TREATMENT OF IMPERILED NEWBORNS: THE SOCIAL QUALITY OF LIFE MODEL IN LIGHT OF CATHOLIC SOCIAL TEACHING

A Dissertation

Submitted to the Graduate School
of the University of Notre Dame
in Partial Fulfillment of the Requirements
for the Degree of
Doctor of Philosophy

by

Charles Christopher Camosy

Maura A. Ryan, Director

Graduate Program in Theology
Notre Dame, Indiana
April 2009
TREATMENT OF IMPERILED NEWBORNS: THE SOCIAL QUALITY OF LIFE MODEL IN LIGHT OF CATHOLIC SOCIAL TEACHING

Abstract

by

Charles Christopher Camosy

Because of the technological shift that our modern medical era has brought to the treatment and care of imperiled newborns, many persons have been saved who otherwise would have died. Though concerns about the quality of life for many of these newborns have come to the fore as a result, the importance of social factors in a broad understanding of what quality of life means is an oft-neglected topic and can be seen clearly within a context of Catholic Social Teaching. If one takes seriously the intrinsically social nature of persons, a preferential option for the poor, the universal destination of goods, and other like principles, the central thesis of the dissertation becomes clear: though all newly born human infants are full moral persons, what kind of treatments are beneficial or burdensome cannot be seen apart from complex social questions with regard to distribution of resources. Though more research is needed on treatment outcomes and their long-term costs before most specific reforms could be prudently enacted, the dissertation argues that certain neonatal treatments are disproportionate with the common good and ought to be foregone.
DEDICATION

This dissertation is dedicated to my parents and grandparents. Each one a model of an ethical life, time and time again they made sacrifices without which I could never have taken path I am walking.
CONTENTS

Introduction.....................................................................................................................1

Chapter One: The Social Quality of Life Model and the Moral Status of Human Infants............................................................................................................................16

Chapter Two: Arguments Against the Social Quality of Life Model...............74

Chapter Three: The ‘Weak’ Social Quality of Life Model.........................120

Chapter Four: A Constructive Proposal for Reforming the Treatment and Care of Imperiled Newborns.................................................................166

Conclusion.....................................................................................................................243

Bibliography.................................................................................................................250
INTRODUCTION

Before the advent of neonatology, it was inconceivable to spend hundreds of thousands of dollars to save a baby’s life. Today it has become routine and routinely disturbing...Some worry that physicians and hospitals make decisions on the basis of the profitability of NICU treatments rather than on the best interests of the patients. Such arguments raise questions about distributive justice, economic conflict of interest, and the effect of different methods of financing healthcare on clinical decision making.

John Lantos, MD

Even if one only intermittently follows world news, it is virtually impossible to avoid the fact that ethical issues surrounding the moral status and medical treatment of newly-born infants receive lots of popular attention. For instance, a much anticipated and controversial report from the Nuffield Council on Bioethics1 has called for a uniform policy under which newborns born under 22 weeks gestation are to be refused treatment regardless of prognosis.2 Almost on cue, a record was set in Florida when, remarkably, a baby of less-than 22 weeks gestation survived NICU treatment with a good prognosis.3

The Church of England’s Bishop Bulter created headlines all over the world by arguing in January of 2007 that when considering whether or not to treat imperiled newborns, “The principle of justice inevitably means that the potential cost of treatment itself, the

---

1 An internationally respected group of clinicians, lawyers, philosophers, scientists and theologians established by the Trustees of the Nuffield Foundation (UK) in 1991 to identify, examine and report on the ethical questions raised by recent advances in biological and medical research. The report in question came out 16 November 2006 and can be found at: www.nuffieldbioethics.org/go/ourwork/neonatal/introduction


longer term costs of health care and education and opportunity cost to the NHS in terms of saving other lives have to be considered.\textsuperscript{4}

The media’s coverage of the issues surrounding the medical treatment of imperiled newborns, however, leaves much to be desired—and is often mistaken in its analysis. For instance, a typical headline in response to the ‘shock’ claim of the bishop was, “Outrage as Church Calls for Severely Disabled Babies to be Killed [emphasis added] at Birth.”\textsuperscript{4} But there was no such claim—indeed, the broadly Christian moral tradition prohibits aiming at death as part of one’s intentional act. Rather, the call was for the refusal of a treatment deemed to be too burdensome for the patient. In addition, the author of the above article claimed that this flew in the face of the history of Christian thought which, “has longed argued that life be preserved at all costs.” Though the issues surrounding withholding or withdrawal of life-sustaining treatment are complex (and, admittedly, the diverse Christian community today has differing opinions on these matters), the last five centuries of Catholic teaching directly contradict this assertion.\textsuperscript{5} If those whose job it is to professionally cover these stories can make these kinds of errors, it is not surprising that others are often confused by these issues as well. Indeed, as we will soon see, the technological advances in neonatology over the last 40 years or so have produced some of the most complex dilemmas in medicine and ethics. As Michael Panicola pointed out in his important dissertation on the topic of the quality of life and


\textsuperscript{5} Indeed, this dissertation will show in some detail just how mistaken this claim is.
the critically ill newborn, “Nowhere is this [complexity] more evident that in cases involving critically ill newborns.”

Neonatal patients, unlike more traditional ones:

have never expressed either explicitly or implicitly what values they want to pursue in life, what condition they find too burdensome, or what treatments they consider contrary to their best interests. Consequently, proxy decision makers must make value-laden assumptions for them before deciding whether to initiate or continue life-sustaining treatment. (Panicola, 56)

Though still quite complex, the issues surrounding the treatment of newborns were not always so connected with technological options—and go back to ancient times. Soranus of Ephesus, a second century Greek physician, gave midwives a practical handbook for newborn infants that were ‘worth rearing’ or ‘suited by nature for rearing.’ In addition to evidence of systematic treatment in the ancient pagan world, these issues are a focus, from the beginning, for the very first Christian traditions. Sources like the Didache, Justin Martyr’s First Apology, and Athenagoras’ Plea are all at pains to critically engage pagan practices with regard to imperiled newborns. Chapter 1 will go into more detail regarding these historical manifestations of the ethical issues central to this dissertation, but it is worth noting here that though many times infants were killed or let die due to poverty and other social factors, the point of contention was often the moral status of the newly born—and especially of newborn females. The early Christian traditions generally spoke up in favor of the moral status and treatment of imperiled newborns—and many acted on this conviction by saving ‘exposed’ infants who had been left to die or be picked up for slave trade or forced prostitution.

6 Michael R. Panicola, "Quality of Life and the Critically Ill Newborn: Life and Death Decision Making in the Neonatal Context" (Ph.D., Saint Louis University), 2.

7 Soranus, Gynecology, Vol. 3 (Baltimore: Johns Hopkins Press, 1956), 258.
Of central interest to this dissertation, however, is the added layer of complexity that the technological shift of our modern era—an era which begins in earnest when premature infants with Respiratory Distress Syndrome start to survive due to new technical innovations in the mid-to-late part of the 20th Century. Millions of infants survived who otherwise would have died—and even more have been treated without saving a life. As Panicola notes, “Not long ago few newborns weighing less than 750 grams were treated because treatment was considered futile. Today, however, newborns weighing at least 500 grams and newborns born at 24 weeks gestation routinely receive intensive care in the United States.” (Panicola, 18)

The results of this shift are open to interpretation. While it is true that many persons have been saved who otherwise would have died:

An alarming number of newborns saved by neonatal medicine experience significant medical problems, and must often contend with mental and physical impairments, multiple surgeries, chronic pain and suffering, lengthy dependence on ventilators, prolonged hospitalization, extensive rehabilitation, and special education…Families often experience significant financial burdens and society is drained of previous healthcare resources in caring for sick newborns, especially those born extremely small and immature. (Panicola, 20-21)

Following the technological advances which produced the above outcomes, concerns about the quality of life for imperiled newborns began to come to the fore. In the last several years, we have been forced to “accept the responsibility for the power we have obtained and ask the frightening question, ‘What kind of life are we saving?’” (Panicola, 3)

In attempting an answer to the above question, a ‘quality of life’ model of decision-making has been advocated by certain ethicists and physicians. What exactly counts as quality of life, however, is certainly a disputed question. One way to think
about it, Panicola suggests, is how proxy decision makers evaluate the benefits and burdens of various life-sustaining interventions in light of the overall medical condition of critically ill newborns. For instance, one might weigh the burden of a medical treatment that involves the burden of extreme pain and a very long hospital stay versus benefit of a chance at continued life. But even if one accepts this quality of life model at a general level (and there are many who do not), how one defines ‘benefit’ and ‘burden’ can be contentious. (Panicola, 4) Some claim that these concepts are too vague or ambiguous to be applied with any consistency in neonatal decision-making. Do they refer only to something about the medical realities of the child herself? What about psychological or spiritual realities? Can the best interests of a newborn include how others are affected by her care? What or who counts as ‘others’? Family? Community? A globalized world?

