulgated in the entire history of

what he wrote in an encyclical, a recognized medium of his teaching office, carries much weight.

The United States Conference of Catholic Bishops (USCCB), however, implies that ANH is a medical act when it uses the phrase “medically assisted nutrition and hydration” as a section heading in its “Nutrition and Hydration: Moral and Pastoral Reflections.”

But the question remains: is ANH a medical act or ordinary care? ANH requires a medical act to insert the feeding tube, but once it is in place, it delivers food and fluids, things that are typically considered ordinary. ANH is not a “place-and-forget” procedure, nor are feeding tubes “place-and-forget” devices. Insofar as ANH requires medical personnel to oversee the procedure and consult with families regarding the cleaning and maintenance of feeding tubes and associated equipment, the treating of complications as they arise, etc., I regard ANH as a medical act. Families also sometimes provide care for patients on respirators with oversight from medical personnel, but that does not make the maintenance of respirator-dependent patients a nonmedical process. In order for us to rethink the Catholic position on ANH, we must consider it to be a medical act.

2.4 Redefining “Ordinary” and “Extraordinary”

Medical and technological advances can render terms such as “ordinary” and “extraordinary” obsolete when these terms do not take into consideration many of the factors in situations that modern families find themselves in when caring for ILTCs. Therefore, definitions

the Roman Catholic Church: the Doctrine of the Immaculate Conception (by Pope Pius IX in 1854) and the Doctrine of the Assumption of the Blessed Virgin Mary (by Pope Pius XII in 1950). No infallible statements have ever been made about morals. Many people—including lifelong, faithful Catholics—are surprised to learn that Pope Paul VI’s encyclical *Humanae Vitae* (which condemned the practice of artificial contraception) is not an infallible teaching. Nevertheless, Catholics are encouraged to inform themselves to the point where they can understand the teaching and live in accordance with it. Papal infallibility has nothing to do with a pope’s being unable to sin. As Pope, Wojtyla was famously known for going to confession once a week.

for terms such as “ordinary” and “extraordinary” must be reviewed and refined. While my comments surely will not put an end to the debate over ANH for ILTCs, they may at least keep the debate open and even be one step closer to resolving it.

In “A History of Ordinary and Extraordinary Means,” Donald E. Henke mentions that in 1950, Gerald Kelly classified artificial means to help sustain life “as a remedy for a particular disease or illness. The distinguishing characteristic of a remedy was that an individual might employ it as a useful means toward recovering from or halting a disease” (61). Sometimes, however, an illness, condition, or injury so overwhelms a patient that no matter what remedy is attempted, it cannot stop the dying process. It is upon this realization that we may call a remedy useless. But we must be careful in how we label medicines, procedures, and so forth. ANH is an artificial remedy for malnutrition or dehydration, but it by itself cannot cure an ILTC of the underlying condition(s) that will eventually cause his death. Commenting on Kelly’s position, Henke says, “Simply because a means to preserve life was not completely natural did not mean that it automatically became extraordinary” (61). Agreeing with Kelly, Daniel Cronin in 1958 wrote, “‘[T]he terms artificial means and extraordinary means are not coextensive. An artificial means can be an ordinary means of conserving life’ ” (61). But when ANH does not seem to help an ILTC who is dying from one or more underlying conditions, it appears that ANH is an artificial means that becomes extraordinary.

Kelly’s contributions helped establish definitions based on 400 years of intense debate. Kelly’s definitions of ordinary and extraordinary means are as follows:

Ordinary means are all medicines, treatments, and operations, which offer a reasonable hope of benefit and which can be obtained and used without excessive expense, pain, or other inconvenience.

Extraordinary means are all medicines, treatments and operations, which cannot be obtained or used without excessive expense, pain, or other inconvenience, or which, if used, would not offer a reasonable hope of benefit. (62)

Not everyone, however, was content with Kelly's definitions. Cronin, for example, believed that Kelly focused too exclusively on medical procedures. Cronin thought other considerations were just as important: "physical condition, mental and emotional state, etc." (62). Cronin's definitions of ordinary and extraordinary are as follows:

Ordinary means of conserving life are those means commonly used in given circumstances, which this individual in his present physical, psychological and economic condition can reasonably employ with definite hope of proportional benefit.

Extraordinary means of conserving life are those means not commonly used in given circumstances, or those means in common use which this individual in his present physical, psychological and economic condition cannot reasonably employ, or if he can, will not give him definite hope of proportionate benefit. (63)

As we can see from Cronin's definitions, the patient is given more latitude to decide for himself what he may or may not want. As I have mentioned before, parents of ILTCs find themselves making these decisions as proxies.

Even after redefining "ordinary" and extraordinary," there may still be confusion, since these terms can be used in both the medical and moral sense (Gomez 37). "Proportionate" and "disproportionate," therefore, may provide greater clarity. Gomez says, "The terms ethically

ordinary and extraordinary are interchangeable with the terms ethically proportionate and disproportionate as they apply to life-sustaining methods” (37). Defining “proportionate,” he refers to Directive 56 of *The Ethical and Religious Directives for Catholic Health Care Services* (ERDs):

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. (37)

Defining “disproportionate,” Gomez refers to Directive 57 of the same document:

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 community. (37-38)

Having in mind the notions of “proportionate” and “disproportionate,” I believe that Cronin’s definitions can be refined even further to reflect Pacelli’s considerations of the family and the community at large. I propose my definitions below. For the sake of clarity, I provide separate definitions of these terms for patients themselves and for those deciding and acting on their behalf (e.g., parents of ILTCs).

1a. *Ordinary (or proportionate) means of conserving life* are those means commonly used in given circumstances, which this individual (i.e., this patient) in his present and future physical, psychological and economic condition can reasonably employ with definite hope of benefits that outweigh burdens for himself.

1b. *Ordinary (or proportionate) means of conserving life* are those means commonly used in given circumstances, which others deciding for and acting on

an individual's behalf in their present and future physical, psychological and economic condition can reasonably employ with definite hope of benefits that outweigh burdens for the individual and/or themselves.

2a. *Extraordinary (or disproportionate) means of conserving life* are those means not commonly used in given circumstances, or those means in common use which this individual (i.e., this patient) in his present and future physical, psychological and economic condition cannot reasonably employ, or if he can, will not give him definite hope of benefits that outweigh burdens.

2b. *Extraordinary (or disproportionate) means of conserving life* are those means not commonly used in given circumstances, or those means in common use which others deciding for and acting on an individual's behalf in their present and future physical, psychological and economic condition cannot reasonably employ, or if they can, will not give them definite hope of benefits that outweigh burdens for the individual and/or themselves.

While an ILTC is primarily affected by his condition(s) on the physical level, his family and others in the community suffer not only on the physical level, but also the psychological, economic, and other levels such as the social and spiritual. Consideration of the present and the future is also important. Successful or failed treatment results do not always present themselves immediately. Doctors and families may have to wait to determine whether certain treatments deliver expected benefits. Doctors may give a hopeful prognosis, only to find that the patient is not responding well to treatment. Likewise, doctors may give a grim prognosis, only to discover the patient responding better than expected. Also, regardless of how the ILTC responds to a treatment, the burdens and benefits to the family of extended NICU care will continue to unfold

far into the future. As we can see from redefining “ordinary” and “extraordinary,” the debate over whether to administer, continue, withhold, or withdraw must take much more into account than the claim that ANH must be provided on the basis that it employs relatively simple equipment or does not cost very much.

Because we are dealing with human beings, there will always be difficulties when making choices based on estimates (e.g., time left to live, whether or not certain treatments will work, what side-effects a patient may encounter, etc.). Even though two ILTCs may have the same condition, their families may arrive at completely different decisions based on their respective extenuating circumstances. While no one wants to make mistakes—especially in matters where mistakes cost lives—they do happen. But families cannot put off making these difficult decisions indefinitely for this reason. Waiting until they are sure of their decisions is not really any different from deciding. If families are this fearful of making mistakes, it is even more important for doctors, pastors, and chaplains to give them useful information and unwavering support.

2.5 Conclusion

It is important to revisit the notion of why food and fluids are always considered ordinary and therefore obligatory, at least in Wojtyla’s opinion. Recall that not all technically simple means of care are ordinary. Conversely, not all technically complex means of care are extraordinary. As medicine and technology have advanced, means that would have been extraordinary in the past are now considered ordinary. That is why I believe it is especially important to redefine “ordinary” and “extraordinary.” These definitions need to take into account circumstances that modern families find themselves in when caring for ILTCs. Wojtyla does not provide an argument for the view that providing food and fluids is always ordinary; he

simply states that it is. Since Pacelli does not address ANH in his speech, we must question whether Wojtyla has read too much into Pacelli's responses about resuscitation and, as a result, placed an undue burden on ILTCs and their families.

Not all infants are born healthy. Some may recover with a minimal amount of medical care. Others may recover after undergoing much more aggressive treatment. Still others may survive but may nevertheless be permanently affected by their conditions (e.g., trisomy 21, or Down syndrome) no matter what treatment is attempted. The "culture of life"—coined by Wojtyla (whose name is synonymous with being pro-life)—calls for the protection of every human life, but we must accept the fact that some infants will die before the age of two, no matter what treatment doctors attempt. The major concern with withholding or withdrawing ANH is that for Wojtyla and others within the Catholic tradition (including some bishops), it is a form of prolonged neglect. The culture of life finds its roots in the sanctity-of-life ethic, which is often viewed as the antithesis of the quality-of-life ethic. In chapter 3, I will discuss both of these ethics and propose a way to reconcile them using the principle of contentment.

Chapter 3: Reconciling the Sanctity- and Quality-of-Life Ethics within the Culture of Life

Even if we were to become what Wojtyla calls a “culture of life,” we would still have to face the reality that some infants are born with life-terminating conditions and will die before the age of two. Wojtyla believes that every human life—including the life of every infant with life-terminating conditions (ILTC)—is sacred and no one is permitted to violate it. His notion of the culture of life promotes what many people understand to be the sanctity-of-life ethic. But there is another ethic at work within Catholic teaching, the quality-of-life ethic, which can be used to determine what should be done in cases where there seems to be little to no quality left to a person’s life. Wojtyla’s fear is that if judgments about life are based solely on quality, then those who do not “measure up” are in danger of being aborted, euthanized, or executed. Wojtyla holds that artificial nutrition and hydration (ANH) constitutes an ordinary form of care; therefore, it is wrong to withhold or withdraw ANH from ILTCs unless they are just about to die (i.e., in their final hours). ANH, however, can cause harm. So even if we hold life to be sacred (as the sanctity-of-life ethic does), we must make decisions based on the ILTC’s present and future quality of life if we are to avoid causing further harm by the use of ANH. Wojtyla would object to my proposals about withholding and withdrawing ANH from an infant on the grounds that it violates the sanctity-of-life ethic. He would claim that my proposals are based merely on a quality-of-life ethic. But I believe that these two ethics can be reconciled using the principle of keeping an infant content.

3.1 Revisiting the Culture of Life

I introduced what Wojtyla thinks the culture of life would look like in chapter 2. Probably the closest that Wojtyla comes to defining the “culture of life” is as follows:

In a word, we can say that the cultural change which we are calling for demands from everyone the courage to adopt a new life-style, consisting in making practical choices²⁹—at the personal, family, social and international level—on the basis of a correct scale of values: *the primacy of being over having, of the person over things*. This renewed life-style involves a passing *from indifference to concern for others, from rejection to acceptance of them*. Other people are not rivals from whom we must defend ourselves, but brothers and sisters to be supported. They are to be loved for their own sakes, and they enrich us by their very presence. (*Gospel* 174 [98])

Individuals whom we consider “less than perfect” should not be judged to be worthless or expendable. As I shall argue, making decisions based on an ILTC’s quality of life is not a judgment of worthlessness or expendability. The sanctity of life permits natural death and thus does not require that we always prolong life. But then the question arises as to when it is permissible to let natural death occur.

Deciding to withhold or withdraw life-prolonging procedures (e.g., an artificial respirator) is a very delicate and complicated matter. It is not always clear whether an infant will survive if he is taken off the respirator, and often, doctors can only give a best estimate as to his prognosis. Death may occur if the infant is taken off the respirator, but it may still occur even if the infant is left on it. When there is little to no hope of recovery (e.g., the infant has several life-terminating conditions causing system failure), the Church permits the removal of life-prolonging equipment.

²⁹ It is my hope that the Church can provide families with practical moral guidance to help them make practical choices. To review what I mean by “practical moral guidance,” See footnote 10 in section 2.1.

ANH is a different matter, however. It is a fact that the complete suspension of food and fluids will result in death, not only for terminal infants, but for anyone at all. In the case of removing a terminal infant from the artificial respirator, the Church recognizes the act as one of allowing death versus euthanizing the infant. But unless the infant is in the final stages of dying, or what the U.S. Bishops in “Nutrition and Hydration: Moral and Pastoral Reflections” call “imminently dying” (119), complete suspension of food and fluids is viewed by the Church as an act of euthanasia and therefore prohibited.

Wojtyla’s words carry great weight because he speaks as Pope. But other high-ranking Church officials have also commented on the sanctity of life. Joseph Cardinal Bernardin (1928-1996), Archbishop of Chicago, delivered one of the most influential statements to ever come out of the Catholic Church in the United States on the topic of the universality of the sanctity of life. I now turn to his address.

3.2 Bernardin’s “Seamless Garment”: A Consistent Ethic of Life

In his 1983 address entitled “A Consistent Ethic of Life: An American-Catholic Dialogue,”³⁰ Bernardin notices that despite the efforts to incorporate teachings from the Catholic moral tradition (e.g., St. Thomas Aquinas’ *Summa Theologiae*) into arguments as to why we should respect human life, the Church had not provided up to that point a framework to support a consistent ethic of life. It would be an inconsistency to condemn abortion but support nuclear deterrence, or vice versa. In his introduction, Bernardin says, “No other major institution presently holds these two positions [on abortion and nuclear deterrence] in the way the Catholic

³⁰ [“A Consistent Ethic of Life: An American-Catholic Dialogue”](#), delivered at Fordham University, was a reflection on [“The Challenge of Peace: God’s Promise and Our Response”](#), the pastoral letter addressing war and peace. The National Conference of Catholic Bishops (NCCB), now the United States Conference of Catholic Bishops (USCCB), published the letter in May of 1983.

bishops have joined them.” He wants to show how these two issues are linked, and what the resulting ramifications would be when we consider other matters pertaining to human life. His purpose for the address is to clarify “the Church’s role in helping to shape a public policy debate” (sec. 1).

In essence, we notice an inconsistency if, on one hand, we condemn abortion because “the fetus is judged to be both human and not an aggressor” but allow the presence of nuclear arms as a form of deterrence, even though the use of nuclear arms would be a “[direct] intended [attack] on civilian centers” (sec. 2). Civilians not directly involved in the war cause are considered innocents. So we see the inconsistency here: one group of innocent persons (unborn children) is granted protection, while another group is not. And, of course, we can see the inconsistency in the other direction: we grant innocent civilians protection from being targeted during war, while at the same time, allow the abortion of unborn children (on the assumption, of course, that fetuses are indeed persons). A consistent ethic of life, he argues, respects life—regardless of its form or condition—from “womb to tomb,” that is, from the moment of conception to the moment of natural death.³¹

The purpose of Bernardin’s address is not to spell out in detail possible solutions to problems such as killing soldiers during war or executing condemned criminals. He leaves that to the audience. The solution, he says, lies in a *change of attitude* towards life itself. In addition, he says that “an inner relationship does exist among several issues not only at the level of general

³¹ The consistent ethic of life that Bernardin presents here is often referred to as the “seamless garment”—though he himself does not use this phrase in this address—referring to the seamless garment for which the Roman soldiers cast lots at Jesus’ crucifixion. The soldiers recognized the value of such a garment and decided not to tear it (John 19.23-24). Valuing life in the same regard, we should avoid doing anything that “tears” life’s fabric.

attitude but at the more specific level of moral principles” (sec. 2). Consider what he says about how far this attitude should extend:

If one contends, as we do, that the right of every fetus to be born should be protected by civil law and supported by civil consensus, then our moral, political and economic responsibilities do not stop at the moment of birth. Those who defend the right to life of the weakest among us must be equally visible in support of the quality of life of the powerless among us: the old and the young, the hungry and the homeless, the undocumented immigrant and the unemployed worker. Such a quality of life posture translates into specific political and economic positions on tax policy, employment generation, welfare policy, nutrition and feeding programs, and health care. Consistency means we cannot have it both ways. We cannot urge a compassionate society and vigorous public policy to protect the rights of the unborn and then argue that compassion and significant public programs on behalf of the needy undermine the moral fiber of the society or are beyond the proper scope of governmental responsibility. (sec. 2)

Notice that in his discussion, Bernardin mentions the “quality of life.” In the last several years, “quality of life,” when used as an ethic, has been taken to mean some kind of measuring stick against which to determine whether particular individuals’ lives should be prolonged or not. But Bernardin talks here about this notion in terms of improving everyone’s living conditions. A compassionate society, on his view, requires judgments about the quality of life. Wojtyla does the same in *The Gospel of Life*: “Another welcome sign is the growing attention being paid to the *quality of life* and to *ecology*, especially in more developed societies, where people's expectations are no longer concentrated so much on problems of survival as on the search for an

overall improvement of living conditions” (50 [27]). Our challenge here is to somehow incorporate the notion of the quality of life into Wojtyla’s culture of life, which is, in turn, based on the sanctity of life. We must try to find practical solutions—as Bernardin suggests—to this very real problem.

3.3 What Do We Mean by “Life?”

When we use phrases such as “culture of life,” “sanctity of life,” and “quality of life,” we must ask the critical question, what do we mean by “life?” Christianity recognizes the distinction between earthly and heavenly existence. At the same time, Christianity often uses the term “life” equivocally, especially when addressing pro-life issues such as abortion, euthanasia, and capital punishment. We can talk about how certain actions can affect a person’s biological life, his family life, his social life, his religious life, his eternal life, etc. I believe that it is on account of these several different meanings that there is some confusion as to what exactly the “culture of life” is. Let us examine some of Wojtyla’s statements about “life”:

- The life which God bestows upon man is much more than mere existence in time. It is a drive towards fullness of life; *it is the seed of an existence which transcends the very limits of time*: “For God created man for incorruption, and made him in the image of his own eternity” (*Wis 2:23*). (62 [34])

- The life which the Son of God came to give to human beings cannot be reduced to mere existence in time. (66 [37])

- Sometimes Jesus refers to this life which he came to give simply as “life”, and he presents being born of God as a necessary condition if man is to attain the end for which God has created him: “Unless one is born anew, he cannot see the kingdom of God (*Jn 3:3*). To give this life is the real object of Jesus’ mission: he

is the one who “comes down from heaven, and gives life to the world” (*Jn* 6:33).

(66 [37])

- At other times, Jesus speaks of “eternal life”. Here the adjective does more than merely evoke a perspective which is beyond time. The life which Jesus promises and gives is “eternal” because it is a full participation in the life of the “Eternal One”. (66 [37])

- Jesus himself, addressing the Father in the great priestly prayer, declares what eternal life consists in: “This is eternal life, that they may know you the only true God, and Jesus Christ whom you have sent” (*Jn* 17:3). (67 [37])

- Eternal life is therefore the life of God himself and at the same time the *life of the children of God*. (67 [38])

As we would expect, Wojtyła’s aim is directed toward God. This makes sense, as *The Gospel of Life* is first and foremost a theological document. But this is not to say that Wojtyła discredits our existence in time as embodied creatures. The problem is that if we do not completely understand what Wojtyła is calling for in *The Gospel of Life*, we may place ourselves in a position where we find ourselves providing ANH to infants who do not need it, or worse, creating unnecessary distress for them.

Eternal life is not the same as earthly life. Many people believe that in order to attain eternal life, they must take care of earthly things—including their bodies—as a means of cooperating with God’s plan. The problem with appealing to cooperating with God’s plan is that we can never truly be certain what that might be. Since earthly life does have a temporal end, we have a duty to take care of it until it reaches its completion. When or how this completion occurs is, in many instances, unfathomable. That is why dealing with end-of-life issues—especially in

an age where modern medical technology can prolong biological life indefinitely—has become more difficult than it was in the past. Now that we have access to much more advanced medicine and technology, we must ask, “Am I doing God’s will by prolonging my infant’s life until every medical procedure available is attempted but fails, or am I doing God’s will by allowing my infant to die without all the assistance of modern medicine?” There is no way of knowing for sure, but we want to spare families from lifelong guilt and suffering, especially suffering that comes from second-guessing decisions made for their infants regarding end-of-life care.

Recall Pacelli’s admonition that temporal goods are always subordinate to eternal goods.³² No matter what route we take, we are still left with the question of how best to care for people who are, undeniably, bodily creatures and require care that they cannot provide for themselves.

3.4 Inheriting Eternal Life: Lessons from the Gospels

For Wojtya, fullness of life is found in Jesus Christ. Many people are familiar with Jesus’ miracles, many of which involved healing of the sick. What was so significant about these kinds of miracles? Certainly, when people were cured of their illnesses and conditions, they were better able to go about their daily lives. Hearing about Jesus’ powers, people sought Him out so that He might cure them of their ailments. From a socio-religious standpoint, many ailments rendered a person ritually unclean, resulting in his being treated as an outcast from

³² We learn in chapters 23 through 25 in the first book of *Bede’s Ecclesiastical History of England* that at the end of the sixth century, Pope Gregory I (Gregory the Great) sent St. Augustine of Canterbury and his missionaries to England. Gregory recognized the importance of providing temporal goods such as medical care and education, but of utmost importance to him was spreading the Gospel so that the English would be saved. St. Augustine’s first act upon arriving in Kent was converting King Ethelbert. Only after his conversion did the King allow St. Augustine and his missionaries to provide temporal goods to the English people.

society. Even today, society tends to treat sick people as outcasts—not so much based on ritual uncleanness—but perhaps out of fear of being reminded that at some point in their lifetimes, they themselves may become sick and/or debilitated.

Jesus, however, was not intent upon healing just physical ailments, but, more important, healing souls from sin's effects. Sin is to the soul what sickness is to the body. Just as sickness can isolate a person from the community in which he lives, sin separates a person from God. Catholics believe that if a person dies with venial sin on his soul, a process of purification (e.g., a “stay” in Purgatory) is necessary before entering heaven, since without holiness, “no one will see the Lord” (Heb. 12.14). A person dying with mortal sin on his soul, however, suffers eternal damnation.

Jesus' answer to the question of inheriting eternal life is the parable of the Good Samaritan, which is quoted again and again in the literature on ANH:

There was a scholar of the law who stood up to test [Jesus] and said, “Teacher, what must I do to inherit eternal life?” Jesus said to him, “What is written in the law? How do you read it?” He said in reply, “You shall love the Lord, your God, with all your heart, with all your being, with all your strength, and with all your mind, and your neighbor as yourself.” He replied to him, “You have answered correctly; do this and you will live.”

But because he wished to justify himself, he said to Jesus, “And who is my neighbor?” Jesus replied, “A man fell victim to robbers as he went down from Jerusalem to Jericho. They stripped and beat him and went off leaving him half-dead. A priest happened to be going down that road, but when he saw him, he passed by on the opposite side. Likewise a Levite came to the place, and when he

saw him, he passed by on the opposite side. But a Samaritan traveler who came upon him was moved with compassion at the sight. He approached the victim, poured oil and wine over his wounds and bandaged them. Then he lifted him up on his own animal, took him to an inn and cared for him. The next day he took out two silver coins and gave them to the innkeeper with the instruction, ‘Take care of him. If you spend more than what I have given you, I shall repay you on my way back.’ Which of these three, in your opinion, was neighbor to the robbers’ victim?” He answered, “The one who treated him with mercy.” Jesus said to him, “Go and do likewise.” (Luke 10.25-37)

The kind of life Jesus promises in the Gospels is everlasting life with God in heaven. Even though eternal life is a gift from God, Catholics believe that we must cooperate with God’s will in order to share in this gift.³³ We cannot do anything we please and hope to inherit eternal life just because we presume that God is loving and forgiving. Notice that the young man asks Jesus what he must *do* to inherit eternal life. Obeying the two greatest commandments (love of God and love of neighbor) is essential. But also notice that when the young man asks Jesus for clarification, Jesus responds with a story about one person helping another in need. At the very end, Jesus says that we must *do* likewise. So actions of some type are necessary.

Let us look more closely at the Good Samaritan’s actions. Jesus says that the Good Samaritan poured oil and wine over the victim’s wounds, and bandaged them. In *The Cultural Dictionary of the Bible*, John J. Pilch says that oil—most likely olive oil—could be used “as a

³³ To cooperate with God’s will in His plan of salvation runs counter to the fifth-century heresy known as Pelagianism, which [denied] . . . our need for divine help in avoiding sin and . . . [insisted] that we could earn our salvation by our own efforts” (Thomas Bokenkotter, *A Concise History of the Catholic Church* 68).

salve for wounds” (55). *The New World Dictionary Concordance to the New American Bible* states that “[w]ine was also noted for some of its therapeutic qualities” (“Wine”). The Samaritan performed what we today would probably call “first aid.” The Samaritan’s main intent—or so it seems—was to get the victim off the road and to a place where he might recuperate. It appears that he kept watch over the victim through the night. Though he had no obligation to do so, he paid for the victim’s stay at the inn and even promised to pay any additional fees that the victim might have incurred.

Without further details, we are left asking further questions. Did the victim live, or did he die from his wounds? Was there a doctor available who could have done more than the Samaritan or the innkeeper? If the victim lived, what was his quality of life afterwards? If Jesus’ main intent was to show how far our love should extend (e.g., even to our enemies, as there was at that time great enmity between Jews and Samaritans), then these other details might not have been so important for Him to address. But especially today, when we have access to modern medicine, equipment, and technology, we must ask, what is the extent to which we should care for a sick person? If the Samaritan was traveling with silver, he was probably wealthy. What happens today if a sick person or his family does not have the means to pay for medical care? If the victim was half-dead, he might not have been able to eat for quite some time. Feeding him while unconscious would have proven fatal. At the same time, he could have died from his injuries without ever regaining consciousness or the ability to eat. If a person is dying, it may be in his best interests not to eat or drink.

Another passage from the Gospels often appears in the literature on ANH, especially in the mandates to Catholic healthcare workers “‘to cure if possible, always to care’ ” (Wojtyła, “Care” 207). Jesus speaks about the rewards we will receive if we feed the hungry: “‘Amen, I

say to you, whatever you did for one of these least brothers of mine, you did for me' ” (Matt. 25.40). But what if we decide not to? Jesus also warns of punishments to come:

“Then [the Son of Man] will say to those on his left, ‘Depart from me, you accursed, into the eternal fire prepared for the devil and his angels. For I was hungry and you gave me no food, I was thirsty and you gave me no drink, a stranger and you gave me no welcome, naked and you gave me no clothing, ill and in prison, and you did not care for me.’ Then they will answer and say, ‘Lord, when did we see you hungry or thirsty or a stranger or naked or ill or in prison, and not minister to your needs?’ He will answer them, ‘Amen, I say to you, what you did not do for one of these least ones, you did not do for me.’ And these will go off to eternal punishment, but the righteous to eternal life.” (Matt. 25.41-46)

Again, the fact that Wojtyla speaks as head of the Catholic Church and quotes Jesus Himself on what we may expect at our judgment carries great weight for anyone encountering others who need care, and not just those whose profession it is to provide care. It is understandable, then, that families agonize over end-of-life decisions, especially if they take seriously Jesus’ words about heaven and hell.

A very subtle point to consider—but one which I think has significant ramifications—is Jesus’ statements about being hungry, thirsty, and sick. Notice that the requirement to give food or drink to someone is a response to the person’s being hungry or thirsty. Recall from chapter 1 that modern clinical evidence suggests that when a person is ill or dying, he may not actually be hungry or thirsty. “Tube feedings [and] IVs . . . are obviously not the same thing as eating [and] drinking. Not only are they mechanical and not responsive to our feelings of hunger [and] thirst

. . . but they also are troubling, uncomfortable, and efficient—just what human contact is not” (Lynn and Harrold 130). Notice, finally, that Jesus expects us to *care for* or *visit* the ill. There are many ways to care for a sick or dying person that do not necessarily involve feeding or hydrating him. We must be careful to distinguish *what a person needs* from *what we think he wants*.

In *The Gospel of Life*, Wojtyla twice mentions the parable of the Good Samaritan. In the first instance, Wojtyla praises those people within the Church who have followed “the example of Jesus the ‘Good Samaritan’ . . . freely giving of themselves out of love for their neighbour, especially for the weak and needy” (49 [27]). Citing Matthew 6.6, Wojtyla refers to rewards bestowed by God that these people will enjoy both in this life and in the next (48-50 [27]).

In the second instance of referring to the Good Samaritan, Wojtyla says the following:

By his words and actions Jesus further unveils the positive requirements of the commandment regarding the inviolability of life [i.e., “You shall not kill”]. These requirements were already present in the Old Testament, where legislation dealt with protecting and defending life when it was weak and threatened: in the case of foreigners, widows, orphans, the sick and poor in general, including children in the womb (cf. *Ex* 21:22; 22:20-26). With Jesus these positive requirements assume new force and urgency, and are revealed in all their breadth and depth: they range from caring for the life of one’s *brother* (whether a blood brother, someone belonging to the same people, or a foreigner living in the land of Israel) to showing concern for the *stranger*, even to the point of loving one’s *enemy*.
(71-72 [41])

Wojtyla does not go into detail here as to what care should be provided. What we must then ask is how we will accomplish this care, for medical care may involve a complicated web of many types of simple actions, administration of various medications, complicated and/or invasive procedures, and people (e.g., family members, nurses, physicians, specialists, etc.). Wojtyla arrives at the conclusion that “the deepest element of God’s commandment to protect human life is the *requirement to show reverence and love* for every person and the life of every person” (72 [41]). Wojtyla cites Paul’s letter to the Romans: “Love does no evil³⁴ to the neighbor; hence, love is the fulfillment of the law” (Rom. 13:10).

We must be very careful not to harm an ILTC in providing medical care. We may have no intention of doing so, but if we are not aware of the unintentional harm we may cause, we may nevertheless subject the infant to unnecessary pain and distress. Even if one medical treatment is deemed a success, it may create a complication that in itself is not life-terminating, but may still cause the infant pain and/or distress. Also, doctors should not assume that just because a treatment has proven successful in the past, the ILTC undergoing treatment here and now will respond well to it.

3.5 The Sanctity-of-Life Ethic

Doing no harm to a person is at the heart of the sanctity-of-life ethic. Let us now turn our attention to the sanctity-of-life ethic, and especially to the concerns that it raises. Consider first the propositions that it defends. In “Who Shall Live?” Leonard Weber defines them as follows:

1. That human life is sacred by the very fact of its existence; its value does not depend upon a certain condition or perfection of that life.

³⁴ In quoting this verse from Romans, Wojtyla’s text states, “Love does no *wrong* to a neighbour. . .” (emphasis added). We can also safely substitute “harm” here as well. The point we should take away from this verse is that we should not do violence to anyone against his will.

2. That, therefore, all human lives are of equal value; all have the same right to life. (111)

Where does the first proposition come from? Why is human life sacred? Catholics (and some non-Catholics, too) look to the first story of creation in Genesis. On the sixth day, God created the beasts, creeping things, and finally man. But something peculiar happened when God created man:

Then God said: “Let us make man in our image, after our likeness.³⁵ Let them have dominion over the fish of the sea, the birds of the air, and the cattle, and over all the wild animals and all the creatures that crawl on the ground.” God created man in his image, in the divine image he created him; male and female he created them. (Gen. 3.26-27)

God did not utter words about imparting His image and likeness to anything else He created, not even the more intelligent animals such as the higher primates and dolphins. For our purposes here, I leave it as a given that we are created in God’s image and likeness. But a reasonable question to ask is, why do human beings exclusively have this special status? There seems to be no clear answer to this question. In *Feeding the Dying: Religion and End-of-Life Decisions*, Patricia Talone states that many people accept the teachings of Augustine of Hippo and Thomas Aquinas as to how we are created in the image and likeness of God: it is because of our rational intellect (51-52).

This threshold appears at first to be a possible solution, but Talone highlights a very serious consideration:

³⁵ Many people wonder to whom God is speaking when He says: “Let *us* make man in *our* image, after *our* likeness” (emphasis added). A possible interpretation is that this was a conversation among the Three Divine Persons of the Holy Trinity (Father, Son, and Holy Spirit).

. . . [W]hen we wrongly locate the essence of the human in functional rationality (alone) we automatically assume a hierarchical structuring that relegates those who do not possess the acceptable reasoning skills to the lower strata of being. Obviously this is prejudicial to those who may not “measure up” to the highest standards of what it means to be rational. Children, the mentally handicapped and the illiterate, not to mention women, are frequently treated as if they are not truly human, an abuse with striking ethical overtones for the treatment of the sick and dying. (52)

So if we accept the two sanctity-of-life propositions, we find ourselves bound to care for all human life from womb to tomb. Imperfections (i.e., physical or mental handicaps, or combinations of both) do not absolve us from this responsibility. ILTCs who do not live past the age of two will never meet standards based on reasoning skills.

But when human life is unable to sustain itself (as in the case of ILTCs), and the means of caring for it seem to cause more problems than they solve, we must reexamine what it is that the sanctity-of-life ethic demands. The problem that ILTCs face is that their conditions jeopardize their very survival. It is one thing if an infant is truly dying and no matter what is done, death is imminent. It is another thing entirely, though, if an infant may be kept alive but only with medical treatments and procedures, or if the infant is not yet dying but is also not expected to live beyond the age of two. Especially if an infant is severely handicapped—both mentally and physically—there is really no opportunity for him to develop to a point where he can experience what life has to offer or appreciate it. According to the sanctity-of-life ethic, decisions to terminate life cannot be made for this reason. But Weber also says, “It should be noted very carefully, though, that the sanctity of life ethic does *not* insist that everything possible

must be done to prolong life in all cases; it is not opposed to the practice of withholding or ceasing treatment at times. That does not directly attack the goodness of life; it recognizes that death is natural and that life is not the only good to be concerned with” (113).