Panicola helpfully distinguishes between three different sub-models of a quality of life approach to treatment of imperiled newborns. The ‘individual quality of life’ model centers explicitly in the newborn. The ‘relational quality of life’ model focuses on the newborn’s ability to pursue life’s goals: understood as material, moral and spiritual values which transcend physical life. Finally, the ‘social quality of life’ model centers on the newborn specifically in her familial and social context.

The dissertation will argue that, for several important reasons, the Social Quality of Life Model is the best of the three. This model is the only one which is able to give social factors the weight they deserve—especially in light of an important point made by John Lantos:

Neonatal intensive care has become some of the most expensive in pediatrics. Before the advent of neonatology, it was inconceivable to spend hundreds of
thousands of dollars to save a baby’s life. Today it has become routine and routinely disturbing…Furthermore, because of the idiosyncrasies of healthcare financing rules, NICUs have become profit centers for many U.S companies.⁸

In addition, it might be natural to think that neonatal bioethics would focus on

a frontier filled with cataclysmic struggles fought by heroic crusaders against implacable biological constraints, with tiny human infants as the battleground. Mostly, it [does] not. Instead, today’s NICU is a surprisingly mundane place that runs like a happy factory, churning out healthy baby after healthy baby, with mostly routine efforts by highly trained professionals. Undeniably, dramatic and morally charged events occur, including agonizing decisions about whether to continue treatment; however, they do not occur very often. (Lantos, 10)

The dissertation will argue, then, that the ‘everyday’ issues of neonatal bioethics are primarily social in nature—and therefore the ‘social quality of life’ model is the most helpful in this regard. It will also argue, however, that the current debate surrounding this model has important shortcomings. First, if full moral status is affirmed for imperiled newborns this is often times a ‘conversation stopper’ when it comes to discussion of the Social Quality of Life model—as if there were no further questions to ask. This dissertation will argue, along with the broadly Christian moral traditions, that intending the death of a person is not permitted; but this still leaves a host of questions remaining to answer about treatment and care. Second, those who argue for a ‘strong’ version of the Social Quality of Life Model (that is, a version which sees social factors as primary considerations in the benefit/burden calculation) tend to connect it to less than full moral status for imperiled newborns. Third, those who argue for a ‘weak’ version of the Social Quality of Life model (that is, a version which sees social factors as merely secondary considerations in the benefit/burden calculation for a particular treatment), while

affirming full moral status for imperiled newborns, generally do not appreciate the full
weight that social considerations should play in whether or not to treat. There appear,
then, to be three main approaches to the Social Quality of Life model:

1. It is a good model. Many, most or all infants have something less than full moral
status. Given a lack of medical resources for those with full moral status, those
human infants with less than full moral status can or should be denied treatment
based on broad social factors and such factors have primary importance.

2. It is a bad model. Human infants have full moral status, and as such have intrinsic
dignity which cannot (theory-based objection) or should not (practice-based
objection) be overridden by treatment decisions made on the basis of social
considerations such as cost or resource allocation.

3. It is a good model. Though many, most or all human infants have full moral
status, social factors can and should play a role in the treatment decision-making
process. But rather than being primary, they are secondary, balance-tipping
factors—often focusing on the narrowly considered ‘best interests’ of the infant.

This dissertation will show that each approach above is fundamentally flawed.

The first mistakenly claims that imperiled newborns do not have full moral status. The
second, insofar as it has Christian commitments in this area (and the thinkers that I
address here will), misunderstands the role the social factors have played in the broadly
Christian tradition in distinguishing between ordinary and extraordinary means and also
does not appreciate the human person’s identity as essentially social. The third misses
the full weight that social factors should play in determining whether or not a treatment is
extraordinary—something seen clearly when the principles and theological anthropology
of Catholic Social Teaching are brought to bear.

The dissertation will argue for a fourth approach:

4. It is a good model. Though all human infants have full moral status, if one
accepts Catholic Social Teaching’s principles of theological anthropology,
universal destination of goods, and a preferential option for the poor, broad social
factors have more than secondary importance when it comes to treatment of
imperiled newborns.
It will also claim that while consideration of the moral status of newborns should be a first step in the inquiry of the dissertation, it should be seen as distinctive from formal discussion of the Social Quality of Life model. Once separated from the issue of the moral status, the dissertation will consider the other two approaches to the Social Quality of Life model in light of Catholic teaching on Ordinary and Extraordinary Means and Catholic Social Teaching. The central thesis of the dissertation is that though all newly born human infants—including those with no *practical* potential for personal capacities—are full moral persons in light of their *natural* potential, which treatments are beneficial or burdensome cannot be seen apart from primary consideration of complex social questions with regard to distribution of resources.¹

The above argument is not without important challenges to be overcome. First, it looks as if human dignity, at least in the Christian traditions, cannot be reduced to a calculus of the social consequences—and the Social Quality of Life Model (and, in particular, in its strong version) seems to either do this explicitly or creates the conceptual space for a slippery slope which leads there. Second, this model appears to be open to the charge of wrongful discrimination against those with disabilities. Third, the argument seems to be based on the premise that medical resources are scarce to the point of a ‘triage’ situation—but (1) it is not clear we are in this situation and (2), even if one argued that we were in this situation, we should reject the circumstances that lead us to this conclusion in the first place. Fourth, it may challenge the very concept of what we

---

¹ The dissertation will limit itself to the question of how resources should be distributed on a state or national level. Factoring in social questions with regard to global health inequities would be exponentially more complex—but would, I think, do nothing but make the central thesis of the dissertation that much stronger.
take to be the physician/patient relationship by asking the physician to act against her patient’s best interests. Fifth, it appears that the problems highlighted in the dissertation apply not only to NICUs and neonates, but to the broad spectrum of healthcare in the United States. Some argue that, in fact, the NICU is the best place to spend money and that the Social Quality of Life Model would be best applied in some other area of medicine.

Each of these challenges can be overcome. The dissertation will show (1) that insofar as it discriminates against those on whom the community must use a disproportionate number of resources (disabled or not), such discrimination is not wrong; (2) the focus of the social quality of life model is certainly not disability per se, but rather its focus is on treatment’s proportional benefit over burden—a calculation which might take place without any reference to disability; (3) nearly 50 million US citizens are without health insurance, and that we have the healthcare system we do, means we are in a de facto triage situation already—the question left to us is how we are going to triage our limited resources; (4) if a broad concept of ‘the best interests’ of the patient is understood the argument does not imply a problematic shift in the patient/physician relationship; and (5) the costs for imperiled neonates go well beyond the NICU costs, and include follow-up care (that often lasts decades) and special education. However, the conclusions of the argument not only do, but indeed should, go well beyond treatment of imperiled newborns and have broad implications for how we should structure a healthcare system in general.

Each of the chapters of the dissertation will correspond with the four approaches to the Social Quality of Life Model described above.
Chapter One

As mentioned above, most who have a strong version of the Social Quality of Life Model rely on the claim that a human infant is not a person; therefore, we should spend valuable medical resources on personal human beings rather than non-personal newborns. But isn’t it simply a brute fact that newly born humans are persons in the moral sense? Isn’t the opposite conclusion, in Singer’s words, ‘too shocking to be taken seriously’? History suggests otherwise—and this chapter will begin by highlighting some important examples which show this to be the case. And when these historical considerations with powerful supporting arguments it becomes clear why it is important reasons to ask the central question of this chapter. There are serious and talented ethicists who attempt to frame an intellectual position defending a radical rethinking of the moral status of human beings—and often with serious implications for newborn infants. In fact, as will be shown in this chapter, some argue that a position which permits infanticide is in fact the more traditional position in the intellectual heritage of the Western world, and that Christianity, by inserting a foreign and misguided ethic, has backed us into a morally indefensible position on the moral status of newborns—unless one accepts uncritically an unfounded and speciesist ‘sanctity of life’ ethic. This chapter will examine in some detail the arguments of thinkers like Peter Singer who defend such controversial points of view and will respond to their arguments with a detailed discussion about the role of potential in determining moral status. Important in this discussion will be a distinction between practical or mathematical potential and natural potential or potential of kind. The dissertation will argue that all those beings which have a natural potential for personal qualities, regardless of species, are persons in the moral sense—and that this includes
newly born human infants. This is distinguished from practical potential which simply refers to the mathematical probability of a being ever having personal qualities or traits. This latter kind of potential might apply to those who obviously do not have personal moral status (spare sperm and ova in a lab, pre-cloning somatic cells, etc.), whereas the latter apply to a ‘kind’ of being—biological, metaphysical, etc.

Further questions, however, might be raised about the moral status of imperiled newborn infants. The chapter will conclude by considering four different cases of imperiled infants, each case attempting to highlight different questions. In each of these cases the chapter will argue that, though there are certainly further questions to ask about care and treatment of such infants, they are all full persons in the moral sense—despite the peril they face. By having a personal nature in light of their ‘kind’ or species, each has the natural potential for personal traits. Indeed, if a treatment were found for their ailment, they would not suddenly become persons in light of a new practical potential: rather, they would have had the natural potential all along—just as these imperiled newborns have the natural potential even if there is no cure currently available. The fact that even the most imperiled newborn is a person is important for at least two reasons in the context of this dissertation: (1) the argument of most who use the strong version of the Social Quality of Life Model is fundamentally flawed; and (2) direct killing of infants, because it violates the good of human life in a fundamental way, is prohibited.

Chapter Two

As mentioned above, many believe that once the moral status question is settled in favor of personhood for the infant, the conversation about the Social Quality of Life
Model is over. The chapter begins by exploring Paul Ramsey’s ‘medical indications’ approach to treatment of the imperiled newborn and then subjecting it to the scrutiny of the Christian tradition on the social nature of the human person and the distinction between ordinary and extraordinary means. Having found his theological anthropology to under-value the social nature of human persons (or at least some of its implications), the chapter then turns to the subtle arguments of Richard McCormick and John Paris—both of whom argue that while social factors may in theory be considered as part of the benefit/burden calculus, for practical reasons this should be avoided. The chapter responds by attempting to allay their fears of a slippery slope—and showing how their own internal safeguards for the general quality-of-life approach can apply to the Social Quality of Life Model as well. Next, the chapter considers the argument of John Arras that the Social Quality of Life model is de facto wrongful discrimination against the disabled. The response here attempts to get clear what exactly is meant by ‘disability’ and ‘wrongful discrimination’ and concludes that (1) the model is not concerned with patients as disabled, and (2) even if one were to (questionably) change the definition of disability to include those under consideration for non-treatment under the Social Quality of Life Model, the kind of discrimination (based on just allocation of resources) in play is not wrongful. The chapter then turns to two final arguments: first, Panicola’s serious charge that the use of a social quality of life model ‘poses a serious threat to the foundations of medicine’ because it causes a physician to consider someone other than her patient and (2) Ramsey’s claim that human infants cannot be expected to have moral duties with regard to just distribution of resources. Both arguments are countered with a discussion of relational anthropology—showing (1) how a broad understanding of ‘best
interests’ of essentially social human being (whether volitional or not) would mean that a physician could not act in the best interests of her patient without taking social factors into consideration and (2) the reason we can say of adults that they have certain obligations with regard to distributive justice it is not precisely because they are adults, but because, just as newborns, they are human beings that exist in a social relationship and that entails social obligation.

Chapter Three

Even if one accepts that all imperiled infants are persons, and that social factors are legitimate considerations in determining whether or not to treat them, there remains the question of the relative importance of such social factors and how strongly to weigh them in the benefit/burden calculation. The chapter will begin by considering arguments from Richard Sparks, Anthony Shaw and Paul Johnson who give some, but relatively little, weight to social considerations. The central argument of the dissertation is brought to bear on this position by examining it in light of the principles and underlying anthropology of Catholic Social Teaching. Key concepts will include the universal destination of goods, the relationship of the common good to personal autonomy, the preferential option for the poor, structural/institutional sin, and consideration of developing world disease vs. developed world disease. A particular focus, in light of these duties, will be not only how to take into consideration the cost of treatment to the individual, family and community at the infant stage—but also further costs to the community, both medical and otherwise. The chapter will conclude by considering the argument that our current situation is analogous to a ‘triage’ situation—in which case it
becomes even clearer that social factors should be considered as primary in the benefit/burden calculation.

**Chapter Four**

The constructive proposal of the dissertation argues that in light of Catholic Social Teaching and our current crisis in healthcare (a *de facto* ‘triage’ situation) there may be duties on the part of parents and guardians, physicians, healthcare institutions, and the community itself not to treat certain imperiled newborns.

The chapter will outline the current situation of healthcare distribution in the United States and then explore and critically evaluate practical attempts to ‘ration’ care (Europe, Oregon, etc.) and think about how it might work with regard to neonatal care. The current ‘culture’ of the American NICU will be evaluated and will be critiqued by the Social Quality of Life Model in light of Catholic Social Teaching. At this point the dissertation will bring in significant empirical research from healthcare systems in various places (Oregon, the UK, etc.) to determine if there are any *practical* models already in place that might give insight to the dissertation’s understanding of the social quality of life model. What are the relative advantages and disadvantages of having hard and fast policies like those of, say, the Holland National Healthcare System which refuses to resuscitate infants born before week 25 gestation? What practical avenues, if any, exist specifically in the U.S. healthcare system if we were to attempt to implement the ‘Social Quality of Life’ model? Reforms, both specific and suggestive/general, will be recommended for treatment of imperiled newborns across the board and those who are on Medicaid. Though the dissertation, for practical purposes, will limit itself to suggesting
reforms which assume a two-tiered medical system (a public system for the poor and retired with a private system for those who wish to buy their own), the dissertation will conclude that this kind of argument cannot stand in the abstract but must be accompanied by a call for more system-wide reform.
CHAPTER ONE

THE SOCIAL QUALITY OF LIFE MODEL AND THE MORAL STATUS
OF HUMAN INFANTS

If you are delivered of child before I come home, if it is a boy, keep it, but if it is a girl, discard it.

Hilarion of Alexandria
Letter to his pregnant wife Alis (1 BCE)

What we are saying to the people is have your children, don’t kill them. And if you don’t want a girl child, leave her to us.