What are other goods to consider? Recalling Pacelli’s speech, we are reminded that eternal goods (e.g., truth, virtue, eternal life, etc.) are superior to temporal goods (e.g., health, beauty, money, etc.). In the case of ILTCs, however, none of these goods are things that they themselves can appreciate. If a baptized infant dies, Catholics believe that his soul will go straight to heaven, since the stain of Original Sin is removed, and the infant is incapable of committing any other sins.³⁶ But an infant does not know this. Likewise, an infant neither knows what virtue or eternal life is, nor does he know what health, beauty, or money is. But an infant benefits from the virtuous acts of people acting on his behalf. Similarly, an infant benefits from being healthy, beautiful, or born into a wealthy family. Good health means an infant will have to undergo few, if any, medical procedures. A beautiful baby—versus one who is deformed in some regard—is more likely to be given attention, even by strangers. And being born into a wealthy family means that the infant may benefit from not only having the necessities of life provided, but also luxuries. We must be careful to note, however, that temporal goods such as health, beauty, and wealth can disappear instantly. These goods are transitory; they are

³⁶ The *Catechism of the Catholic Church* teaches that “[s]in is an offense against reason, truth, and right conscience; it is failure in genuine love for God and neighbor caused by a perverse attachment to certain goods. It wounds the nature of man and injures human solidarity. It has been defined as ‘an utterance, a deed, or a desire contrary to the eternal law’ ” (n. 1849). “*Mortal sin* destroys charity in the heart of man by a grave violation of God’s law; it turns man away from God, who is his ultimate end and his beatitude, by preferring an inferior good to him” (n. 1854). “For a sin to be *mortal*, three conditions must together be met: ‘Mortal sin is sin whose object is grave matter and which is also committed with full knowledge and deliberate consent’ ” (n. 1857). “One commits *venial sin* when, in a less serious matter, he does not observe the standard prescribed by the moral law, or when he disobeys the moral law in a grave matter, but without full knowledge or without complete consent” (n. 1862).

subordinate to eternal goods, which do not change. But eternal goods such as truth, virtue, eternal life, etc. do not in and of themselves provide what an infant needs to sustain physical life.

Having said this, we must ask, when is it permissible to allow a person to die, if we are operating from a sanctity-of-life ethic? If we say that we should allow a person to die because he is no longer healthy, beautiful, or wealthy, we appear to be making a choice based on his quality of life. Simply stated, if life does not provide a person with all these goods, perhaps it is better that he should die. Rather than simply saying that these are poor reasons from the start, they are worth considering.

Consider, for example, Wojtyla's own decline in health over the years before he died in 2005. When Wojtyla was dying in late March and early April of 2005, there had already been speculation for years over whether he would or should retire. In the last week of his life, Wojtyla appeared at his apartment window on Easter Sunday to give the crowds his blessing, but he was completely unable to speak because of a recent tracheotomy. During an interview with EWTN's Raymond Arroyo on the weekend of Wojtyla's beatification,³⁷ Cardinal Stanislaw Dziwisz, Wojtyla's personal secretary and friend, recounted the incident:

It was a difficult time, because every shepherd needs his voice. Especially for this Pope, who was an actor in a certain sense, which means he worked with his voice. That was a great sacrifice on his part, just to lose his great predilection, his great ability to use the voice.

I remember the last blessing at St. Peter's Square. He really wanted to speak before, and he even made a serious attempt before to speak, but when he went to the window, he could not speak a word. He came back very sad. Then he said to

³⁷ Wojtyla's beatification occurred on 1 May 2011.

us, “If I cannot celebrate in public—that was Easter—if I cannot speak to the people, it might be better for me to die.” But then immediately he added, “May God’s will be done.” (Dsiwisz)

We can see here at play a mixture of both the sanctity- and quality-of-life ethics. Wojtyla judges himself incompetent to carry out his duties and laments—wondering aloud—whether death is a better alternative to his current condition. That is his human side speaking. But notice immediately after this statement, he places his trust in God. Wojtyla died six days later, after having said goodbye to close friends and associates.

Being sick often involves pain, and prolonged pain can drive people to the point where they wish nothing else but to die. Being deformed because of illness or injury can make people feel isolated, even when others are committed to caring for them. ILTCs, too, are aware of pain and discomfort, and they are capable of suffering from isolation. Determining appropriate courses of action based on considerations such as these involve quality-of-life judgments. Sometimes the decision to provide care—even costly care—seems obvious, so much so that we do not even realize that we are making quality-of-life judgments. For example, when doctors determined that both our son and our daughter (nine and six at the time, respectively, and in good health except for periodic bouts of strep throat) needed tonsillectomies, it was not so much a question of whether to perform the procedures, but when. Quality-of-life judgments become more recognizable as such when decisions to treat or not to treat are not as easy to make. But a sanctity-of-life ethic cannot avoid judgments about the quality of life without lapsing into medical vitalism or denying that there is no obligation to subject oneself or others to heroic suffering, which I address in section 3.7.

3.6 The Quality-of-Life Ethic

Often contrasted with the sanctity-of-life ethic is the quality-of-life ethic. Basic questions to ask are 1) what the quality of an ILTC's life is; and 2) whether, given the infant's condition (by "condition" I mean here "well-being," or lack thereof), attempts at sustaining life are worth the effort. Just as "life" can take on different means, so can "quality."

We can use "quality" to refer to an infant's physical condition. Is his current health improving, stabilized, or declining? We can also use "quality" to refer to the kind of medical care he is receiving. Are particular treatments helping him or not? The quality of care depends on the competence of the doctors, availability of resources, etc. "Quality" can refer to his family's home situation. If he goes home, will it be to a home that is clean and a family who is committed to providing him good, loving care, etc.? Or will his living conditions be unfit, especially for a sick infant?

Then there is, of course, "quality" as it refers to his future human development (i.e., intellectual, psychological, emotional, social, and/or religious life). Healthier infants progress through successive stages of development and benefit from interpersonal relationships with others. How they interact and what they appreciate depend on their current level of maturity. Especially in the case of ILTCs, though, we do not expect them to 1) live long enough to reach adolescence or adulthood; and/or 2) have the mental capability to respond deliberately to stimuli. We must also realize that although an ILTC seems to be comfortable now and may not be dying yet, he may live to the point where his condition worsens and makes his life not much more than a struggle for mere survival.

Consider a newborn infant who is not expected to survive. No newborn infant—healthy or imperiled—has any duties or responsibilities to anyone, including himself. At the same time,

unlike Wojtyla, a newborn cannot think, “If I cannot do certain things, it might be better for me to die.” When infants have life-threatening conditions but are expected to mature to normal, responsible adulthood, we subject them to considerable physical pain and suffering (e.g., from the isolation of an incubator in a neonatal intensive care unit [NICU]) if that is needed to get them through a medical crisis. But an ILTC will not survive to reach adulthood, so the perspective of a future, competent adult is not relevant to his care. So why is it that some people are adamant about preserving imperiled newborns’ lives? Their lives are sacred, and, within the sanctity-of-life ethic, they have no less value than the rest of us. But what do these affirmations commit us to? And what does preserving an ILTC’s quality of life consist of?

Again, we must remember that we can only approach problems like these from the perspective of a healthy, competent adult. If an infant, then, lives with serious disabilities and will die before the age of two, we may not be able to say with certainty that there is little to no quality of life. I propose the idea of keeping him content as the appropriate concept of an adequate quality of life for an ILTC who will die before ever maturing.

3.7 Contentment: A Guiding Principle

I believe that we may already be operating from both the sanctity- and quality-of-life ethics without recognizing that we are. Just because we may believe that life is sacred does not mean that we believe it is of infinite value, at least in its earthly form. We ought to care for human life in its earthly form as long as it lasts, but at the same time, we must accept and become knowledgeable about the dying process, especially when an infant enters it. With all ILTCs, but especially as an infant approaches death, we should begin a constant state of watchfulness in order to know what comforts the infant, as well as what does not. We can then add knowledge gleaned in one case to an ever-increasing body of knowledge about the dying

process. When we cannot or ought not to sustain the infant's life any longer, we must make the difficult decision to let go. So our question now becomes, how do we reconcile these two ethics so that we can respect life while simultaneously making the right decisions (e.g., appropriate time, method, etc.) to let go?

The sanctity-of-life ethic does not espouse medical vitalism, that is, the belief that biological life is so sacred that it must always be preserved at any cost. The sanctity-of-life ethic admits death and allows for individuals to die, while at the same time aims at protecting human life from being wasted, especially at the hands of others and without the individual's consent. The sanctity-of-life ethic itself requires judgments of the quality of life, as both Bernardin and Wojtyla acknowledge. We often speak of a person's potential, and the decision to put off difficult decisions about end-of-life care—especially the one to provide nothing more than palliative care—is perhaps the result of not knowing what a person's potential is or whether it will be realized. But notice that if we are always looking (far) into the future, we run the risk of bringing a person to the threshold of death numerous times in the hope that he will survive. An ILTC may survive the present crisis, but there will be no growth into adulthood or even into childhood. Prolonging the life of an ILTC (who is very unlikely to survive to age two) often imposes considerable pain and suffering on an infant who may already be suffering, both from the underlying condition and/or from the treatments that extend life. It is not a far stretch to say that such treatment and care borders on experimentation, as we are not sure whether this infant will survive to face yet another crisis. At what point do we say that we have done what we should (not just what we can) and let the individual die in peace?

We must be careful not to go to the other extreme and say that anyone who embraces the quality-of-life ethic is looking to exterminate an infant at the first sign of illness. The quality-of-

life ethic looks not only in its present condition, but also its future condition. Wojtyla warns us against becoming too focused on efficiency: if others cannot measure up or produce enough, they are somehow not worthy of living (*Gospel 22* [12]).

This notion of measuring up or producing enough raises the question, from whose point of view is this judgment being made? An infant does not technically have a point of view, but placing ourselves in his position, we can ask, “If prolonging my life means that I will experience pain and/or isolation more often than not, would I want to continue living?” We allow older patients to make the choice to forgo medical treatment and die sooner rather than later when they believe that their continued existence produces more burdens than benefits for themselves and/or others. Why, then, can we not make this decision for an ILTC out of concern for his best interests, especially if his continued existence consists mostly of one medical treatment after another?

It does happen, however, that decisions to end an ILTC’s life earlier are based on society’s expectations for its members to contribute something. Even healthy infants cannot produce something as can older people, but as infants mature, our expectations for them to produce something increase.

What, exactly, do we expect people to produce or contribute to society? It often happens that even the healthiest, most productive people fail to meet our expectations on a variety of levels. For example, a person may fail to produce a good product. Perhaps he produces a good product, but fails to deliver it on time. Or perhaps he may produce a good product and deliver it on time, but he is not particularly pleasant to deal with. While we may be frustrated with this person for reasons such as these, it would be morally wrong to eliminate him for these reasons.

It is very often the case that people with various disabilities (e.g., trisomy 21) bring great joy to others not so much based on what they accomplish, but because of their happy, infectious dispositions. When people hold happy or sleeping infants, they often remark about how good it makes them feel. We often do not consider infants' smiles, hugs, peaceful sighs, etc. to be products or contributions, but that is in fact what they are. We cannot put a price tag on things such as smiles, laughter, affectionate gestures, etc. It goes without saying that life would be much less pleasant without them.

Let us again examine the two propositions given by Weber earlier in this chapter:

1. That human life is sacred by the very fact of its existence; its value does not depend upon a certain condition or perfection of that life.
2. That, therefore, all human lives are of equal value; all have the same right to life. (111)

I propose that if we hold the sanctity-of-life ethic, we should act in such a way so as to bring contentment to the infant in need of medical attention. What all people strive to avoid is distress of one sort or another. No one wants to be in distress. By removing sources of distress, we can keep people content. To be clear, by "contentment" I mean a state of total comfort, not necessarily the emotion we often call "happiness." We can provide comfort to an ILTC by holding him, talking and singing to him, rocking him, patting him on the back, keeping him warm, etc. (in other words, "high touch"). These are very simple actions not requiring great expense. All that is truly required is time, attention, and love. And we should provide these things precisely because we hold human life to be sacred.

This is not to say, however, that pain and/or distress will be completely avoidable during treatment or care. Let us consider cases in which parents allow doctors to initiate ANH for their

infants. One common complication of ANH is aspiration of the lungs, which can easily lead to aspiration pneumonia, a life-threatening condition. According to Wojtyla, both ANH and treatment of pneumonia are ordinary and therefore obligatory. Let us suppose there is an infant who is otherwise healthy, expected to mature to adulthood, but suffers a bout of aspiration pneumonia. He experiences distress in a number of ways. First, the infant is in distress from pneumonia itself. Second, he is in distress from medical personnel's attempts to suction fluid out of his lungs. This is by no means a comfortable procedure. And of course, he is in distress at this moment by being restrained by medical personnel rather than cuddled in the arms of a family member. But once the treatment is over, he will soon be content once again. If we know that this procedure will save his life, we will agree to it, without a lengthy weighing of benefits and burdens.

Consider next, however, a case in which ANH has become more than a bridge treatment for an ILTC. For him, aspiration pneumonia is not a one-time occurrence, but a routine complication. If we hold Wojtyla's position, we must not only provide ANH, but also treat the ILTC for aspiration pneumonia each time he suffers it. Consider all the ways the ILTC will be in distress each and every time he is treated for pneumonia. Moreover, an ILTC will not survive beyond two years. We must begin to question, is there not something we can do to prevent this vicious cycle from repeating itself, or even beginning in the first place?

It is this vicious cycle that leads to heroic suffering, about which Wojtyla himself says "cannot be considered the duty of everyone" (*Gospel* 118 [65]). Here he is talking about patients who choose to forgo palliative care so as to share more deeply in the suffering of Christ (what is commonly called "redemptive suffering," which I shall address in chapter 5). If infants—healthy or imperiled—have neither duties nor choice, then they certainly cannot be expected to undergo

heroic suffering. An infant also cannot participate in redemptive suffering, for that requires knowledge and spiritual awareness beyond the capabilities of an infant. In my opinion, ILTCs especially should be spared from any unnecessary suffering if possible. Complete relief from suffering keeps an ILTC content. And it may be that only withholding or withdrawing ANH offers complete relief. If so, withholding or withdrawing ANH *is* what respectful, loving care for an ILTC would be.

If we make contentment a priority, we should think twice about invasive procedures such as surgery, if surgery will not truly be of benefit to the infant. Likewise, if an infant seems perfectly content sucking on a pacifier or having just a taste of food, forcing food and fluids through ANH may do nothing more than cause the infant distress. Medical personnel can deliver enough food and fluids to keep an ILTC comforted without necessarily providing enough for growth (Ellis³⁸). Ultimately we must ask ourselves, is it better for an ILTC to die content, or in distress due to the employment of various life-prolonging measures including ANH? For an ILTC will soon die³⁹ regardless of what treatment measures we employ.

Giving food and fluids for comfort rather than growth raises the question of what the proper amount to deliver to an ILTC is. The Church does not address this question in her literature. I believe that were the Church to do so, she would be overstepping her bounds

³⁸ Wendy Ellis is a registered nurse with further certification in neonatal resuscitation. She has more than twenty years of experience working with babies, including premature infants and those with illnesses. For the last eight years, she has worked with families whose newborn infants have conditions that are incompatible with life.

³⁹ For dying patients, being in a hospice is preferable to being in a hospital, since a hospice is designed to meet dying patients' basic needs for warmth, cleanliness, and human presence without the discomfort of aggressive medical treatments designed to reverse or cure illnesses or conditions. Dying ILTCs may benefit more from being in an infant hospice instead of an NICU, where the emphasis is placed on saving at-risk infants' lives, often through aggressive medical treatment. I thank Glenn Graber for his thoughts on the matter.

(reminiscent of Pacelli's remarks about the Church's declaring a person dead from a clinical point of view). Based on what we have learned from chapter 1, I believe that once an ILTC has entered the dying phase or suffers more harms than benefits from ANH, ANH should be withheld or withdrawn. This, I submit, would be "the deepest element of God's commandment to protect human life" that the sanctity-of-life ethic requires: "*to show reverence and love for every person and the life of every person*" (Wojtyla, *Gospel* 72 [41]). But if a very small amount of something in the mouth (e.g., tastes of food, a few drops of water, or even just a moist swab) comforts the ILTC to the point of contentment, then families or medical personnel should by all means provide it.

3.8 Conclusion

It is because of the Church's insistence on the sanctity of life that Catholic parents find themselves facing ethical dilemmas when medical treatments seem to be the only thing keeping their infants alive. Lessons from the Gospels (e.g., the parable of the Good Samaritan and Jesus' words about heaven and hell) play a major role in the Church's attitude toward the provision of ANH for the sick and/or dying. But modern medicine provides evidence that underlying conditions themselves or other forms of medical treatment can affect an infant's hunger or interfere with his digestive process. Seemingly, there is a conflict to resolve between the sanctity- and the quality-of-life ethics. Doing harm by neglecting the needs of an ILTC violates the sanctity-of-life ethic. But causing an infant harm in the process of providing forms of care we think he needs violates the quality-of-life ethic. We may already be operating from some combination of both ethics when we provide basic care to ILTCs but make decisions based on both their current and future quality of life. If we discover that certain forms of ordinary care or medical treatment other than ANH are enough to keep an infant who has entered the dying

process or suffers more harms than benefits because of ANH content, then it is in the infant's best interests for us to withhold or withdraw ANH—and we should do so. This is a departure from Wojtyła's position, but as we shall see in the next chapter, Ratzinger's answer to the AIDS⁴⁰ problem in Africa may be a step in a direction that would enable the Church to move toward adopting my proposal as a practical choice for parents of ILTCs.