Renuka Chowdhury
Indian minister of state for woman and child development (2007 CE)

Introduction

As mentioned above, not every version of the Social Quality of Life Model gives social factors the same weight when making treatment decisions. Though there is overlap and grey area, approaches to the Social Quality of Life Model can generally be characterized as either ‘weak’ or ‘strong.’ The weak versions of the model tend to see social factors as being ‘valid but secondary’ considerations when making decisions about treatment of imperiled newborns. Perhaps they should be taken into consideration as a balance-tipping factor when more primary factors do not indicate a clear treatment decision, but they themselves should not form the primary basis for a treatment decision. These views will be considered in some detail in chapter three. The strong versions of
the model, by contrast, tend to see social factors as primary considerations. However most, if not all, strong versions of the Social Quality of Life Model come to their conclusions—at least in part—because they also hold that, “newborns are not considered equal members of the moral community.” (Panicola, 112) H. Tristram Engelhardt, Jr., Joseph Fletcher, Earl Shelp, Michael Tooley and Peter Singer all hold the position that at least some imperiled newborns do not have the same moral status as most other human beings and are not ‘full persons’ in the moral sense of the word.\(^\text{10}\) Having this position certainly paves the way for accepting the strong version of the social quality of life model because it seems clear that limited medical resources should certainly be used on persons before non-persons—and if 50 million persons in the United States (with many hundreds of millions more around the world\(^\text{11}\)) do not have health insurance then some newly-born human non-persons should have their treatment foregone in favor of using such resources on actual persons.

The goal of this chapter is to both (1) take seriously the argument that the imperiled newborn is a non-person and (2) call this argument, and its use in support of the strong version of the social quality of life model, into serious question. In doing so, the chapter will first consider some ancient and modern historical highlights which, when seen in combination with cogent arguments, give us good reason to take the question of the moral status of imperiled newborns seriously as something more than an abstract argument made by a tiny minority of philosophers and theologians. Second, it will make

\(^\text{10}\) Engelhardt, as we will see later in the chapter, maintains that this is what a secular ethic must conclude. This dissertation is at pains to show that this need not be the case.

\(^\text{11}\) For reasons that will become clear in chapter four (mostly having to do with having a controlled pool of resources), this dissertation will mostly table the question of global distribution of resources—though such considerations could conceivably make its central argument even stronger.
a distinction between ‘healthy’ and ‘imperiled’ newborns and, in considering the arguments of Peter Singer, reply to the position that even healthy newborns are non-persons. Third, in considering the arguments of Engelhardt, Fletcher and Shelp, the chapter will conclude by replying to the position that imperiled newborns, specifically, are non-persons.

Before proceeding, however, it might be helpful to highlight a point for the reader. In considering these arguments seriously the dissertation in no way is endorsing the arguments against the moral status of newly born human infants. Indeed, precisely the opposite is intended: by taking on these arguments on their own terms, and showing them to be untenable, the dissertation is arguing quite strongly for the personal dignity of even the most imperiled newborn human being. As will be shown in some detail, this dignity prohibits the direct, intentional killing of such neonates—but does not prohibit foregoing of life-saving treatment that is not in the child’s best interests.

Some Historical Highlights

We have already seen that the issues of medical treatment of imperiled newborns are rooted clearly in practical, real-life situations which demand our attention—and we will see this at the individual case level as this chapter proceeds. However, it might be less clear that theoretical questions regarding the moral status of such infants are equally as grounded. Indeed, later in this chapter, several arguments will be bolstered by thought experiments that have theoretical, but no practical application to our current technological reality. It is then important to show—especially for a topic so rooted in real-life practical situations—that the central question considered in this chapter should be given careful
and unbiased consideration. If the claim that a newborn infant is not a person, in any context other than that of academic ethics, is just “too shocking to be taken seriously” then perhaps it something like a ‘brute fact’ that newborn infants are persons in the full moral sense of the word and the tiny minority of philosophers who hold this view should not even be given a hearing. 

But even if today this is the attitude toward the moral status of human infants (and the dissertation will argue later there are some good reasons to think it is not), one could certainly argue that even a quick look at ancient and more contemporary historical examples suggests that there is a very different attitude toward this question that can be articulately defended. Direct infanticide has been a socially accepted practice, Singer points out, “from Tahiti to Greenland […] and from the nomadic Australian aborigines to the sophisticated urban community of ancient Greece and mandarin China.” (Singer, 172) William Silverman has claimed that “Infanticide is the oldest method of human family planning” and that “child murder was common” in cultures preceding ours. 

Lisa Schwartz and Natalie Isser add that: neonaticide and infanticide have been practiced on every continent and by people on every level of cultural complexity, from hunters and gathers to those in ‘higher’ civilizations, including our own ancestors and contemporaries. Rather than being the exception, it has been the rule.

References:


13 This is the reaction, in fact, of many neonatal physicians and nurses when presented with this kinds of arguments.


Given the vast amount of historical material with which to work, this chapter will merely highlight examples from only two eras: ancient Greece and Rome and the modern age.

**Imperiled Newborns in Ancient Greece and Rome**

Before looking at specific historical examples, it would behoove the serious and humble investigator to proceed with at least three cautions in mind. First, one thing that must be considered in investigating every historical era is the possibility (indeed, the likelihood) that there is a significant divergence between theoretical values espoused in a text on the one hand, and actual cultural practice on the other. Second, even if we end up concluding that practices are based on theoretical values, Earl Shelp asks us to consider that though these practices and values “might be viewed as regrettable, [they] could be understood [emphasis added], given the societal and cultural forces at work during any particular time and place.” Indeed, it may be that they should not be seen as moral rogues, but instead as, “people in crisis attempting more or less conscientiously trying to find their way.”16 Finally, Post reminds us that we need to see a particular practice in its full historical context—not isolated in a vacuum. Perhaps the fact that Greece and Rome had many practices which demonstrated disrespect for human life, would lead us to see their understanding of infanticide and exposure in a different light. (Post, 4) These warnings will prove prescient not only in our brief historical exploration, but also in examining our own cultural situation with regard to these issues.

So, we already know that infants were exposed in the ancient Mediterranean, but one question which needs to be asked is about the frequency of the practice. For if it was the exception rather than the rule,\textsuperscript{17} then perhaps we would take a different stance toward what the historical record shows. In considering this question, let us begin by examining a letter written by an ancient husband, Hilarion, to his pregnant wife Alis that dates from 1 BCE:

Know that I am still in Alexandria. And do not worry if they all come back and I remain in Alexandria. I ask and beg you to take good care of our baby son, and as soon as I receive payment I shall send it up to you. If you are delivered of a child [before I come home], if it is a boy keep it, if a girl discard it. You have sent me word, “Don’t forget me.” How can I forget you? I beg you not to worry.\textsuperscript{18}

This is a remarkable passage. If he is being truthful in this letter, Hilarion is a man of deep feeling: along with the clear affection for his baby son, he loves his wife and attempts to ease her worry with this letter. However, this makes his matter-of-fact discussion about the discarding his future daughter that much more jolting. How could someone with such deep affections be so cavalier about the exposure (and, presumably, death) of his daughter unless such a practice was tied to deeply help cultural beliefs about the moral status of such an infant? Indeed, a father in ancient Greece had a right to take some time to decide whether or not the newborn child would be welcomed into his family—a kind of second or ‘social’ birth.

\textsuperscript{17} Indeed, child ‘exposure’ in the form of abandonment takes place in our culture as an exception rather than the rule. This, by itself, does not tell us much about our culture’s attitude toward the moral status of infants.