⁴⁰ "AIDS" is the acronym for "acquired immunodeficiency syndrome."

Chapter 4: Rethinking the Catholic Position on ANH for ILTCs

End-of-life decisions we make for others are difficult, especially when these individuals cannot speak for themselves. Based on our decisions to provide or withhold treatment, a patient can 1) die sooner and in peace; 2) die sooner but in pain and/or distress; 3) die later but in peace; or 4) die later and in pain and/or distress. We can assume that no one desires to die in pain and/or distress, no matter when death occurs. One benefit to dying sooner and in peace is that the patient is more quickly released from his condition, illness, pain, and/or distress. One benefit to dying later and in peace is that the family may be able to spend more time with and care for the patient. But since it is the patient (for our purposes, an infant with life-terminating conditions [ILTC]) who is dying, his needs should come first, even if that means that his family has less time to spend with and care for him. But as we have seen in chapters 2 and 3, the Catholic Church teaches that not every possible way to help a patient die free of pain and/or distress is morally permissible (e.g., euthanasia). So the Church finds herself having to speak on medical matters, such as the provision of artificial nutrition and hydration (ANH) for sick and/or dying patients.

When ILTCs are in pain and/or distress for an indefinite period of time, all kinds of questions arise regarding what forms of care should be provided and to what extent. In *Caring for Each Other, Even Unto Death*, a pamphlet designed to instruct families about various end-of-life issues, including ANH, Marie Hilliard states,

Many families are unsure about moral options for the care of their loved ones. Fortunately, the popes and bishops of the Catholic Church have provided invaluable guidance concerning end-of-life decisions, including issues of pain control and consciousness, the provision of food and water to dying or

unconscious patients, the right to refuse certain treatments, and the duty to care, even when a cure is no longer possible. (3)

I agree with some of Hilliard's statements, but not all of them. It is because families are unsure of Catholic teaching that they ask for guidance in the first place. The fact that most, if not all, contemporary Catholic commentators quote Pacelli's "The Prolongation of Life" is a testament to both his grasp of a very complex issue and his foresight.

As I argued in chapters 2 and 3, however, Wojtyla's position is inconsistent. His 2004 address, "Care for Patients in a 'Permanent' Vegetative State," contains the following statements:

- The person in a vegetative state [PVS], in fact, shows no evident sign of self-awareness or of awareness of the environment and seems unable to interact with others or to react to specific stimuli. (203)
- . . . [T]he 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. (205)

So a PVS patient cannot suffer since he cannot react to stimuli. But Wojtyla states that administering ANH is a way to alleviate a PVS patient's suffering. This makes Wojtyla's position inconsistent with itself. In addition, from chapters 1 and 2, his position seems to be inconsistent with the findings of medical experts who advocate the withholding or withdrawing of all food and fluids in order for the patient's body to alleviate suffering by producing its own

analgesics. Moreover, as I showed in section 2.2, by Pacelli's understanding of ordinary and extraordinary means, ANH is by no means always ordinary treatment. Thus Wojtyla's statements are also inconsistent with Pacelli's. As I argued in section 3.2, a culture of life and any sanctity-of-life position need to include judgments about the quality of life if they are not to risk lapsing into medical vitalism. At the same time, a culture of life and any sanctity-of-life position need quality-of-life judgments to support their quite appropriate denunciation of degrading practices (e.g., slavery, prostitution, poor working conditions, etc.) that are not in and of themselves life-shortening. And we have just seen Wojtyla appealing to "the alleviation of suffering" in one of his statements about ANH. Given these inconsistencies and tensions, there is no way for anyone to be faithful to the whole of Church teaching on the issue of ANH for ILTCs.

It is important to note that several recent Church documents addressing the care of the sick and/or dying either refer to or directly quote Wojtyla's statement about the status of ANH (i.e., ordinary and therefore obligatory). Such documents include the Congregation for the Doctrine of the Faith's (CDF's) "Responses to Certain Questions of the United States Conference of Catholic Bishops [USCCB] Concerning Artificial Nutrition and Hydration" and its subsequent Commentary on "Responses," both published in 2007. After hearing from the CDF, the USCCB subsequently published its own comments in its 2007 "Q&A from the USCCB Committee on Doctrine and Committee on Pro-Life Activities regarding The Holy See's Responses on Nutrition and Hydration for Patients in a 'Vegetative State.'" Directive 58 of the USCCB's 2009 version of *Ethical and Religious Directives for Catholic Health Care Services* (ERDs) also refers to Wojtyla's statement. Two recent resources designed to help families make end-of-life decisions for their loved ones, Gomez's *A Will to Live: Clear Answers on End of Life*

Issues (2006) and Hilliard's *Caring* (2010),⁴¹ both directly quote the statement in question.

But none of the documents listed above address the inconsistency of Wojtyla's statement with itself in his 2004 address or with Pacelli's position; the authors use Wojtyla's statement as the final authority for their position on providing ANH to anyone who appears in need of it. To remain faithful to at least part of Catholic teaching, then, we should consider withholding or withdrawing ANH from ILTCs in light of Pacelli's position instead. As I shall show in section 4.4, using Pope Benedict XVI's⁴² (Ratzinger's) position on condoms to help stop the spread of acquired immunodeficiency syndrome (AIDS) in Africa, identifying a situation as hopeless from the outset may pave the way for allowing the Church to approve of withholding or withdrawing ANH under certain circumstances.

4.1 Building a New Framework from "The Prolongation of Life"

There are advantages to considering my proposal in light of Pacelli's position. While he does not address ANH specifically as Wojtyla does, his position is not inconsistent with itself. Despite the inconsistencies in Wojtyla's position, though, there are benefits to comparing it with Pacelli's. Remember Wojtyla's call to respect, protect, love, and serve each and every single human life. The sanctity-of-life ethic demands it. But Wojtyla's intense focus on every individual human life seems at times to eclipse the family's concerns. Individuals do not live in

⁴¹ While all of these references can be found in print, the reader may prefer to read Wojtyla's "[Care for Patients in a 'Permanent' Vegetative State](#)," the CDF's "[Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration](#)" and [Commentary](#), the USCCB's "[Q&A from the USCCB Committee on Doctrine and Committee on Pro-Life Activities regarding The Holy See's Responses on Nutrition and Hydration for Patients in a 'Vegetative State'](#) " and [Ethical and Religious Directives for Catholic Health Care Services \(5th ed.\)](#), and Hilliard's [Caring for Each Other, Even Unto Death](#) on the Internet.

⁴² From now on, I shall refer to Pope Benedict XVI as "Ratzinger." Joseph Cardinal Ratzinger became Pope Benedict XVI upon his election to the papacy in 2005. His pontificate continues to the present.

complete isolation; what happens to one person also affects others. So in this regard, Pacelli's consideration of the family and the community at large is also important. Tempering Pacelli's position with Wojtyla's concerns, we are reminded that even though it is the family who decides what treatments an ILTC does or does not receive, it is the ILTC who should remain the focus of medical care, as he is the one most directly affected by it. But all throughout the ILTC's life, dying process, death, and the period following his death, the family's needs must also be considered, and they also need care. And spiritual care is also the central mission of the Church. I discuss the provision of spiritual care to families of ILTCs in chapter 5. The tension remains, then, between the burdens of treatment that the ILTC bears in certain ways and burdens of providing treatment that the family bears in others. Withholding or withdrawing ANH from ILTCs should be done with the ILTC's best interests in mind.

4.1.1 Burdens of Treatment for Families of ILTCs

So that we may narrow our focus on ILTCs in the next section, let us first consider the burdens of treatment for an ILTC's family. Financial costs of medical treatment are often what first come to mind. Determining whether a medical treatment is ordinary or extraordinary is a relatively simple task where finances are concerned: either the family has the money or the medical insurance to cover the treatment or not. But we cannot think only in terms of the treatment itself; we must take into account the overall cost of providing medical care. Other financial costs to consider include hospital stays, medications, follow-up visits with the doctor, travel expenses (especially extensive travel), home medical equipment, in-home nursing care, etc. Financial costs of medical care can overwhelm a family's financial well-being very quickly.

We cannot underestimate the physical toll that caring for an ILTC takes on a family, either. Even if the parents are young and healthy, their health can deteriorate if they fail to keep

themselves healthy with proper rest, diet, and exercise. Family members may unwittingly sacrifice their own health by focusing too exclusively on that of the ILTC's. But if they themselves become sick, it becomes that much harder to care for the infant and other family members.

The emotional burdens of caring for an ILTC are overwhelming. The joy of childbirth immediately turns to sorrow when the parents realize that their child will not live very long. Not knowing when the child will die creates all kinds of anxiety. Parents may routinely forgo sleep if they think there is a chance that the infant might die during the night. A working parent may feel torn about going to work if the parents have made it a priority for both of them to be present when the infant dies. But the obligation to support the family still remains. Parents may feel guilt no matter what they decide—either to have their infant undergo any number of treatments or to let him die. For example, a family will always wonder whether it would have been better to let their infant die if the decision to treat prolongs the ILTC's dying process and/or adds to his pain and/or distress. On the other hand, a family will always wonder what could have been had they decided to treat their infant rather than let him die. Other children and relatives living in the home (e.g., grandparents) have emotional needs that need to be met as well. Everyone in the household will be affected in some way by the situation, and it usually falls to the parents to ensure each and every family member receives the love and attention he deserves.

The burdens on the family's social well-being are also important to consider. It is through friends, organizations, activities, hobbies, etc. that family members connect with other people outside the home, develop their own talents, and relieve stress. Families may find themselves torn over what to do once the ILTC is born and/or comes home from the hospital. Should all social events be put on hold so that the family can give their full attention to the

infant? Without taking care of their own needs, however, family members may become irritable, resentful, etc. And rather than support one another through this tragic situation, they may find themselves taking out their anger and frustration on one another, or, worst of all, on the ILTC himself.

When any of these kinds of burdens become overwhelming for an ILTC's family, it can change any treatment from ordinary to extraordinary, at least on Pacelli's position. Pacelli says, "The rights and duties of the family depend in general upon the presumed will of the unconscious patient if he is of age and *"sui juris"* ['one's own master']. Where the proper and independent duty of the family is concerned, they are usually bound only to the use of ordinary means" (96). Since no infant is of age or his own master, treatment decisions in cases where an ILTC is not expected to survive or where he undergoes substantial pain and/or distress become even more complicated and agonizing. Once again, if we make the ILTC's comfort a top priority, the decision to forgo extraordinary means may make the decision less complicated, but not necessarily less agonizing for the family. Especially if a family is religious or spiritual, these decisions will impact their spiritual lives.

Serious illness can place tremendous burdens on a family's spiritual life, especially if they take seriously Jesus' command to love: "As I have loved you, so you also should love one another" (John 14.34). Even families who are spiritually strong may find themselves asking, "Why did this happen to us?" or "If God is so good and loving, why would He permit something like this to happen?" As a result, it may be difficult, if not impossible, to strive for what Pacelli calls "the higher, more important good" or "spiritual ends" (94).

It is important to note the distinction between the spiritual goods of the family and those of the ILTC. It may be a family's highest priority to have their ILTC baptized. For example,

Catholic couples who have their infant baptized fulfill their marriage vow to raise their children in the faith. Even though all the family members receive spiritual benefits when they pray together, participate at Mass, receive various sacraments, etc., parents and older siblings participate in spiritual matters in ways that infants cannot. And especially since we are talking about ILTCs who will die before the age of two, they will never have any concept of spiritual goods.

But just because an infant has neither the concept of spiritual goods nor the ability to appreciate them does not mean he does not benefit from them. At the same time, the fact that an infant does not have a concept of spiritual goods also means that he does not have a concept of things such as sin, doubt, fear, etc. He cannot even attempt to find meaning in his circumstances. In this way, then, an infant does not bear spiritual burdens. An infant, however, can neither have his suffering alleviated by spiritual means (e.g., finding meaning in it) nor participate in redemptive suffering, which I briefly mentioned in section 3.6 but shall address in more detail in chapter 5.

The most important of any ILTC's spiritual needs—eternal salvation—is obtained through the sacrament of Baptism, which anyone—not just a priest—can perform in an emergency.⁴³ If a family is unsure as to whether their infant will live even for a few minutes, someone—even a non-Catholic—can perform Baptism moments after birth. In cases where an infant dies before Baptism, ecclesiastical funeral rites are allowed if it was the parents' intention

⁴³ The Catholic Church's *Code of Canon Law* addresses infant Baptism in cases of emergency in Canons 867-868.

to have him baptized.⁴⁴ Granting, then, that Baptism places the ILTC in a state of grace and assures his salvation (especially because he will die well before the age of reason [approximately seven years of age] and is therefore incapable of committing subsequent sins needing forgiveness), we can set this concern aside and focus primarily on the “earthly care”⁴⁵ that ILTCs need.

4.1.2 *Burdens of Treatment for ILTCs Themselves*

4.1.2.1 **Considering Reasonable Hope of Success**

Before proceeding to discuss my recommendations for the earthly care of various ILTCs, I believe it is necessary to consider the burdens of treatment for ILTCs themselves in light of Pacelli’s remarks, especially since ILTCs are not the focus of “The Prolongation of Life.” First is the notion of “reasonable hope of success”⁴⁶ (Pacelli 92). Recall that in developing my own

⁴⁴ The commentary for Canon 1183 (*Rites for Catechumens, Non-Baptized Children, Non-Catholics*) states, “The *Sacramentary* contains a Mass for a child who dies before baptism. . . . The unbaptized child may receive these rites if the parents intended to have the child baptized.”

⁴⁵ By “earthly care” I mean any basic care (physical, medical, emotional, etc.) that affects the ILTC in his earthly existence. I distinguish earthly care from spiritual care, as spiritual care does not usually result in physical benefits (e.g., miraculous healing) for ILTCs. While I personally believe that miraculous healing is possible, for the purposes of this dissertation (and realistically speaking), I assume that if an infant is born with life-terminating conditions, they will remain with him as long as he lives.

⁴⁶ In “The Prolongation of Life,” Pacelli, addressing older patients who somehow suffer some kind of trauma to the brain that leaves them in a state of deep unconsciousness, says, “It happens at times—as in the aforementioned cases of accidents and illnesses, the treatment of which offers reasonable hope of success—that the anesthesiologist can improve the general condition of patients who suffer from a serious lesion of the brain and whose situation at first might seem desperate” (92). There is an important distinction to make here, that is, between the reasonable hope of success that a particular medical treatment provides the intended medical benefit and the reasonable hope of success that a patient will recover from his condition. In the case of older patients in a state of deep unconsciousness, the hope is that the treatment is successful *so that* they will once again regain consciousness. In the case of ILTCs, however, they may recover from something like aspiration pneumonia, but they will never be cured of their underlying condition (e.g., trisomy 13, duplication 3q syndrome, etc.). I thank John Hardwig for drawing my attention to this distinction.

definitions for “ordinary” and “extraordinary” in section 2.4, I used the phrases “present and future” and “definite hope of benefits that outweigh burdens.” Hope is future-looking; it does not focus on the past or even strictly on the present. For example, suppose doctors take an ILTC to the operating room to insert a percutaneous endoscopic gastrostomy (PEG) tube, and the operation is successful. Right now, “successful” means that the ILTC survives the procedure, the PEG tube is in place, and there do not appear to be any complications. But looking into the future, there is no way of knowing whether providing food and fluids through the PEG tube will continue to deliver benefits that outweigh burdens. Perhaps the ILTC will develop an infection or aspiration of the lungs. And if he does develop an infection or aspiration of the lungs, there is no telling whether this is a one-time occurrence or just one of many episodes requiring treatment. This is where the vicious cycle of feeding, complications, and treatment begins, and parents must ask themselves whether they want this cycle to continue or not.

4.1.2.2 Considering Circumstances of Persons, Places, Times, and Culture

The second point to consider is the circumstances which make various forms of treatment ordinary or extraordinary: “persons, places, times, and culture” (94). A treatment becomes extraordinary and therefore optional if these circumstances present even one grave burden. Recall that Pacelli says, “A more strict obligation [i.e., to use extraordinary means] would be too burdensome for most men and would render the attainment of the higher, more important good too difficult” (94). Because we are dealing with ILTCs, his “higher, more important good” (i.e., his eternal salvation, the greatest “spiritual end”) is attained through Baptism. But his Baptism must be arranged by someone else, since he cannot request it for himself. That being said, ILTCs have no duties, responsibilities, or obligations. They cannot seek higher, more important goods as can older children and adults. And we should not expect them to.

So what is it about circumstances of persons, places, times, and culture as they relate to ILTCs that would make medical treatments extraordinary? We must ask the question, what is the difference between an ILTC and an older child or an adult? I believe the key difference—and the consideration that determines treatments to be ordinary or extraordinary—has to do with a person's ability to understand what is happening to him, the reason why it is happening, and for what purpose.

For example, I was involved in a serious car accident when I was nine years old. Because of internal bleeding, the doctors inserted a Foley catheter. Before proceeding, though, they first explained to me in terms I could understand what a catheter is, what insertion would involve, and why they needed to insert it. Needless to say, I found it very uncomfortable, and I wanted it removed as soon as possible. When it came time for the nurses to remove the catheter, they told me what I needed to do to prepare myself for some brief but intense pain. In addition, they told me that by the end of the afternoon, I would need to urinate at least once to avoid developing an infection and the need to have another catheter inserted. The nurses warned me that because of irritation to the urethra, urinating for the first time would create pain similar to that which I experienced when the nurses withdrew the catheter. They were correct about the pain, but because I did not want to have another catheter inserted, I was willing to endure another episode of intense pain.

One key difference between my situation and that of an ILTC needing some kind of treatment is that he cannot understand what doctors are doing or why they are doing it. All he knows is that he is in pain, but he has no idea why or how long it will last. I at least was given some choice in the matter: either urinate or have another catheter inserted. The nurses also told me that after urinating the first time, voiding my bladder would not be painful. So I knew what

to expect. Weighing my options, I chose what would cause me the least amount of pain and discomfort, even though I knew that some would be involved. An ILTC has no choice in what happens to him. He can resist or “fight off” doctors and nurses trying to help him, but this may be more from instinct than choice. I do have to say, though, that had the doctors and nurses not explained to me everything I needed to know and proceeded with the treatment, I certainly would have been less willing to cooperate with their efforts, especially if it meant additional insertions of a catheter. But this is what happens to every infant—regardless of health—when doctors and nurses provide treatments that cause pain and/or discomfort.

Another key difference between my situation and that of an ILTC is that I was expected to make a full recovery. In addition to the Foley catheter, I had to undergo exploratory surgery to ensure that I did not have more substantial internal injuries. So the burdens of having a catheter inserted and undergoing exploratory surgery did not outweigh the benefits of a full recovery. But an ILTC will not make a full recovery; he will probably die before he reaches the age of two. So here is an important consideration: if a healthy person were to be placed in the ILTC’s situation and be given the choice of undergoing medical treatments to prolong his life that may or may not induce pain and/or distress but at the same time will not give him hope of a full recovery, would the healthy person agree to it?

The third and final key difference is that an ILTC cannot see the greater purpose beyond what is happening to him now. At the time of my accident, I did not know about redemptive suffering. Had someone explained to me that I could help other people spiritually by offering my pain and distress for their benefit, I probably would have done so. Having experienced intense pain myself, though, I can understand how difficult it may be to see past one’s own

situation and offer up one's own pain and distress for the benefit of others. But no infant—either a healthy one or an ILTC—can offer anything of himself, including redemptive suffering.

That an infant has one or more life-terminating conditions but lacks the ability to choose for himself what treatments he does or does not receive makes his circumstances extraordinary as far as his own person is concerned. From my discussion, we can see why many ordinary medical treatments for older patients may be extraordinary for ILTCs. If there is no hope of recovery or purpose that holds any relevance, would anyone be willing to undergo treatment? And since an ILTC attains the highest spiritual end (i.e., salvation) through others' efforts, what more should he be expected to do? Once again, we see the need for addressing ILTCs as a unique category in debates over providing medical care, to include ANH. Considerations that apply to many other groups do not address ILTCs' particular needs.

The fact that there is no hope of recovery for an ILTC can make treatments extraordinary based on circumstances of place. Granted, a patient receives better medical care in a hospital than he does at home. A hospital is designed, equipped, and staffed to meet a wide range of medical needs all hours of the day. Despite attempts to make hospital rooms more inviting, an ILTC would probably be most comfortable at home, away from all the noise and activity that occur in a hospital or, more specifically, the neonatal intensive care unit (NICU). An ILTC needs quiet and comfort from his family. An NICU also tends to interfere with human contact (e.g., holding, cuddling, talking, etc.) that all infants need. Think of how many older patients want to die at home rather than in a hospital. An ILTC should be afforded that same option.

Time is one thing that an ILTC does not have much of, so for the time he does spend on earth, he should be free of pain and/or distress as much as possible. If an ILTC's situation is hopeless, the parents must ask, how long will certain procedures take, how long will it take the

ILTC to recover from them, how long will the ILTC need to remain in the hospital before being able to go home, etc.? Older patients would much rather spend time out in the world, especially if they know they do not have much time left to live. Of course, some older patients' conditions prevent them from doing everything they want to. But the desire to stay out of the hospital is still there. Suppose that inserting a PEG tube gives an ILTC a few more weeks to live. If his spiritual needs have already been met, and he does not have much time left to live, is it worth an extra few weeks of life *for the ILTC* to have a PEG tube inserted? The family may argue that inserting the PEG tube gives them more time with the infant. But once again, we must ask, what is in the ILTC's best interests? Perhaps the decision to do everything possible to save the ILTC's life is based on the family's fear of being left behind. But death is inevitable, and families need to learn to let their infants go as peacefully as possible, even if it means that the end comes sooner than they would like.

Circumstances of culture can have an impact on how families care for their ILTCs, but culture, like spiritual goods, holds no relevance for ILTCs. Doctors should be mindful of families' cultures when they treat their infants, but from the perspective of medical science, certain conditions call for certain treatments. And it ultimately does not matter to what culture an ILTC belongs. If the ILTC gains no benefits from certain treatments, he should be spared from anything that causes him undue discomfort.

4.1.2.3 Considering Doctors' Responsibilities

Third and finally is the notion of doctors' responsibilities. Pacelli says, "In general, [the doctor] can take action only if the patient explicitly or implicitly, directly or indirectly, gives him permission" (96). Since ILTCs cannot speak for themselves, their parents are responsible for speaking for them. Pacelli also says, "Where the proper and independent duty of the family is

concerned, they are usually bound only to the use of ordinary means” (96). But as I have argued in section 4.1.2.2, the fact that an ILTC’s condition(s) will cause his death before the age of two makes some of the most ordinary treatments for an older child or adult extraordinary for him. Once again, the ILTC’s needs must come first, since he is the one most directly affected by the medical treatment he receives. If the ILTC’s health deteriorates to the point where it appears that he has entered or will very shortly enter the dying process, the family should request the doctor to discontinue treatment. I go so far as to say that if the family is unrealistic about their infant’s situation and prognosis, doctors should encourage the family to make the decision to discontinue treatment. Because these decisions involve the most untimely death we can imagine—that of an infant—doctors must exercise great compassion when counseling families about treatment options.

4.2 Considering My Proposal in Light of Pacelli’s Position

I now consider my proposal to withhold or withdraw ANH from ILTCs under various circumstances. Recall that in chapter 1, I listed four categories of ILTCs based on their situations:

1. Infants who receive prognoses of two weeks or less
2. Infants who will live longer than two weeks but no more than two years and who are not yet suffering or in distress. (An infant presently in distress falls within one of the next two categories.)
3. Infants who are not dying, but are in distress from the use of ANH
4. Infants who are not dying, but are in distress from their conditions and/or ANH

There are countless infants born with all types of life-terminating conditions. Especially when ILTCs are born with syndromes, not all ILTCs will have the same anomalies, and even if they

do, the same anomalies may affect these infants differently. In section 1.4, I briefly discussed some of the most common life-terminating conditions that tend to claim the lives of infants within the first two years. In what follows, I shall propose under what conditions it is in ILTCs' best interests not to be provided with ANH.

4.2.1 Infants Who Receive Prognoses of Two Weeks or Less

Recall from section 1.4.1 that ILTCs with trisomy 18, trisomy 13, and trisomy 9 are expected to die within the first two weeks of life. There will be instances where ILTCs live longer than doctors' prognoses. In cases where there is a high degree of certainty that an ILTC will die within two weeks, however, doctors should not initiate ANH so that 1) possible complications may be avoided; and 2) the ILTC's body will be allowed to produce its own analgesics. Feeding such an infant via ANH would produce only burdens with no hope of benefit. To proceed and cause the infant pain and/or distress (in other words, harm) would be morally impermissible. This recommendation may be difficult to accept, especially since many parents view feeding their infants as an act of love.

Why would we not want to feed these infants? First of all, these infants' life-terminating conditions make practically every medical procedure extraordinary. Not even the most advanced, aggressive medical procedure will cure conditions such as trisomy 18, trisomy 13, and trisomy 9. In other words, there is no reasonable hope of success for their recovery.

Physiological complications alone may make ANH extraordinary. Severe facial deformities prevent many of these infants from being able to breastfeed, bottle-feed or be fed with a nasogastric (NG) tube. The insertion of either a PEG tube or jejunostomy PEG (JPEG) tube requires surgery. Complications can arise either during surgery or afterwards, possibly even resulting in death. Many parents want to be present when their infants die, but surgery would

preclude this. And even if an infant survives surgery, he can still suffer from a compromised gastrointestinal system or an inability to assimilate food and fluids through a tube for various other reasons. If parents decide to provide food and fluids by total parenteral feeding, there is still the issue that after a few months, complications will begin to present themselves. While doctors can attempt to provide various forms of ANH, it is not as if ANH can be used on a rotating schedule. And regardless of the form of ANH doctors may consider, no form of it will cure these—or any—infants of their conditions. And as I discussed in section 1.2, withholding food and fluids provides several benefits and avoids several complications.

Parents must ask themselves the following question. Thinking strictly in terms of the infant's best interests, is it better for him to die comfortably within a two-week time frame, or prolong his life to the point where he begins to suffer from his underlying condition(s) and/or complications resulting from the use of ANH? We may lean towards what we consider to be the best interests of the family, since they are the ones who are making decisions about the infant's medical care. But the infant's circumstances are such that he will be subjected to one medical procedure after another just to keep him alive. There is no reasonable hope that these infants will be able to overcome both the physical and mental difficulties lying ahead of them. We must realize that there are conditions that preclude some infants from ever maturing to childhood or adulthood.

Some people may wonder, why not see how long an ILTC may live, even if we provide ANH but no other medical treatment other than palliative care? After all, if a family can provide loving care for perhaps several months or even up to a year, is that not a sign that they love their infant more than if they let him die after only two weeks?

At issue is the ILTC's body's ability (or lack thereof) to sustain life. Because of modern medicine and technology, we sometimes find ourselves at the crossroads of life and death. As I discussed in chapters 2 and 3, the culture of life and the sanctity-of-life ethic allow for natural death to occur. But modern medicine and technology can make it very difficult to determine whether or not it is artificial life support that is keeping an ILTC alive. Modern medicine and technology have given us the capability of sustaining ILTC's lives much longer than in the past. But at the same time, modern medicine and technology can keep an ILTC alive too long, thus forcing him to suffer heroically, something that is never morally required of anyone and that most, if not all, of us hope to avoid ourselves.

So when we say that an ILTC's situation is hopeless, we need to focus on his body's inability to sustain life rather than what we hope he might be able to do in the future. Having neither a sense of time (especially the long-term future) nor expectations, an ILTC will not be disappointed that he is not able to live longer. But he will be content by having his other basic needs (e.g., warmth, cleanliness, and human presence) satisfied. As a result, we arrive at the conclusion that it is in the ILTC's best interests to withhold ANH from him and allow him to die within the first two weeks of life.

4.2.2 Infants Who Will Live Longer than Two Weeks but No More than Two Years and Who Are Not Yet Suffering or in Distress (An infant presently in distress falls within one of the next two categories.)

ILTCs in this category can suffer from various conditions such as triploidy syndrome, duplication 3q syndrome, deletion 4q syndrome, duplication 10q syndrome, and Wiedemann-Rautenstrauch syndrome. Infants with these conditions often have the following health problems: congenital heart defects, brain anomalies, renal anomalies, asphyxia, apnea,

gastrointestinal defects, feeding problems, and respiratory infections. Some of these problems will, of course, cause immediate distress, but some will not. We expect these infants to die before they reach the age of two, but we do not know exactly when their conditions will cause them to die. If it appears that these infants have not entered the dying phase within the first two weeks (as ILTCs in the first category have), we must treat them as we would any other person—healthy or sick—who derives more benefits than burdens from eating and drinking.

The fact that doctors should feed and hydrate ILTCs in this category raises the following question: how will they provide food and fluids? Remember that food and fluids taken orally are not automatically ordinary means of care and ANH as a medical treatment is not automatically an extraordinary form of care. ILTCs' circumstances are what determine what forms of treatment are ordinary or extraordinary. Remember also that our goal is to keep ILTCs content as much as possible. It is preferable, then, to feed and hydrate without ANH if possible. If ANH becomes necessary, however, then doctors should initiate the form of ANH that 1) is least invasive; and 2) provides and allows for the most benefits; and 3) minimizes burdens.

What makes the decision to provide ANH to ILTCs in this category difficult is that they may not be in pain and/or distress right now, but we can expect them to be at some point in the future (in which case they fall into one of the next two categories I shall discuss shortly). Based on doctors' experiences and case histories, doctors can provide families with some kind of estimated life expectancy, but an ILTC may die earlier than expected or outlive doctors' prognoses.

Recall that in section 3.7, Ellis states that it is possible for doctors and nurses to provide enough food for comfort but not growth. Doctors and nurses must be watchful for the first signs of complications, whether they be from an ILTC's underlying condition(s) or from the use of

ANH. But because of the ILTC's condition(s), we know that at some point the ILTC will develop complications as one or more of his conditions progress or ANH becomes a medical treatment that delivers more harms than benefits. At this point, then, the ILTC no longer falls under this category but must be placed in one of the next two.

Before moving on to the next two categories, however, it is worth mentioning again that modern forms of ANH have only been around since 1979. Before then, infants who were not able to assimilate food and fluids orally simply died. When there are advances in medicine and technology, we typically welcome them because they improve the quality of life for those who benefit from them. But once again, we must remember that ILTCs in this category are not going to recover from their conditions; they will still die before they reach their second birthday. If it is possible to keep ILTCs comfortable with ANH until doctors and nurses can determine that these infants have entered the dying process and no longer need food and fluids, there is a case for both administering ANH and then withdrawing it at the appropriate time. We are not starving or dehydrating these patients; we are allowing nature to take its course, as well as allowing the ILTCs' bodies to cooperate in the dying process. In this way we accept natural death as part of the human condition while at the same time avoid medical vitalism.

4.2.3 Infants Who Are Not Dying, but Are in Distress from the Use of ANH

An ILTC becomes a member of this category if he experiences pain and/or distress from the use of ANH (e.g., an infant with deletion 3p syndrome). An ILTC can suffer pain and/or distress related to the placement of the various devices for supplying ANH, to complications resulting from ANH, or to an inability to assimilate food and fluids supplied by ANH on the physiological level. Recall from section 1.1.3 that there are burdens that a patient himself may

suffer regardless of the type of ANH that doctors employ; there is not one form of ANH that is completely trouble-free.

In terms of the placement of ANH, an ILTC may experience pain and/or distress from an NG tube if it causes ulceration or a sinus blockage, which could also lead to an infection. And any patient, not just an ILTC, may have to be restrained if he attempts to remove the NG tube out of discomfort. And of course, restraint is another source of discomfort for not only an ILTC, but anyone else in this situation. Infants with deletion 3p syndrome are often fed with an NG tube, but pneumonia is a frequent result. The insertion of either a PEG tube or a JPEG tube could cause perforation of the gastrointestinal tract, bleeding, and/or infection at the placement site. Placing a line for total parenteral feeding can lead to thrombosis, vascular perforation, and/or bacterial and/or fungal infection.

Not only can the placement of a feeding tube or line cause an ILTC pain and/or distress, but also the body's inability to assimilate food and fluids administered by ANH. Aspiration of the lungs—which can lead to aspiration pneumonia—is common when ILTCs are fed by NG tubes or PEG/JPEG bolus feedings. Feeding by JPEG tube can lead to diarrhea, which can be life-threatening for any infant, but especially an ILTC. Total parenteral feeding can lead to cholestasis with possible resulting sepsis, liver disease, and hepatic failure, especially when used for several months.

We must remember also that we are dealing with ILTCs who need ANH to keep them alive indefinitely, not otherwise healthy patients who may need ANH only as a bridge treatment. While a healthy person may recover from an infection rather easily, an infection could become life-threatening for an ILTC. Recall also that the Church considers injections and antibiotics ordinary care. So according to Church teaching, doctors must treat infections (provided, of

course, that the treatment is available and can be administered by a competent medical professional with reasonable hope of success). It is not morally permissible to administer ANH to a patient to the point where he develops an infection, refuse to treat the infection, and allow the patient to die from it. But again, if we view this situation from the ILTC's point of view, we must ask whether we would want to undergo the vicious cycle of feeding, infection, and treatment indefinitely. While a treatment may not in and of itself cause that much pain and/or distress, we must look at the overall situation and consider the pain and/or distress of an ILTC who experiences one complication after another. Sometimes it is difficult to determine whether a complication is a one-time event, the first of many, or the last one before the ILTC dies. If it appears, then, that the use of ANH produces more burdens than benefits, doctors should discontinue it and allow the ILTC to die comfortably.