But though it seems clear that this era had a different understanding of the moral status of newborn infants than in the contemporary era, there are complexities that should be taken into consideration. For purposes of the topic of this chapter, and for the dissertation’s ultimate conclusion, we might want to make a distinction between the moral status of imperiled newborns who were often directly killed and those relatively healthy newborns who were often exposed. Though exposure was well-known and socially accepted in ancient Greece and Rome, there were various reasons for exposure and several different ways that it could be done—and these variables make the understanding of the moral status of these infants a complex matter indeed. For instance, we have already seen exposure suggested as a response to the child being female and to the child being illegitimate. In addition, complex relationships with the gods sometimes lead to exposure of newborns—either in response to an omen of doom or sometimes as a protest in response to events that were considered gravely unjust. But, though many affluent ancients exposed their children, by far the most common social reason for exposing a newborn was poverty. One more mouth to feed might all too easily mean taking food from family members who already suffered hunger. (Bakke, 30) Indeed, though many times exposure seems to have meant certain death, it appears some families had genuine hope that their children would be saved—leaving the infant at a street corner, near a public building like a temple, or even at spots just outside a city or village that were specifically designed for exposure. Such hope was not always misplaced. Though scholars disagree as to the rates of survival, it appears that at least some of these infants became foster children and less fortunate ones were picked up to be used as slaves or prostitutes. (Bakke, 31-32) At any rate, the fact that this kind of exposure was
common may say less about the attitude of the parents or culture toward the moral status of such infants than it does about the social realities with regard to scarcity of resources—and the desperation that such scarcity would drive some families who clearly wanted to give their infant child a chance at life.\textsuperscript{19}

But even when one takes into consideration these complexities, it seems clear that ancient Greeks and Romans did not consider newly born infants—whether healthy or imperiled—to have the same moral status of adults or even older children. Indeed, the intellectual elite defended this view in theory and in law, and the data we have for the actual practice, though complex, seems to indicate that both direct killing and exposure of the newly born were common, and commonly accepted, events. One might be tempted to dismiss these historical considerations as relics of a time long-past with virtually nothing to teach us. Indeed, slavery was also practiced in these cultures and surely that historical consideration, all by itself, says nothing about the moral legitimacy of slavery for today. However, when these historical considerations are combined with an examination of our contemporary attitudes and practices (and cogent arguments), we have good reason indeed to take this position seriously.

\begin{center}
\textbf{Contemporary Attitudes and Practices}
\end{center}

Even in today’s modern world there is plenty of evidence that, upon reflection, perhaps we are not as sure about the moral status of infants as one might think. As John-

\textsuperscript{19} This distinction between moral status and actions (or non-actions) taken in light of scarcity of resources is an essential distinction for this dissertation. Also important to note is the fact that ancient Christians were well-known, and even made fun of, for rescuing such exposed infants. The fact that this is one of the identifying features of early-Christianity will have implications for the conclusion of this dissertation.
Thor Dahlberg has pointed out, “in rural India, the centuries-old practice of female infanticide can still be considered a wise course of action.” According to Dahlberg, infants are killed in various ways: by feeding them dry, unhulled rice that punctured their windpipes, making them swallow powdered fertilizer, smothering them with a wet towel, or simply allowing them to starve to death. A study by the Community Service Guild of Madras found that of the 1250 families covered by the study 740 had only one female child and 249 admitted to having killed at least one female infant. Nor is this a problem limited to the 1990s. In March of 2007 human rights groups launched a new campaign to combat infanticide in 13 Indian districts. They report that, “Killing baby girls soon after birth is widely practiced in poor southern districts of the state, with some areas reporting 15% death among female babies.” The Indian government has acknowledged the severity of the issue and has set up orphanages around the problem districts to raise abandoned baby girls in an attempt to halt the practice. The event which sparked the energy behind the initiative was the discovery of the remains of 400 female fetuses and newborns buried in a pit behind a hospital in the central Indian city of Bhopal. When asked if the scheme would encourage women to abandon their infant girls Chowdhury said, “It doesn’t matter. It is better than killing them.”

Lest one think modern examples of infanticide are limited to the developing world, it is worth looking at the so-called ‘Groningen Protocol’—named after a medical center in the Netherlands which created a public written proposal to permit physicians to actively end the lives of infants. Newborns which are suitable candidates for infanticide fall into three categories:

1. First, there are infants with no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally. These infants have severe underlying disease, such as lung and kidney hypoplasia.

2. Infants in the second group have a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim. They are infants with severe brain abnormalities or extensive organ damage caused by extreme hypoxemia. When these infants can survive beyond the period of intensive care, they have an extremely poor prognosis and a poor quality of life.

3. Finally, there are infants with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering. Although it is difficult to define in the abstract, this group includes patients who are not dependent on intensive medical treatment but for whom a very poor quality of life, associated with sustained suffering, is predicted. For example, a child with the most serious form of spina bifida will have an extremely poor quality of life, even after many operations. This group also includes infants who have survived thanks to intensive care but for whom it becomes clear after intensive treatment has been completed that the quality of life will be very poor and for whom there is no hope of improvement.

Though infanticide is still technically a crime in the Netherlands, the culture seems to support it in some circumstances—and the legal exceptions involve an appeal to desperate circumstances in which nothing else could be done. Despite national surveys

24 Those who are sympathetic to this kind of protocol might object to lumping it into other procedures also described as ‘infanticide’ in this section (killing infant girls based on the gender, for instance). However, all that is meant by using this term here is simply the direct killing of an infant—not a moral equation with other kinds of practices. Indeed, the aim of this section is merely to present evidence that, perhaps, one should not be so quick as to think that today’s modern world simply accepts de facto that infants are full persons. Some evidence presented is stronger than other kinds.
suggesting that this kind of infanticide takes place 15-20 times per year, no physicians have been prosecuted for it since the adoption of the protocol in 2002. Nor is this the only European country to have mixed attitudes toward the practice. The respected Royal College of Obstetricians and Gynaecologists in England has submitted a proposal to the Nuffield Council on Bioethics which urged them, “to think more radically about non-resuscitation, withdrawal of treatment decisions, the best interests test and active euthanasia [emphasis added] as they are ways of widening the management options available to the sickest of newborns.” Catherine Damme has shown that this kind of attitude has its roots in English common law which separated infanticide as a separate offense from homicide in that it had a lesser punishment and established a very liberal insanity defense for mothers who committed infanticide.

Even the United States has a problem with infanticide. According to Steven Pinker, “every year hundreds of women commit neonaticide” and in response, “Prosecutors sometimes don’t prosecute; juries rarely convict; those found guilty almost never go to jail.” A CNN review of FBI statistics bears out the numbers. It appears


28 Steven Pinker, "Why they Kill their Newborns," *The New York Times* November 2, 1997. Many of these women are suffering from mental illness, but discussion of the complex issue of what our practices with regard to prosecution of infanticide versus other kinds of homicide says about our understanding of the moral status of infants follows below.
that about five infants a week are killed in the United States—and interestingly, male infants are almost always killed more frequently in a given year than are females.29

But perhaps more interesting than hard infanticide numbers are other indications of some American attitudes toward the newly-born. During US Senate debate over a bill which would ban partial-birth abortion the following exchange took place between Senators Santorum (R-PA) and Senator Boxer (D-CA) on October 20th 1999.30 A public argument in which a distinguished US senator refuses to condemn infanticide on the floor of the US Senate is powerful evidence about our current attitudes toward the moral status of newborn infants and bears full quotation. It is important to note that the issue being pressed by Senator Santorum is about the moral status and treatment of a newborn infant and not the moral status of a fetus:

Mr. SANTORUM. But I would like to ask you this question. You agree, once the child is born, separated from the mother, that that child is protected by the Constitution and cannot be killed? Do you agree with that?

Mrs. BOXER. I would make this statement. That this Constitution as it currently is--some want to amend it to say life begins at conception. I think *when you bring your baby home* [emphasis added], when your baby is born--and there is no such thing as partial-birth--the baby belongs to your family and has the rights. But I am not willing to amend the Constitution to say that a fetus is a person, which I know you would. But we will get to that later. I know my colleague is engaging me in a colloquy on his time. I appreciate it. I will answer these questions.

Mr. SANTORUM. I ask the Senator from California, again, you believe--you said ``once the baby comes home." Obviously, you don't mean they have to take the baby out of the hospital for it to be protected by the Constitution. Once


30 All transcripts in the main text quoted directly from the official congressional record available at Thomas.loc.gov. (Accessed on April 4, 2007) Some non-relevant or procedural text has been omitted.
the baby is separated from the mother, you would agree--completely separated from the mother--you would agree that baby is entitled to constitutional protection?

Mrs. BOXER. I will tell you why I don't want to engage in this. You had the same conversation with a colleague of mine, and I never saw such a twisting of his remarks.

Mr. SANTORUM. I say to the Senator from California, I am not twisting anything. I am simply asking a very straightforward question. There is no hidden question here. The question is----

Mrs. BOXER. I am answering the question I have been posed by the Senator, and the answer to the question is, I stand by Roe v. Wade. I stand by it. I hope we have a chance to vote on it. It is very clear, Roe v. Wade. That is what I stand by; my friend doesn't.

Mr. SANTORUM. Are you suggesting Roe v. Wade covered the issue of a baby in the process of being born?

Mrs. BOXER. I am saying what Roe v. Wade says is, in the early stages of a pregnancy, a woman has the right to choose; in the later stages, the States have the right--yes--to come in and restrict. I support those restrictions, as long as two things happen: They respect the life of the mother and the health of the mother.

The discussion continues at some length about what would qualify as ‘birth’ for Senator Boxer—and she simply claims that over and over that ‘it is obvious’ in response to Senator Santorum’s pressing questions. Perhaps her difficulty in answering his questions is understood best in light of her using the striking phrase ‘when you bring your baby home’ as describing birth in her the original answer. Santorum simply dismisses this as too absurd to be believed and therefore a mistake, but this is too quick. Boxer here, though she retreats from the position, interestingly seems to have invoked the ancient Greco-Roman concept of *social* birth over and against mere biological birth. Why would someone want decisions about the infant born during a botched partial-birth abortion to be made by parents and physicians? At least one likely answer is that it is the parents and
physicians themselves\(^{31}\) which decide the moral status of newly born infants—they do not have the objective personal moral status of more mature human beings.

This part of the chapter was an attempt to show that the claim that either all or some human infants are not full members of the personal moral community deserves a place at the table in the debate over moral status. It is a claim that has been explicitly held throughout history in cultures which varied widely with regard to their practices and level of sophistication. Indeed, it is a claim that seems to have not totally disappeared from view in our own culture—though its remnants are not as explicit as the attitudes and practices in older cultures. As mentioned previously, the fact that something was widely practiced in ancient times and still remains with us today is not by itself an argument for that practice—but it does clear the conceptual space needed for those who consider the abstract philosophical argument ‘too shocking to be taken seriously.’ The chapter now turns to specific philosophical arguments for the claim that either (1) all human infants are not full members of the moral community (Singer and Tooley) or (2) some imperiled human infants are not full members of the moral community (Engelhardt, Shelp, Fletcher).\(^{32}\)

**The Social Quality of Life Model and the Moral Status of Newborns**

Recall that the major reason for invoking a strong version of the Social Quality of Life Model was precisely the fact newly born human infants are not persons. Are there

\(^{31}\) This is also the position, as we will see later, of Engelhardt and Shelp when they invoke the concept of ‘social’ personhood.

\(^{32}\) These are two different ‘families’ of arguments thus are considered in separate areas of the chapter.
serious arguments which can defend the proposition that human infants are not persons and therefore deserve less medical resources than persons? When looking at those who make arguments in support this version of the Social Quality of Life model, a name that is consistently invoked is that of Peter Singer, the Ira W. DeCamp Professor of Bioethics at Princeton University.33 Richard Sparks, for instance, in dealing with the Social Quality of Life Model spends many pages dealing with Singer’s view that “if parents regret the child’s birth and are truly burdened by the continued existence of a child” they have the “right to kill the infant in the name of their own social welfare.”34 This part of the chapter will take a detailed look at Singer’s argument about the moral status of newborn infants.

Let us begin with Singer’s general ethical theory can be described, roughly, as ‘interest utilitarianism’:

The way of thinking I have outlined is a form of utilitarianism. It differs from classical utilitarianism in that ‘best consequences’ is understood as meaning what, on balance, furthers the interests of those affected, rather than merely what increases pleasure and reduces pain.35


34 Richard C. Sparks, To Treat Or Not to Treat: Bioethics and the Handicapped Newborn (New York: Paulist Press, 1988), 240.

35 Singer, Practical Ethics, 14.
Another theoretical principle of Singer’s, ‘equal consideration of interests,’\textsuperscript{36} entails that “we give equal weight in our moral deliberations to the like interests of all those affected by our actions.” (Singer, 21) Nothing should factor into our moral calculation, then, except considerations related to a being’s interests.

Further principles are formed when this reasoning is applied to specific situations. Animals, Singer points out, have interests (say, in avoiding pain). Given this, Singer is able to morally condemn as ‘speciesist’ those who:

give greater weight to the interests of members of their own species when there is a clash between their interests and the interests of other species. Human speciesists do not accept that pain is as bad when it is felt by pigs or mice as when it is felt by humans. (Singer, 58)

Therefore, the \textit{comparable} interests of non-human animals should factor equally into our moral calculations.\textsuperscript{37} This does not necessarily mean, however, treating animals as morally equal to (all) humans. Singer admits that “the greater the degree of self-awareness and rationality and the broader the range of possible experiences, the more one would prefer the kind of life”—and thus “it would not necessarily be speciesist to rank

\textsuperscript{36} Some have claimed that this principle is Singer’s principle weakness as an ethicist, for how can a utilitarian ethic sustain or justify anything like this egalitarian streak? If the best consequences could be attained by considering comparable interests \textit{differently} then shouldn’t it be done? Singer’s response here, however, is that he is a \textit{rule} interest utilitarian—and that, on balance, best interests are maximized over time by treating comparable interests equally.

\textsuperscript{37} Some might claim that such a principle is not at all neutral when it comes to infanticide—or any other kind of killing of human organisms. Indeed, something like ‘speciesism’ might be not only morally permissible, but perhaps morally \textit{required}. Mary Midgley, for instance, argues that species preference is “an absolutely central element in human happiness” and “the root from which charity grows.” (103) She suggests that it is “a necessary part of our social nature,” and that, unlike racism, it is not “a product of culture.” (105) But these claims are too strong, for even in Midgley’s conclusion on this issue she claims only that “a developing social creature needs to be surrounded by beings \textit{very similar to it} [emphasis added].” (107) Mary Midgley, \textit{Animals and Why They Matter} (Athens: University of Georgia Press, 1984), 158. This is the admission that Singer would hammer—claiming that his position still stands. Mere species preference is not the relevant consideration, but rather social capacity and example.
the value of different lives in some hierarchical ordering.” (Singer, 107) Therefore, the varied interests of different beings allow us to rank their moral value in a hierarchy.

Things get more difficult, of course, when we start attempting to justify such a ranking. Singer spends quite a bit of time considering the moral status of a person—that is, for him, “a rational and self-conscious being that is aware if itself as a distinct entity with a past and a future.” (Singer, 111) Singer is not clear whether he believes that persons have a right to life, but he does believe that interest utilitarianism gives us good reasons for thinking that it is more serious to kill a person than a non-person. Persons, because they can have plans for the future and are aware of themselves existing over time, would be have their interest violated in a way by being killed in ways that non-persons would not. Because Singer is a rule-interest utilitarian—that is, he believes we should be “guided by a set of well-chosen intuitive principles” rather attempting to “calculate the consequences of each significant moral choice” (Singer, 93)—he can generalize about the moral value of persons. Indeed, he says, “Killing a person who prefers to continue living is therefore wrong, other things being equal.” (Singer, 93) We now have a Singerian principle which is neutral with respect to infanticide:

Other things being equal, it is wrong to kill a person (as opposed to a non-person) because that person has an interest in continuing to live.