4.2.4 Infants Who Are Not Dying, but Are in Distress from Their Conditions and/or ANH

Recall from section 1.4.4 some of the infants who fall within this category: those suffering from Smith-Lemli-Opitz syndrome, Noonan syndrome, Costello syndrome, Opitz G/BBB syndrome, and Marshall-Smith syndrome. Infants with these syndromes suffer from cardiac defects, renal abnormalities, gastroesophageal reflux, milk or soy allergies, etc. Their physiological conditions alone can make feeding burdensome. The question for this group of ILTCs is, if it appears that they will survive the first two weeks of life, when must we consider withdrawing ANH if it is ever implemented?

Diagnosing an ILTC's source of pain and/or distress is easier if doctors know whether it stems from an underlying condition or the use of ANH. It is much more difficult when doctors cannot determine whether an ILTC's condition stems from one or more underlying conditions, the use of ANH, or the combination of both. Many of the same considerations from the third

category of ILTCs apply here. Doctors should avoid prolonging life through ANH if it means the infant must endure the vicious cycle of feeding, complications, and treatment. Likewise, if an ILTC is in pain and/or distress that cannot be relieved, doctors should withdraw ANH as a means of comfort. To prolong an ILTC's life under either circumstance subjects him to heroic suffering, something which the infant cannot understand, appreciate, or utilize for his own or others' benefit.

Once again, some people may claim that I am suggesting starving or dehydrating ILTCs to death. I respond by stating that if our intention is to provide ILTCs comfort, then we should avoid anything that produces suffering. If the continued provision of ANH prolongs ILTCs' lives to the point where they suffer harm for any reason, ANH should be withdrawn. Recall once again my definitions of "ordinary" and "extraordinary" from section 2.4. While a treatment may provide some benefit in the short term, we must also consider what benefit—if any—ILTCs will derive in the long term. We cannot focus so intently on an ILTC's present status that we lose sight of what harms he is likely to suffer in the future.

The most important consideration is determining what will keep the infant content from day to day. That is why doctors and nurses need to be watchful for progression of life-terminating conditions or complications resulting from the use of ANH. This is assuming, of course, that the ILTC is in the hospital. If the family is able to take the infant home, then it is even more important for doctors and nurses to maintain contact with the family and give them information that is easy for them to understand. Such information should include how to care for the infant, what complications are minor and whether/how they can be treated at home, and what complications are life-threatening.

Life-threatening complications can be difficult for the family. On one hand, an untreated life-threatening complication will result in the infant's death. But if they rush a dying ILTC to the hospital, doctors and nurses will do what they are trained to do: save the ILTC's life. As a culture, we are unfamiliar with the dying process and with death, and when confronted by death, we panic, especially if the patient seems to be in pain and/or distress. We rush healthy people to the hospital in emergencies with the hope that they will recover because we sought medical treatment for them in time. But here we are dealing with ILTCs who are expected to die.

So the real question is this: if an ILTC seems to be dying but is in pain and/or distress, what can the family do at home to keep him comfortable? As the infant's condition or conditions progress, doctors should explain to the family what to expect, and what can be done to keep their infant comfortable. And as difficult as it may be, doctors should discuss end-of-life care, to include palliative medicine and the withdrawal of ANH at the appropriate time. If the family wants and expects the infant to die at home, doctors should help them prepare for that and explain to them that the infant's body will shut itself down in various ways that can be unsettling to family members who are unfamiliar with dying and death. Of course, there may be instances where families do not believe they may be able to hold their infants while they die. For the sake of everyone's comfort, families should discuss this issue with their doctors to determine the circumstances under which the ILTC may die in peace. In some situations, it may be better for ILTCs to die in the arms of a nurse in the NICU.

Before proceeding any further, I summarize my proposal for the withholding or withdrawing of ANH from ILTCs within each of the four categories. For infants who receive prognoses of two weeks or less, I propose that doctors should not initiate ANH. For infants who will live longer than two weeks but no more than two years and who are not yet suffering or in

distress, I propose that doctors should provide food and fluids by the form of ANH best suited for their situations, and only to the point where these infants are satisfied and do not suffer complications resulting from ANH. For infants who are not dying, but are in distress from the use of ANH, doctors should determine what the source of distress is. If these ILTCs are in distress from complications that produce more burdens than benefits that ANH provides, I propose that doctors withdraw ANH, administer palliative care as needed, and allow these infants to die comfortably. For infants who are not dying, but are in distress from their conditions and/or ANH, doctors again need to determine what the source or sources of pain and/or distress are. If the burdens associated with either the condition(s) or the use of ANH are greater than the benefits ANH provides, doctors should withdraw ANH, administer palliative care as needed, and allow these infants to die comfortably. What distinguishes these last two categories is the difficulties doctors may have in trying to determine whether the source of pain and/or distress is ILTCs' conditions, complications from the use of ANH, or a combination of both.

4.3 Difficulties in Assigning ILTCs to Categories

There is no distinguishing feature that allows doctors to determine infallibly how long an ILTC will live, what his quality of life will be, or how much pain and/or distress he will experience from medical treatments, including ANH. Some ILTCs who appear as though they might die within a few days outlive doctors' prognoses, while others who appear to be stronger die much sooner than anticipated. As we have seen throughout my dissertation, decisions to provide, continue, withhold, or withdraw ANH have an impact on not only how long an ILTC may live, but also on his quality of life. We want to provide ANH to ILTCs as a means of loving comfort, but we must also realize that ANH can harm ILTCs.

Consider the case of a trisomy 18 infant named “JR” who was treated by Dr. Benson Shih-Han Hsu, author of “Cost of a Life” (*Pharos* 32-33). “JR was born with significant congenital heart disease” (32). In addition, “he developed severe pulmonary hypertension” (32). He was given a grim prognosis, but “his parents were clear that there be no limitations on care” (32). One wonders what kind of information Hsu gave the parents on which to base their decision. Hsu relates, “Knowing the overall poor prognosis of this condition, I wondered if his continued medical care was appropriate—not from a perspective of futility but from one of resource allocation” (32).

The parents waited until JR was four months old—the age at which trisomy 18 infants are able safely to undergo cardiac surgery—before having him undergo the procedure. Dr. Hsu lists the complications resulting from surgery:

Unfortunately, given his heart failure and feeding difficulties, he suffered multiple medical setbacks over the following eighteen months, undergoing several operations including gastric and duodenal tube placements, central lines placements, and pulmonary artery banding. His postoperative recovery was constantly fraught with complications as he developed multiple infections and respiratory failure. Despite the repeated setbacks, his parents maintained their resolve to not limit his care. (32)

JR underwent another round of surgery to fix other heart defects at eighteen months. “But after over four weeks in pediatric intensive care with multiple failed extubations, his parents decided to withdraw care, convinced that he had endured more than enough suffering” (32). Summarizing all the care JR received, Hsu says,

JR had been admitted over fifteen times to the wards as well as the neonatal and pediatric intensive care units. He underwent numerous operations and procedures. He received consultations from more than eight separate pediatric services. He suffered countless infections and was mechanically ventilated on several occasions. He spent most of his life in the hospital and the cost of his care exceeded that of most hospitalized patients. (32)

Hsu says that JR “was aware of his environment, withdrawing from pain, having vital sign changes with stress, and even occasionally smiling” (32). Dr. Hsu estimates that “[m]illions of dollars were spent on his care” (32). Hsu writes, “After JR died, I felt comfortable in saying that his care was necessary” (33). His conclusion is that “limiting care on arguments of allocation makes no sense, ethically or economically” (33).

Hsu’s article focuses more on resource allocation than on futility as a deciding factor in providing medical treatments to someone like JR. Considering the family’s circumstances is important, but the problem in JR’s case seems to be that there was no limit to all the resources that were utilized. Between the parents’ desire to save their child and the team’s efforts to accommodate them, JR’s best interests were ignored. Two important questions arise: to which category did JR belong first, and what decisions should have been made in his best interests?

Considering the fact that JR was born with trisomy 18 with “significant congenital heart disease” and multiple anomalies, I would have considered him to be an ILTC in the first category (32). Therefore, my recommendation would have been to refrain from initiating ANH. Certain symptoms such as a dry mouth could have been alleviated by keeping his mouth moist. And there would have been nothing wrong with providing him tastes of formula to keep him content.

It was JR's heart disease that would have ultimately caused his death. JR's parents decided to have him undergo corrective surgery, but he needed to be at least four months old before he could undergo that surgical procedure. ANH was necessary, then, to keep him alive that long. I am sure that when JR's parents made the decision to have the doctors initiate ANH, they hoped he would not suffer complications as a result. If JR had not been in pain and/or distress, we could have considered him to belong to the second category of ILTCs. But because he suffered from both his heart condition and complications resulting from different forms of ANH, he belonged to the fourth category of ILTCs. As we can see from this case, ILTCs do not progress sequentially from one category to another. It is their particular circumstances that determine to which category they belong.

Since financial burdens were not a factor in JR's case, and JR's parents were willing to give him every chance at life, I set these and other concerns of the family aside to consider JR's best interests. Recall from the case history that he spent more time in the hospital than at home, underwent numerous operations and procedures (including mechanical ventilation), and suffered multiple complications. The fact that he lived approximately eighteen months indicates that he outlived the vast majority of infants with trisomy 18. The question is, should he have been allowed to live that long, considering what he endured?

Given the original diagnosis and prognosis, I would have withheld ANH from JR and allowed him to die within the first two weeks of his life. Numerous operations and procedures, multiple setbacks, and countless infections indicated that he had been in a vicious cycle his entire life. There is no doubt that JR's parents loved him, but it appears that they made one loving decision far too late: the decision to let him go. All the money in the world and the determination to "help" JR live as long as possible did not change the fact that his situation was

hopeless from the outset. Recalling my discussion throughout chapter 3, the judgment that an ILTC's quality of life is virtually or totally nonexistent does not mean that we value his life any less. It simply means that the ILTC's body is unable to function properly on its own to sustain life. Dying after having been kept as content as possible through a short struggle for life is preferable to dying after a long, painful struggle that could have been avoided in the first place, especially when we consider that ILTCs cannot grasp why it is they are suffering or for what purpose.

4.4 Ratzinger: A Model for Rethinking the Catholic Position on ANH for ILTCs

There is still the issue of embracing my proposal within the whole of Catholic teaching of caring for the sick and/or dying. From a philosophical standpoint, it is easier to adopt Pacelli's position over Wojtyla's on the grounds that Wojtyla's position is inconsistent with itself and with Pacelli's position. But we cannot forget the fact that these two positions come from two Popes who were and still are regarded as staunch pro-life advocates. The issue of ANH for ILTCs is difficult because we must figure out for ourselves how Pacelli might have specifically addressed the topic, as well as figure out a way of following Wojtyla's command despite the inconsistencies of his position.

Recall Bernardin's claim that a consistent ethic of life calls for a change of attitude toward life. But if we cling too tightly to the sanctity-of-life ethic without acknowledging the benefits of the quality-of-life ethic, we are in danger of embracing medical vitalism, which ultimately does the infant no good and sometimes even harms him. If the sanctity-of-life ethic prohibits us from either withholding or withdrawing ANH from ILTCs, we are left only with the option of watching helplessly as an infant endures what we consider to be heroic suffering. In situations such as the birth of an ILTC, the Church needs to offer parents not only spiritual

support, but also practical options. I believe that Ratzinger's answer to the AIDS problem in Africa can serve as a model for establishing conditions in which it can be morally acceptable to the Catholic Church to withhold or withdraw ANH from ILTCs who are in a constant state of pain and/or distress or have entered the dying process.

Aboard a flight to Cameroon on 17 March 2009, when questioned about the AIDS epidemic in Africa, Ratzinger said, "I would say that this problem . . . cannot be overcome merely with money, necessary though it is. If there is no human dimension, if Africans do not help [*by responsible behavior*], the problem cannot be overcome by the distribution of prophylactics: on the contrary, they increase it" (*Light of the World* 193). Many people worldwide claimed that the Pope had basically issued the people of Africa a death sentence.

Many people throughout the world have objected to the Church's longstanding position against artificial birth control, including condoms. In 1968, Pope Paul VI⁴⁷ (whom I shall refer to as "Montini") issued his last encyclical, *Humanae Vitae* [*Of Human Life*], in which he condemned the use of artificial birth control on the grounds that it rendered the conjugal act incapable of fulfilling both its unitive and procreative functions (10 [12]).⁴⁸ Catholic couples worldwide were outraged over his position, and many people—both within and outside the Church—questioned what business the Church had in matters occurring in couples' bedrooms. Quite often, whenever the Church pronounces a statement that runs counter to popular opinion, people dismiss the Church on the grounds that she is antiquated and/or irrelevant. Papal

⁴⁷ Giovanni Cardinal Montini became Pope Paul VI upon his election to the papacy in 1963. His pontificate lasted until 1978.

⁴⁸ The Church teaches that in order for the conjugal act to remain consistent with the will of God (as He is the Creator and we imitate Him as ministers of creation), it must be both unitive (loving) and procreative (life-giving). In vitro fertilization (IVF) can be procreative but not unitive, while intercourse using artificial contraception can be unitive, but is not life-giving. The reader may access *Humanae Vitae* on the Internet [here](#).

statements issued in encyclicals tend to give the impression that once a pope speaks his mind, the question is closed to debate.

Following Ratzinger's comments, there was massive confusion as to whether Ratzinger had lifted the Church's ban on the use of artificial contraception, most notably condoms. Did Ratzinger give everyone permission to use them? Or did Ratzinger give permission to use them only to people in Africa, or only to people with AIDS regardless of location, etc.? Let us first look at the clarification Ratzinger provides to his interviewer, Peter Seewald:

The Church does more than anyone else, because she does not speak from the tribunal of the newspapers, but helps her brothers and sisters where they are actually suffering. In my remarks I was not making a general statement about the condom issue, but merely said, and this is what caused such great offense, that we cannot solve the problem by distributing condoms. Much more needs to be done. We must stand close to the people, we must guide and help them; and we must do this both before and after they contract the disease. . . .

There may be a basis in the case of some individuals, as perhaps when a male prostitute uses a condom, where this can be a first step in the direction of a moralization, a first assumption of responsibility, on the way toward recovering an awareness that not everything is allowed and that one cannot do whatever one wants. But it is not really the way to deal with the evil of HIV infection. That can really lie only in a humanization of sexuality. . . .

She [the Catholic Church] of course does not regard [the use of condoms] as a real or moral solution, but, in this or that case, there can be nonetheless, in the

intention of reducing the risk of infection, a first step in a movement toward a different way, a more human way, of living sexuality. (*Light* 118-119)

If we pay very close attention to Ratzinger's rationale for his initial comments, we see emerge a method of reexamining a moral dilemma in light of a situation that Montini could not have possibly imagined (i.e., AIDS) when he penned *Humanae Vitae*.

An important phrase to consider is "solve the problem." Before providing a solution, we must first correctly identify the problem. What is the problem in Africa? It is the spreading of AIDS. The ANH-for-ILTCs issue presents a different kind of problem. What is the problem with ANH for ILTCs? They have life-terminating conditions that will cause them to die before the age of two, and providing ANH can cause additional harms and prolong the dying process.

Now we ask, why do we want to solve the problem? We want to solve the AIDS problem so that Africans can live without the devastating consequences of AIDS. Here is the fundamental difference between the AIDS problem and ILTCs. We want to solve the ANH-for-ILTCs problem not so that they can live long, healthy lives, but so that they can avoid unnecessary pain and/or distress and die comfortably.

Having identified the problems and the reasons for solving them, let us turn to the solutions. First, if all we do to solve the AIDS problem is tell people that they cannot engage in sexual intercourse but they do so anyway, AIDS will continue to spread. Science has shown that people can limit the spread of AIDS when they use condoms properly and the condoms do not fail. While the use of condoms may help stop the spread of AIDS, their use does not cure it. Ratzinger hopes that there will one day be a cure for AIDS, but there is none right now. In the meantime, we cannot abandon AIDS victims, regardless of the way they may have contracted it (either through lifestyle choices or through unknowingly coming in contact with contaminated

blood). In particular, infected infants certainly have done nothing to warrant being abandoned; they are truly victims of their circumstances. The ideal situation would be the elimination of AIDS and monogamous sex within marriage. But since that is not the real situation, we must provide solutions that help people in their present circumstances.

What would be the ideal solution for ILTCs? It would, of course, be a cure for their conditions. But that is not the real situation. Just as the Church thinks it is wrong to abandon AIDS victims, it would be equally wrong to abandon ILTCs and their families. The real situation is that ILTCs will die before the age of two, and their families must struggle in numerous ways to care both for their infants and themselves. The next best solution—which is available right now—is to provide comfort to ILTCs through palliative care and the form of ANH that is least invasive and delivers the most benefits while producing the fewest harms. And if ANH becomes such that it produces more harms than benefits, withholding or withdrawing ANH is in itself another form of palliative care.