---

38 He claims that he is “not convinced” that the idea of a right to life “is a helpful or meaningful one.” (96) But because the idea is “popular” he considers whether there are grounds for attributing such a right to persons and not to non-persons. He then launches into a discussion of Michael Tooley’s argument—without coming to any conclusion on the matter. Later, however, (172) he does speak of a “legal” right to life in the affirmative. I cannot tell what his position is on the matter.

39 I continue to use Singer’s original word ‘interest’—rather than ‘preference’—for two reasons. First, when he makes the shift to ‘preference’ (94) he gives us no reason to accept it. Second, it seems clear that even if some person (say, a depressed junior high-schooler) did not currently have the preference to continue to live, it would still be wrong to kill them because it was in their interest to continuing living.
The key question is whether or not an infant is a person with personal interests—that is, whether or not an infant (at least according to Singer’s definition) is “a rational and self-conscious being that is aware if itself as a distinct entity with a past and a future.” (Singer, 151) If an infant is not a person, then, Singer argues, there is no reason to accord its life any “greater value than the life of a nonhuman animal at a similar level of rationality, self-consciousness, awareness, capacity to feel, etc.” (Singer, 151) But an infant is not rational, not self-conscious, and not aware of itself as a distinct entity with a past and future. He baldly states that “the grounds for not killing persons do not apply to newborn infants” (Singer, 171) because infants, frankly, are not persons. They cannot reason and they certainly are not aware of themselves over time. Singer says that there should be at least some circumstances in which a full legal right to life comes into force not at birth, but only a short time after birth—perhaps a month. Here, then, is our key Singerian principle:

Human newborn infants, because they are not persons, do not have a right to life and can be killed up until (at least) a month after birth.

The next section of the chapter will examine this argument in some detail.

A Third Option?

Singer, quite neatly, paints an either/or situation for us. Either the human infant is a person with the actualized capacities he deems necessary for this kind of moral status, 

40 One might wonder why the chapter uses Singer’s definition rather than arguing for one of its own. While it seems clear his definition of ‘person’ needs some expansion and nuance, it is not incorrect—and, again, the point of this section is to defeat the argument on its own terms.

41 It is difficult to understand why Singer chooses this date, rather than one much later. Indeed, an infant at one month is nowhere near as mentally sophisticated as an adult chimpanzee or dolphin—a threshold one would think for being a candidate for personhood even in Singer’s system.
or, if not, she should be treated as having no greater value than the life of a nonhuman animal at a similar level of capacity. Anything other than these two options is going to count as speciesism. But are these the only options open to us? A human infant may not qualify as an actualized person (as Singer defines the term), but it does not follow from this that the moral value of the infant needs to be located in her actualized capacities. A human newborn infant may not be any more rational or aware of itself in time than is a snail (as Singer points out), but there is an obvious distinction to be made between a snail and a newborn human infant—and that distinction lies in the potentiality of the infant. The snail can only develop as snail does—that is, morally speaking at least, not very much at all. The snail will never be able to love or feel love. The snail will never be able to have projects of its own. The snail will never be able to gaze at the ‘starry heavens above’ and certainly will never have a ‘moral law within.’ A snail will never self-consciously wonder about its place in the universe. The infant, under normal circumstances, will experience all of these things. The infant will, under normal circumstances, develop as a human being does—as a rational creature with a sense of itself over time. That is, as a person as Singer defines it.

But because it is difficult to articulate, one might wonder just how the potential of the human infant and fetus is morally relevant. Indeed, even some defenders of the

---

42 Singer claims the strategy this chapter uses to talk about the moral value of potential persons is ad hoc (Singer, 19), but—in light of how he handles the obvious difference between a human infant and a snail—I would argue that precisely the opposite is actually the case. It is Singer who needs, in order to defend his a priori moral commitments to the rights of nonhuman animals, human infants to have the same moral worth as any other similarly actualized animal. If the potential of the fetus or infant gives it a moral status above that of, say, chickens, his project fails to award the very strong defense of animal interests he wants. Singer’s method, then, becomes just as ad hoc as that of any other attempt to give an explanation for our moral intuitions regarding these issues. This is not meant as a criticism of Singer’s method—his arguments should still be evaluated on their own merits—but it should be clear that his charge of ad hoc is one that his own project cannot escape.
personhood of human infants think that appeals to potential are mistaken. Patrick Lee and Robert George, for instance, argue that, “we human beings have the special kind of value that makes us subjects of rights in virtue of what we are, not in virtue of some attribute that we acquire some time after we have come to be.”\(^4\) But what the human infant is, without some reference to future potential, is not more significant morally than a snail or chicken—that is, without an appeal to future potential.\(^4\) Any other kind of evaluation is wrongfully speciesist. Let us take a look at an often-cited example of someone who tries to take into account the future of an infant as it impacts her moral status.

**Don Marquis**

Don Marquis is well-known for his attempts to account for how the future potential of a human infant (and fetus) might be morally relevant. To do this, he starts with what he thinks is an unproblematic assumption, “it is wrong to kill us.”\(^4\) Why? The answer he gives\(^4\) is that “the loss of one’s life deprives one of all the experiences, activities, projects, and enjoyments that would otherwise have constituted one’s future.” (Marquis, 189) These things are “either valuable for the own sakes or means to

---


\(^4\) It is helpful to note here that this dissertation makes the argument that the ‘kind of thing’ an infant is cannot be separated from the ‘future potential’ she has for morally relevant attributes. Much more on this to come.


\(^4\) Surely Marquis could have written an entire book on this question, but this does not take away from the intuitive plausibility of his answer. And, because it focuses on interests, it is one that seems consistent with how Singer would answer this question.
something else than is valuable for its own sake.” (Marquis, 189) In addition, there are most probably goods in one’s future that, while I do not currently value them, will “come to be valued by me as I grow older and as my values and capacities change.” (Marquis, 190) Therefore, what makes killing any “any adult human being”\(^{47}\) seriously wrong is the “loss of his or her future.” (Marquis, 190) Marquis uses this basic insight to draw several conclusions:

1. It is false that it is wrong to kill beings only that are biologically human. Alien species on other planets, for instance, could have a future like ours. It might be seriously wrong to kill them.

2. There is at least the possibility that some nonhuman animals have a future like ours and it might be seriously wrong to kill them.

3. Active euthanasia of some adult human beings who do not have a future like ours might not be wrong.

4. It is \textit{prima facie} seriously wrong to kill children and infants because they have a future like ours.

5. It is \textit{prima facie} seriously wrong to kill fetuses because they have a future like ours. [Marquis, 190-192]

Marquis, then, articulates the potential of the human infant and fetus as its capacity to have “a future like ours”—and locates not only their moral status in this potential, but everyone’s moral status in this potential. It is an intuitively convincing argument—one that has generated quite a bit of response literature—but not one, I think, without important problems.

\(^{47}\) One might ask here what Marquis means by this phrase. Does he mean literally \textit{any} adult human being? What about an adult human in a permanently comatose state? In point of fact, he does not mean to include such a being—and the fact that he is not more specific creates a problem for his project.
But one might wonder, as Peter McInerney does,\(^{48}\) if conclusion (5) above is an obvious as Marquis thinks it is. McInerney argues that because of “the complexity of the biological and psychological connections between earlier and later stages of one person” that “the claim that a fetus has personal future in the way that a normal adult human has a personal future” is invalidated. (McInerney, 265) He claims that though “there is some biological continuity between them so that there is a sense in which the later person stages ‘are the future’ of the fetus, the fetus is so little connected to the later personal life that it cannot be deprived of that personal life.” (McInerney, 267) He cites Derek Parfit’s well-known theory that psychological relations between temporal ‘selves’ constitute personal identity (if we even call it this) through time.\(^{49}\) He notes that there are three “widely considered” kinds of relations: “memory, continuity of character, and intention-to-action.” (McInerney, 265) Because personal identity consists in these kinds of psychological relations, and because there is no psychological relation between a fetus and a ‘future’ in which the same biological animal has such relations, it is simply false to say that a fetus has ‘a future like ours.’ Also, it follows from this argument that not only are human fetuses without moral status, but human infants are without it as well. Indeed, many infants are not connected via memory to their future, nor do they have “continuity of character” with their future biological self, nor can they form intentions to act on the

---

\(^{48}\) Peter K. McInerney, "Does a Fetus Already have a Future-Like-Ours?" *Journal of Philosophy* 87, no. 5 (1990), 264-268.