Second—and this is where we see the new model emerge—Ratzinger commends those who make a conscious decision to protect their partners. Those engaging in sex outside of marriage or using a condom within marriage to avoid pregnancy are not living up to the Church's ideal regarding human sexuality. Ratzinger hopes these that people will eventually adopt the Church's teaching on human sexuality,⁴⁹ but in the meantime, the effort to protect others is better than simply seeking sexual pleasure and jeopardizing their partners' health.

⁴⁹ Ratzinger did not reverse the Church's position against the use of condoms as a means of artificial birth control for married couples. The Church still encourages couples to practice natural family planning (NFP)—not to be confused with the rhythm method—as a practical option of regulating birth. In *Humanae Vitae*, Montini states, "If, then, there are serious motives to space out births, which derive from the physical or psychological conditions of husband and wife, or from external conditions, the Church teaches that it is then licit to take into account the

So how does this different approach apply to the debate over ANH for ILTCs? Like infants born with HIV (who may live for several years; in this way they are different from ILTCs), ILTCs are not responsible for their conditions. Families of ILTCs find themselves in a less-than-ideal situation from the very beginning of their children's lives. We should commend them for providing loving care to their infants rather than abandoning them. Providing ANH to dying ILTCs does nothing to cure their life-terminating conditions. Especially since curing the condition is not an option, comfort should be the top priority. If medical science has demonstrated that the complete withholding or withdrawing of ANH—along with palliative care, if necessary—keeps these infants content, doctors should explain to families that withholding or withdrawing ANH will keep their ILTCs content and reassure them that making that decision is ultimately in their infants' best interests. Again I emphasize that we should not consider withholding or withdrawing ANH an automatic response in providing care—especially since some ILTCs may not enter the dying process or be in a constant state of pain and/or distress according to doctors' original prognoses—but it should be made available as the situation calls for it. In this way, we can make a quality-of-life judgment about an ILTC's present and future life while still respecting the sanctity of his life. Withholding or withdrawing ANH during the dying process or in a constant state of pain and/or distress would “[express]”, as Wojtyla says, “acceptance of the human condition in the face of death” (*Gospel* 118 [65]).

If we look at Pacelli's speech, Wojtyla's encyclical and his 2004 address, and Ratzinger's response to the AIDS problem in Africa, we can see where Pacelli and Ratzinger have left dilemmas involving medical ethics open to debate, while Wojtyla appears to have

natural rhythms immanent in the generative functions, for the use of marriage in the infecund periods only, and in this way to regulate birth without offending . . . moral principles. . .” (13 [16]).

singlehandedly settled the ANH debate once and for all. Pacelli recognized that artificial respiration was only one newly developed medical procedure. He probably could not have imagined the kinds of medicines and new technology we now enjoy. Had he lived (he died in 1958, the year after he delivered “The Prolongation of Life”), he probably would have found it necessary to discuss the moral concerns regarding other new forms of medical technology. Likewise, Ratzinger knows that AIDS will continue to be a problem throughout the world for many years to come. While condoms alone will not eradicate the problem, admitting that their use may be a first step towards adopting more responsible behavior keeps the debate alive. But declaring the withholding or withdrawing of ANH to be morally impermissible and closing the ANH issue to debate (as Wojtyla and other bishops have done) while clinical evidence appears to offer a possible, practical solution may be another source of distress for families already dealing with a devastating situation. And not allowing the withholding or withdrawing of ANH can create further pain and/or distress for ILTCs, whose basic needs should be at the center of the debate.

Worth noting is the fact that forty-one years passed between the time Montini published *Humanae Vitae* and Ratzinger offered his comments about condoms being a possible first step toward solving the AIDS crisis. It has been fifty-four years since Pacelli delivered “The Prolongation of Life.” The Church embraces ILTCs in its arguments for the sanctity of life, but she has not addressed in any great detail the special circumstances surrounding ILTCs and their families in her arguments. It is time for the Church to engage in the debate over ANH for ILTCs.

4.5 Conclusion

When it comes to end-of-life decisions, deciding to allow ILTCs to die is perhaps the hardest decision of all. We are still getting to know them, and they leave this earth much sooner than we would like. But in some circumstances, it is more in an ILTC's best interests to die sooner and in peace rather than linger and suffer heroically. In this chapter, I considered four categories of ILTCs: those who appear to be already dying from birth, those who will die anywhere between two weeks and two years, those who are not yet dying but suffer complications from ANH, and those who are not yet dying but suffer from both their conditions and the use of ANH. In cases where ILTCs are already dying or demonstrating that they cannot assimilate food and fluids through ANH, withholding or withdrawing ANH is a loving form of care designed to ease the ILTC's pain and/or distress. Decisions regarding infants who are not yet dying from their conditions but seem to be able to tolerate ANH are more difficult. If parents can determine that lifesaving treatments are extraordinary, they are morally permitted to allow their infants to die. To ensure that the decision to withhold or withdraw ANH is not made too early, doctors should be watchful for signs that the dying process has begun. It is understandable that parents want to provide every form of treatment so that their children might live. Since it is clear that an ILTC will not survive, doctors should brief the family on the benefits of withholding or withdrawing ANH. It is in the ILTC's best interests, even though his death will create tremendous pain and suffering for the family. Because this decision cannot be taken lightly, doctors must be as compassionate as possible when counseling families about end-of-life decisions for their infants.

Regardless of the position we take—Wojtyla's or Pacelli's—families must still deal with the death of their infants. Serious illness, dying, and death can make families question, "Why

did this happen to us?” Especially from a religious perspective, families often ask, “Why did God allow this to happen to us?” At times like these, families are under considerable stress. People often turn to their faith for guidance and comfort. But as I have argued, Wojtyla’s position places ILTCs and their families in situations amounting to heroic suffering, something Wojtyla himself says not everyone is obligated to undergo. Regarding tensions between different Church teachings on the same issue, Ratzinger’s approach to solving the AIDS problem in Africa can serve as a model for debating the issue of ANH for ILTCs from a new perspective (i.e., an ILTC’s situation is hopeless from the outset, and most treatments are extraordinary for him). Families need to make the correct ethical decisions about the care of their infants, but as I have argued, circumstances make it impossible to follow hard-and-fast rules, especially when there is no way of being completely certain about the future. More than at any other time, families of ILTCs need compassionate spiritual care. My aim in chapter 5 is to offer possible options for the Church to help in this regard.

Chapter 5: Providing Spiritual Care to Families of ILTCs

In the first four chapters of this dissertation, I focused primarily on comforting dying infants with life-terminating conditions (ILTCs) or trying to ensure that they are content. I now wish to focus my attention on their families who must bear the burden of caring for them up to and including the moment of their death. Recall Wojtyla's admonition from *The Gospel of Life*: actions that cause human suffering "poison human society, and they do more harm to those who practice them than to those who suffer from the injury" (7 [3]; Wojtyla quoting *Gaudium et Spes*). Loving families do not intentionally cause their ILTCs harm, but they may unknowingly do so when they permit doctors to perform medical procedures aimed at saving or prolonging these infants' lives. In such cases, these families may feel guilt and remorse if they think that their infants have suffered or died as the direct result of a particular decision they made (e.g., attempting, continuing, withholding, or withdrawing a treatment). There is no immunity from pain and suffering resulting from the death of a loved one. But no one needs to bear pain and suffering alone. The Church is not presently in a position to provide guidance for parents of ILTCs because the Church's teaching on artificial nutrition and hydration (ANH) is not consistent. But the aim of this chapter is to show that by rethinking its position on ANH, the Church can provide spiritual care by easing grieving families' suffering and allowing them to experience the benefits of redemptive suffering.

5.1 Distress versus Suffering

People often make statements such as, "This infant is suffering from heart disease" or "That infant suffered horribly before dying." But infants do not suffer in the true sense of the term. They do, however, experience various types of distress. What is distress? Distress is the state of needing relief from some type of pain and/or discomfort. Older children and adults can

sometimes manage to alleviate their own distress by themselves or by asking others to help them. For example, an adult can flee a burning building, and a student struggling with a particular subject can ask a teacher for help. Infants, however, need help in obtaining relief. Infants can experience life-threatening distress when they are choking or are drowning in the bathtub. Infants can also experience mild distress when they are cold, hungry, or in some type of physical pain (e.g., when they receive an injection). Chronic distress can last indefinitely, while other forms of distress (e.g., an injection) can be momentary. Crying and thrashing are often signs that an infant is in distress. An infant can also be in danger of death without alerting anyone (e.g., sudden infant death syndrome, or SIDS⁵⁰). At the end of chapter 3, I proposed that our goal should be to keep a dying ILTC content. While keeping an ILTC content may do nothing to prevent him from dying, keeping him content will prevent him from being in distress (i.e., feeling pain, crying, and/or thrashing).

About ILTCs, people often say, “It is better for an infant to die than to suffer indefinitely.” We understand what they mean, but to say that an infant suffers is actually incorrect. Therefore, we need to define exactly what we mean by “suffering.” As we shall see, it is not necessarily the ILTC who needs relief from his suffering, but the family who needs relief from theirs. Once we understand the difference, we can begin to help families heal.

Except for those patients who cannot feel pain (e.g., anencephalic infants, patients in a permanent vegetative state [PVS], and patients who are sedated), physical pain is often, but not always, the initial event that causes people to suffer. But not all physical pain leads to suffering.

⁵⁰ I do not consider infants who die from SIDS to be ILTCs. Families of infants who die from SIDS do not have to make decisions about end-of-life care as do families of ILTCs. But the sudden death of an infant from SIDS can cause parents to second-guess everything they did before laying their infant down to sleep. For this reason, we can expect these families to feel guilt, even if they have done nothing wrong.

For example, a marathon runner completing the last mile and in position to win is no doubt experiencing great physical pain. But anticipating his first-place finish, he experiences jubilation, not suffering. Likewise, a mother delivering her child naturally experiences excruciating pain, but once her child is born, she is overcome with joy as she holds her baby in her arms.

Sometimes it happens, though, that someone else is in terrible pain or experiencing an unfortunate turn of events, but I still experience suffering. For example, one of my children may be involved in a serious accident or I may learn that another family member has been evicted from his house or been arrested for some violation of the law. My child's accident involves physical pain for him, but not for me. My other family member's arrest may not involve any physical pain whatsoever. But I still suffer nonetheless. How is this possible?

In "The Meanings of Suffering," Stan van Hooft says, "The very word *suffering* has a resonance that relates to our sense of life's meaning and the threat suffering poses to our hopes of happiness. . . . Suffering is a spiritual phenomenon, an event that strikes at the faith we can have in life" (13). Quoting Stanley Hauerwas, van Hooft writes, "Suffering is not morally significant only because things happen to us that we cannot avoid . . . but because the demand of morality cannot be satisfied without asking the self to submit to limits imposed by morality itself" (15). In "Diagnosing Suffering: A Perspective," Eric J. Cassell writes, "Suffering involves some symptom or process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future" (531).

From these reflections, we begin to see why infants are incapable of suffering. They have not matured to a stage at which they find meaning in anything. Although they can be made comfortable, infants are incapable of happiness in the Aristotelian sense because they cannot

willfully choose to pursue activities leading to a higher end. Infants do not engage in spiritual matters, although they can receive benefits from the spiritual activities of others. Infants cannot comprehend morality, limitations, fear, or the future. But others who care for these infants can and do comprehend these things. This is why families often suffer when their infants experience pain and/or distress.

ILTCs experience pain and/or distress primarily on the physical level, and, to some extent, on the emotional level (e.g., being isolated in an incubator in the neonatal intensive care unit [NICU]). Family members do not feel the physical pain that the ILTC does, but they experience anguish on the physical level in a different way, and on several other levels as well. For instance, providing round-the-clock care can take a physical toll on family members. Worry and fear can cause emotional pain, which in turn can manifest itself in physical ways as well. Family members may feel socially isolated from others. There is a moral dimension to decisions we make about medical care for ourselves and others. And because it is possible to make both ethical and unethical choices when it comes to providing care, families of ILTCs suffer from the weight of the decisions they must make and then, often, also from guilt or remorse about the decisions they did make. And the illness and death of an infant can be spiritually devastating for families. The Church must provide spiritual care to her members, and this is something different from her teaching or guidance function.

5.2 Heroic Suffering

In chapters 3 and 4, I mentioned the notion of heroic suffering. What is heroic suffering? Heroic suffering does not mean acting like a hero in the face of suffering. Heroic suffering is suffering which goes beyond what can be expected or asked of a person. Wojtyla himself says

that not everyone is obligated to endure it. But the history of the Catholic Church is full of saints who suffered heroically.

Both the Old and New Testaments recount stories of the epitome of heroic suffering: being martyred for the faith. Chapters 6 and 7 of 2 Maccabees⁵¹ in the Old Testament give accounts of the martyrdom of Eleazar and the martyrdom of a mother and her seven sons.⁵² Chapter 7 of the Acts of the Apostles in the New Testament provides the details of Stephen's⁵³ martyrdom.

All Christians are called to be Christ's witnesses to the world, and some may experience great suffering as a result, including a martyr's death. But there have been many good Christians who, instead of suffering a martyr's death, endured what we would consider to be heroic suffering on various levels. Countless saints have suffered horrible afflictions or been persecuted without having been put to death. The reason saints are recognized as such is that they willfully chose to forgo much of what this life has to offer in exchange for the glory of God, no matter the cost. It was this willingness to suffer that they earned the Church's highest distinction.

In section 5.1 above, I argued that, strictly speaking, infants do not suffer. But when Wojtyla speaks of "heroic suffering," he is using a broader sense of the term, that is, suffering involving extreme pain or discomfort, which ILTCs can in fact experience. In *The Gospel of Life*, Wojtyla himself says that heroic suffering "cannot be considered the duty of everyone"

⁵¹ Many people may not be familiar with 1 and 2 Maccabees in the Catholic Bible. According to the introduction of 1 Maccabees, "The Books of Maccabees, though regarded by Jews and Protestants as apocryphal, i.e., not inspired Scripture, because not contained in the Palestinian Canon or list of books drawn up at the end of the first century A.D., have nevertheless always been accepted by the Catholic Church as inspired, on the basis of apostolic tradition" (*New American Bible* 468).

⁵² The mother and her seven sons were all martyred on the same day.

⁵³ As the early Church continued to grow, the Twelve Apostles called seven men to assist them in spreading the Gospel. Stephen was one of the first seven assistants. See Acts 6.1-7.

(118 [65]). But infants—healthy or imperiled—have neither duties nor choice, so they certainly cannot be expected to undergo heroic suffering. It is not hard to imagine that an ILTC’s heroic suffering leads to his family’s heroic suffering. If we can keep an ILTC from suffering heroically, we may alleviate—but not totally eliminate—his family’s suffering. Recall from section 4.4 Ratzinger’s challenge for us to relieve suffering where we can. Why should we not try at the very least, then, to prevent ILTCs and their families from suffering heroically?

5.3 Redemptive Suffering

There is a belief within the Catholic Church that we can participate in Christ’s redemptive work by suffering. Such suffering is called “redemptive suffering.” To be clear, redemptive suffering does not mean that Christ’s sacrifice on the cross was in any way inadequate in procuring salvation for all humanity, and we somehow add what is missing. Since suffering is part of the human condition, the question then becomes, what do we do about suffering when we experience it?

To gain a better understanding of redemptive suffering for families of ILTCs, it is best to consider briefly the redemptive suffering of Christ. Paul says in his letter to the Philippians: “. . . [T]hough he was in the form of God, [Christ Jesus] did not regard equality with God something to be grasped. Rather, he emptied himself, taking the form of a slave, coming in human likeness; and found human in appearance, he humbled himself, becoming obedient to death, even death on a cross” (2.6-8). Christ Himself sets the grounds for being one of His disciples: “ ‘Whoever wishes to come after me must deny himself, take up his cross, and follow me’ ” (Mark 8.34). Out of appreciation for the ransom He paid, we need to offer something of ourselves. The willful gesture of offering ourselves out of appreciation is obedience on our part. There is no complete escape from suffering, but the Church teaches that our suffering can somehow be

united to that of Christ's. We learn from the *Catechism of the Catholic Church* that by uniting one's own suffering to Christ's, "[s]uffering, a consequence of original sin, acquires a new meaning; it becomes a participation in the saving work of Jesus" (n. 1521).

St. Thérèse of Lisieux (1873-1897), who nicknamed herself the "Little Flower," was a Carmelite nun who developed what she called the "Little Way."⁵⁴ The Little Way is really nothing more than performing the most ordinary acts or embracing whatever suffering we encounter out of love for Jesus and for the sake of others' spiritual benefit. St. Therese's sister, Céline (who was also a Carmelite nun and took the name Sister Geneviève), says the following about Thérèse:

The saint's voluntary participation in the Passion of Christ (a participation foreseen, to be sure, in her Act of Oblation according to the degree willed by Our Lord) is the reason for her extraordinary sufferings, especially during those last years of her life. The two burning ideals of Thérèse's vocation . . . might be expressed in this way:

- a) . . . when she was fourteen years old, she voiced the desire to suffer and to help save souls by the Cross;
- b) . . . at the summit of her spiritual ascent, she offered herself as a victim to the merciful love of God, to make amends to this love which is ignored on all sides. (Clarke 15; Clarke quoting *A Memoir of My Sister*)

⁵⁴ Because of the Little Way's simplicity and popularity among Catholics worldwide, St. Therese was the latest saint to be declared a doctor of the Church by none other than Pope John Paul II (Wojtyla) himself in 1997. This honor has been given to only thirty-three individuals (only three of whom are women) in the entire history of the Catholic Church.

St. Thérèse died a most painful death from tuberculosis, and thus her suffering was clearly heroic. But even according to her, that does not mean that we must also undergo heroic suffering to participate in redemptive suffering. We can take even the slightest suffering we encounter and offer it on behalf of others. For example, we can offer a prayer to God in the midst of our suffering, even if that prayer is short or expresses anger. Or we can perform some very simple act out of love for others (e.g., holding open a door). Recall from section 3.4 Jesus' words: " 'Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me' " (Matt. 25.40). From the parable of the talents,⁵⁵ we hear the words we hope to have spoken to us at our own judgment: " 'Well done, my good and faithful servant. . . . Come, share your master's joy' " (Matt. 25.21).

In the process of praying and doing works for others, then, a person also obtains spiritual benefits for himself. This appears to be somewhat ironic and raises a very important question: can the willingness to participate in redemptive suffering drive families too far in providing care, especially in cases involving ILTCs? In other words, can the family of an ILTC use his pain and/or distress for their own spiritual benefit while the prolongation of life does not benefit him at all? I believe the answer to this question is yes. As I explained in section 4.3, a family may believe that they are doing what is in their infant's best interests by giving him every chance to survive (e.g., ANH, heart surgery, etc.). From Hsu's "Cost of a Life," we do not know anything about JR's family's spiritual life, that is, if they have one at all. But let us suppose for a moment that they believe that they derive spiritual benefits by providing JR with whatever care is necessary to prolong his life. In doing so, however, they are in fact practicing medical vitalism and subjecting JR to heroic suffering, neither of which the Church demands, especially in cases

⁵⁵ See Matthew 25.14-30.

where the patient has no say about his own medical care. This issue arises not only with ILTCs, but with older, chronically ill patients, whose families sometimes prolong their lives because caring for them is the only source of meaning in families' lives. In any case, it is morally wrong to cause or prolong the suffering of others in order to try to derive spiritual benefits for oneself from their suffering.

So how can the family of an ILTC participate in redemptive suffering without its becoming heroic suffering, especially for the ILTC? The family of an ILTC can participate in redemptive suffering from the moment they discover their infant has life-terminating conditions (even if he is *in utero*), throughout his lifetime (no matter how long or short it is), and indefinitely after he has died. Participating in redemptive suffering can involve praying for the infant and/or any other families undergoing similar situations, donating to foundations aimed at helping families of ILTCs, offering support to other families of ILTCs, etc. These are all ways of helping others without increasing or prolonging an ILTC's pain and/or distress. I believe we reap the most spiritual benefits when we are focused on others' spiritual welfare to the point where we completely forget about our own.

Is it possible for families to participate in redemptive suffering if they do not know what it is? I believe the answer to this question is yes. When Jesus explains what will happen to people based on what they have done or have failed to do in Matthew 25.31-46, notice that both groups of people ask the king when it was that they did or did not do something for him. So people who are unfamiliar with redemptive suffering may provide all kinds of spiritual benefits for themselves and for others without realizing it.

Some people may ask, can only Christians participate in redemptive suffering? What about those who do not belong to any particular denomination or those do not profess belief in

God? Cassell discusses transcendence, which appears to be quite similar to redemptive suffering. Cassell writes, “When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares that meaning. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension it is deeply spiritual” (*Nature of Suffering* 45). It is quite probable that families of ILTCs will find themselves interacting with many people who do not share the same faith. Families may find that some of the people giving them the most comfort are spiritual, but not necessarily religious.

I believe that if people learn about the benefits they can provide to others through redemptive suffering (or transcendence, in Cassell’s terms), they will try to see past their own suffering and try to help others whenever and however they can. St. Thérèse is the perfect example of someone who embraced redemptive suffering after learning about it; it became her life’s mission, long before she succumbed to tuberculosis.

But there is an underlying question we need to answer as well: when does the family’s suffering become heroic? Wojtyla says that not everyone is obligated to undergo heroic suffering. But from Wojtyla’s claim that ANH constitutes ordinary and therefore obligatory care, families find themselves obligated to provide ANH to their ILTCs. But complications resulting from the use of ANH and/or the progression of an ILTC’s condition(s) can cause him to suffer heroically, as well as his family. But recall Pacelli’s remarks about duties of families:

- 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 good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. (94)

- The rights and duties of the family 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 discontinue these attempts, and the doctor can lawfully comply. (96)

Distilling the following arguments from both Wojtyla’s and Pacelli’s comments above, we notice a real dilemma for families of ILTCs. The first argument is as follows:

1. Wojtyla says not everyone is obligated to undergo heroic suffering.
2. The Church teaches that the provision of ANH is obligatory.
3. The provision of ANH can force an ILTC and/or his family to suffer heroically.
4. But (1) contradicts (3).

We now proceed to the second argument:

5. The Church teaches that we are supposed to respect life from its very beginning to the moment of natural death.
6. Medical science maintains that withholding or withdrawing ANH can be a means of facilitating natural death.

7. But the Church teaches that withholding or withdrawing ANH to facilitate death is euthanasia and makes us unable to participate in the sacramental life of the Church.

8. So it appears that in order to be able to participate in the sacramental life of the Church, we must continue to provide ANH.

But (8) can lead us to (3), which contradicts (1). A real dilemma for families of ILTCs develops when, on one hand, they find themselves in most need of spiritual care, while on the other, they may choose an action that is not morally permitted by the Church and so make certain forms of spiritual care such as the sacraments unavailable to them. The ramifications can be quite substantial. They may subject their infants to heroic suffering that is truly unnecessary, and they may become so bitter with the Church that they decide to leave it.

There is no predicting how individuals or their families will suffer during their lifetimes. Some families seem to endure heroic suffering interminably, while other families seem to avoid it by and large. It seems ironic that the full range of spiritual care that the Church provides to its members is available when they are not suffering (provided, of course, that they remain in a state of grace), but not when they believe they have no option but to choose an action that is morally prohibited by the Church.

5.4 How the Church Can Provide Spiritual Care to Families of ILTCs

There is one major obstacle to overcome before the Church can provide adequate spiritual care to the parents of ILTCs, and that is the Church's present teaching that a family cannot withhold or withdraw ANH from an ILTC unless it is clear that ANH produces more harms than benefits or the ILTC is in his final hours.

My son Zachary was born less than three weeks after my wife and I discovered that he had trisomy 13. Not knowing what we would be facing in terms of taking care of him, we told our family, close friends, doctors, and our pastors that we would provide whatever care was necessary to keep him comfortable and remain with him until the time he died. There was nothing that we said or planned to do that conflicted with Church teaching, and since Zachary only lived six hours, providing long-term care was not an issue for us. We received all kinds of support and spiritual care from people within our parish, and we continued to enjoy fully participating in the sacramental life of the Church. Zachary's death was tremendously painful for us, but it did not create moral dilemmas for us or cause us spiritual suffering to the point where we felt that the Church could not help us, or worse, to the point where we felt that leaving the Church might have been a better option for us.

But there are families whose ILTCs live longer than six hours, and providing care for more than a day raises various concerns. Suppose a family tells their pastor, "The doctors and nurses have suggested withholding or withdrawing ANH as a form of palliative care." If the pastor upholds Church teaching on the matter (which he should if he wants to remain faithful to it), his response will probably be, "This is something that the Church does not permit. You must provide ANH to your infant until it is clear that there is no way he can assimilate food and fluids or he is in his final hours. But I will pray for you." This is something no family wants to hear, and we see where this response leaves the family. First, the family is considering an option (i.e., euthanasia, at least from the Church's point of view) that will prevent them from fully participating in the sacramental life of the Church. Second, the family is left without a practical option of providing comfort care for their infant and must resign themselves to heroic suffering. Third, they come away with a feeling that "I will pray for you" really means, "I will pray that

you see the error of your ways and will instead do the right thing.” Rather than feel that they are being provided spiritual care, the family may reasonably feel as though they are being judged by someone who probably cannot completely comprehend how agonizing their situation is. If the parents decide to withhold or withdraw ANH from their infant to relieve pain and/or distress, they are cut off from what they probably need most of all—participating in the sacramental life of the Church—since, as Pacelli says, spiritual goods are superior to temporal goods.

So how can the Church provide spiritual care to families of ILTCs, especially if they decide to withhold or withdraw ANH as a form of palliative care? This is where my discussion of Ratzinger comes into play. If the Church makes the effort to revisit the debate over ANH for ILTCs and consults with experts in palliative care, she may come to the same conclusion that I have: withholding or withdrawing ANH from an ILTC may provide comfort to the ILTC for as long as he continues to live, while at the same time taking both his sanctity of life and quality of life into account. We provide as much earthly care as possible and avoid medical vitalism, which only prolongs the ILTC’s pain and/or distress. We accept natural death. We allow nature to take its course while at the same entrust the ILTC’s soul to God’s care.

Suppose that the Church agrees with my proposal and encourages pastors to provide care to families of ILTCs based on it. What steps would she need to take?

First, the Church needs to rethink her position on ANH in general. As it stands right now, there is a real gap between medical science and religion, or between earthly and spiritual care. Medical science continues to develop all sorts of treatments to prolong a patient’s life, but this does not mean that the Church approves of every treatment. In addition, because medical science can create moral dilemmas, the Church finds herself having to address the morality of science, when her primary expertise and mission involve the spiritual welfare of her members.

Pacelli admits that there are some instances where the Church cannot address scientific matters because she does not have the expertise. When the growing body of medical knowledge seems to indicate that it is in a patient's best interests to stop being fed and hydrated for one or more reasons, the Church should be open to such discussions and rethink her position on the issue.

Second, if the Church does indeed approve of withholding or withdrawing ANH as a form of palliative care, she should inform families that such a decision is permissible and offer whatever spiritual care she can. Recall from section 4.4 that Ratzinger says that the Church "must stand close to the people, we must guide and help them. . ." (118). If families know they have the Church's support, they will be more inclined to ask for help and to continue participating in the life of the Church, especially during a most difficult time like this.

Of course, a family of an ILTC may refuse spiritual care for one or more reasons. Perhaps they are overwhelmed by the situation. Perhaps they are in denial that their infant will die from his condition. Or perhaps they are so angry with God for allowing their child to be born with life-terminating conditions. The Church (by "Church" I mean the local parish) should make herself available to the family with the understanding that the family may refuse help. This does not mean, however, that the Church should abandon the family. It may take some time for the family to accept the situation and realize that they do need help. It is hard to offer help and be rejected, but we must remember that not all families will accept their situation in the same manner or according to an established time frame.

Third and finally, the Church must work with medical science to help her members learn how to deal with dying and death. Illness, dying, and death do not involve just our bodies. Illness, dying, and death involve our souls as well. When faced with issues of mortality, many people turn to the Church for spiritual care. On one hand, the Church teaches that we are to care

for earthly life as long as it shall last, but on the other, the Church also teaches us that at some point we must all die and return to our Creator. Most people look forward to being in heaven, but they fear the process of getting there. We are constantly told that heaven is a place of bliss. But dying and death create all kinds of turmoil for us: worry, fear, anger, bitterness, depression, etc. So there is a tug of war between our bodies and souls. People need help making the transition between life and death

It is not enough for the Church to preach about heaven on Sundays. She needs to engage the medical community, particularly in the area of palliative care for the dying. This is where the Church can help effect a change of attitude towards life that Bernardin calls for in “A Consistent Ethic of Life.” In conjunction with the medical community, the Church can better serve her members by addressing what happens to the body during the dying process, what concerns and emotions may arise as a result, and what palliative options can be chosen to keep dying patients and their families comfortable. If care is provided on all levels, dying patients and families may feel assured that they are choosing Church-approved palliative methods, and they have the full support of the Church.

5.5 Conclusion

Not all suffering can be avoided or eliminated, but the Church has the tremendous task of helping to alleviate it where possible. In providing spiritual care, the Church can help her members participate in redemptive suffering while helping them avoid heroic suffering, especially if it is not their choice. It is easy to provide spiritual care to an ILTC. But as we have seen throughout this dissertation, ILTCs primarily need physical comfort, while families need comfort on several different levels. The Church needs to undertake a number of tasks. First, she needs to consult palliative care specialists to rethink the debate over ANH for ILTCs. Second,

she needs to offer practical moral guidance for families (i.e., giving families moral permission to withhold or withdraw ANH when it is in ILTCs' best interests). Third, she needs to educate all her members about the benefits of withholding or withdrawing ANH towards the end of life. Knowing what a dying patient's own body can do to facilitate natural death will relieve families of having to make some very difficult end-of-life decisions, especially when the continued use of various forms of artificial life support borders on medical vitalism. The Church should respect the wisdom of the medical community and keep her focus where it belongs: on the spiritual care of her members. In this way she can best fulfill her primary mission: the salvation of her members.

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Appendix

Checklist for Determining Necessity of ANH for ILTCs

Families, doctors, and chaplains should consult this checklist during the decision-making process. All parties must answer the following questions honestly and in order, beginning with the first question. Especially if there is a change in the infant's status, it is imperative to start with the first question every time, no matter how many times this checklist has been implemented in the past.

1. *Is the infant healthy?*

Yes. Food and fluids (OFF)⁵⁶ obligatory.

No. Diagnosis of ailment obligatory.

2. *Is the illness/condition at this moment life-threatening?*

Yes. Proceed to next question.

No. Treat the illness, and give OFF as prescribed.

3. *Is there hope of recovery from illness/condition?*

Yes. Treat illness/condition. Provide OFF, unless infant is unable.

No. Administer palliative care, and provide OFF if infant seems hungry or thirsty.

4. *Will the infant survive more than two years?*

Yes. Not included in this dissertation.

No. Dissertation restricted to these cases.

5. *Is the condition itself gravely burdensome for the infant?*

Yes. Allow condition to progress and give palliative care as needed. Provide OFF, unless infant is unable.

No. Continue to provide OFF, and provide simple care to alleviate pain/distress.

6. *Is the treatment for the condition in (5) gravely burdensome for the infant?*

Yes. Treatment optional. Allow condition to progress and give palliative care as needed. Provide OFF, unless infant is unable.

No. Provide treatment and OFF, unless infant is unable.

7. *Will treatment(s) involve extraordinary means? That is, will the family (including infant) face grave burdens in treating infant?*

Yes. Treatment(s) optional. Administer palliative care to keep infant comfortable. Provide OFF unless futile.

No. Treatment(s) obligatory. Use sedatives to keep infant comfortable. Provide OFF.

⁵⁶ For clarification, I shall use the abbreviation "OFF" for food and fluids a person can ingest orally, and "ANH" for food and fluids delivered by any artificial means.

8. *Will grave burdens fall only on infant?*

Yes. Consider physical pain/distress as part of treatment/non-treatment decision. This could happen only if parents were uncaring, uninvolved, and medically indigent.

No. In addition to physical burdens on infant, consider burdens on family such as physical, financial, psychological, social, and/or spiritual.

9. *Can infant ingest OFF?*

Yes. OFF mandatory.

No. Consider alternative method of feeding and hydrating (i.e., some form of ANH). Prioritize methods according to what is easiest to employ/least invasive and delivers most benefit.

10. *Is infant taking enough OFF to sustain life?*

Yes. OFF still mandatory.

No. Provide ice chips, tastes of food, but do not begin ANH unless as a “bridge” treatment. Infant may be dying from condition, complication due to condition, or complication due to treatment. Consult doctor immediately for diagnosis.

11. *Is ANH not a “bridge” treatment but expected to be permanent?*

Yes. ANH is a permanent treatment. Do not begin ANH.

No. Administer ANH until infant can ingest OFF.

12. *Have complications occurred?*

Yes. Determine what complication has occurred (e.g., fluid in lungs, edema, infection) and treat accordingly.

No. Continue ANH.

13. *Have complications reoccurred?*

Yes. Determine whether this is beginning of complication-treatment cycle.

No. Continue ANH.

14. *Do the treatments for complications constitute grave burdens in themselves to the infant?*

Yes. Obligatory discontinuation of treatment.

No. Continue ANH. Treatment for many complications resulting from treatments will be burdensome, but not necessarily gravely burdensome.

15. *Is the complication-treatment cycle gravely burdensome to the rest of the family?*

Yes. Consider discontinuation of treatment.

No. Continue treatment. Some burdens are not grave and should be borne by family due to the infant’s vulnerability.

16. *Is infant now dying from illness/condition?*

Yes. Use palliative care. Determine whether OFF are no longer necessary. If ANH in use, discontinue.

No. Continue ANH.

17. *Is ANH itself now (at this moment) life-threatening?*

Yes. Discontinue ANH.

No. Continue ANH.

18. *Does infant now require extraordinary means of care?*

Yes. Treatment optional. Continue ANH unless treatment itself is gravely burdensome for infant.

No. Treatment obligatory. Continue ANH.

19. *Is ANH futile?*

Yes. Obligation to discontinue ANH.

No. Continue ANH unless one of previous conditions is met.

Vita

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Bill is currently married and has three children, two of whom are still living.