\(^{49}\) Obviously, it is beyond the scope of the paper to engage this theory adequately, but I have argued elsewhere that Parfit’s theory is problematic in the moral conclusions one is forced to draw from its application.
future. By any standard used to argue that a human fetus does not have a personal future like ours, a human infant would fail to have the same future using the same standard.\(^{50}\)

But the human fetus and infant are not the only ones in danger of losing moral status given this paradigm. Consider a human being in a light coma that the doctors have determined, when she wakes, will have severe amnesia—that is, she will not remember who she is. Like the fetus or infant, she is not now currently psychologically connected in the ways that McInerney deems necessary to talk about her having a personal future like ours. Would we deny such an individual the moral status of a person? If the McInerney test is the one to be met, we end up with absurd ethical conclusions.

But while Marquis moves the debate in the proper direction—toward the moral value of the potential future of the infant and fetus (and all those with moral status) and away from discussion about actualized capacities—he needs to be pushed farther. A key question is who counts as ‘us’ in his assumed dictum: it is wrong to kill us. Apparently because it would be “difficult” and “controversial,” Marquis admits that he has no “additional account of just what it is about my future or the futures of other adult human beings which makes it wrong to kill us.” (Marquis, 191) But can he get away with not coming down on this issue? He sees this question as only related to specific questions regarding whether certain animals have a future like ours, but it is not clear why this is the case. Suppose that just what it is that is morally valuable about my future (that which makes it wrong to kill me as opposed to another being without a future like mine) is the

\(^{50}\) Perhaps dreading this implication, McInerney notes that the “possibilities that are available to a person or even to a young infant are not now available to the fetus.” (267) But it is hard to see what such possibilities would be, and why they would be relevant to the psychological connections he puts forth. Again, if memory, character and intention are the relevant relations, a newborn infant is just as lacking in these qualities as is a fetus.
fact that I will be rational and aware of myself in time—Singer’s definition of personhood. This would allow for not only the abortion and infanticide of many thousands of mentally disabled human beings, but also the killing of such human beings as older children or adults. Did former President Reagan, as victim of mental illness such that his future would never be rational or aware of himself in time, have a future like ours? If the answer is no, then we end up denying moral status to Reagan and all those like him in moral capacity (those with advanced Alzheimer’s disease, the severely autistic, etc.)—but if the answer is yes, then what other non-human animals would qualify for full moral status? On what basis would one deny dogs, chickens or even snails full moral status? No, Marquis is onto something here, but he needs to say more about what precisely it is about our futures which makes denying them morally problematic.\footnote{Perhaps, as we will soon see, if has something to do with the kind of being something is—the potential inherent to a being’s nature. This would reflect the insight of Lee and George cited above.}

It seems to be the case that one may accept Singer’s definition of an actualized person—that is, a being which is rational and aware of itself in time—but argue that this is not the only way to talk about the kind of moral status that Singer wants to reserve only to actualized persons. It is the central thesis of this chapter that beings which are potential persons—that is, to use Singer’s categories, those beings that are potentially rational and aware of themselves in time—have the same moral status as beings with actualized rationality and self-awareness in time. This is what accounts not only for our moral intuitions regarding infants, but also many other adult human beings. The enraged, the extremely intoxicated, the asleep, the insane and the temporarily comatose are all human beings which fail to meet Singer’s actualized criteria for personhood—but
virtually no one denies these beings moral status. This charge argues that the reason is because of their potentiality for rationality and/or awareness of themselves in time at some point in the future.\textsuperscript{52} And it is precisely for this reason that moral status should also be extended to human infants and fetuses.

**Objections to the Argument from Potential**

As Massimo Reichlin notes in his *The Argument from Potential: A Reappraisal*, the argument from potential (AFP) “does not have a good press in today’s…debate.”\textsuperscript{53} This is certainly not overstatement. Even Don Marquis, who makes an argument very similar to the AFP, calls its basic inference “invalid.” (Marquis, 192) Others are harsher. Those who object to the AFP seem to make two general kinds of arguments:

1. If, as this chapter’s version of AFP claims to accept, only those with the proper interests can have moral status, then a potential person cannot have moral status because it has none of the relevant interests. Indeed, many kinds of things might be ‘potential persons’ but have do not have the interests proper to persons and therefore cannot have moral status. (NI)

2. If every potential person has moral status, then this leads us into problematic questions about the relationship between probability and possibility. Is any being which has a probability of becoming a person greater than zero a ‘potential person’? If the answer is yes, this may lead us to absurd conclusions about what counts as having moral status. If the answer is no, then we have a problem with deciding at what level of probability of becoming a person we decide grants something ‘potential personhood’—and therefore moral—status. (PP)

\textsuperscript{52} Certainly many proponents of theories like Singer’s interest view disagree and try to locate rationality, etc. in such beings in light of their having had rational interests (and the like) in the past. But the chapter will show that such arguments are fundamentally mistaken.

\textsuperscript{53} Massimo Reichlin, "The Argument from Potential: A Reappraisal," *Bioethics* 11, no. 1 (Ja, 1997), 1.
I will treat the “no interest” (NI) and “problems with probability” (PP) arguments each in turn.

Peter Singer, Ronald Dworkin, and Michael Tooley all make different versions of the NI argument. Singer claims that “the fact that the embryo has a certain potential does not mean that we can really harm it, in the sense that we can harm a being who has wants and desires or can suffer.”54 Indeed, if “it is claimed that destroying an embryo does it harm because of the loss of its potential, why should we not say the same about an egg and sperm?” (Singer, *Rethinking Life and Death*, 99) Would we consider a laboratory technician blameworthy for rinsing spare ova and sperm down a drain and causing the loss of potential personhood?55 A sperm-egg pair, considered jointly, is surely a potential person—but it cannot have interests and therefore cannot have moral status. In the same way, a newborn infant is a potential person but because it cannot have interests it also cannot have moral status.

Dworkin makes a version of the NI argument very similar to Singer’s. He claims that “it is very hard to make sense of the idea that an early fetus has interests of its own”—for, in order to have interests, it is not enough that it might “grow or develop into a human being.”56 He asks us to consider an assemblage of body parts on the laboratory table of Dr. Frankenstein. Suppose that just as the good doctor was about the throw the


55 Depending on what part of Singer one is currently reading, he speaks about either potential life, potential human, or potential person as if they were interchangeable. I use ‘personhood’ here because I assume this is what he must respond to in order to answer AFP as presented in this paper.

lever which would give the assemblage (personal?\textsuperscript{57}) life, an individual (apparently appalled by the experiment) smashes Dr. Frankenstein's machine. We would not, of course, consider the individual blameworthy for harming the assemblage of body parts. But, Dworkin argues, if the assemblage is a potential person, then the AFP insists that it has been harmed. But this is absurd because the assemblage clearly has no interests of its own and cannot be harmed.

Michael Tooley, another supporter of infanticide, gives perhaps the most interesting version of the NI argument considered.\textsuperscript{58} Tooley asks us to imagine that in the future it will be possible to inject kittens with a chemical that will enable them with capabilities consistent with human personhood. These injected kittens, then, would have moral status because they would be rational and aware of themselves in time. But would we think the kitten was seriously wronged if someone, upon finding a stray kitten, refused to inject the kitten, and instead handed them over to an animal control to (probably) be put to sleep? The kitten does not have the morally relevant interests to be wronged as a person, but given the injection technology it appears that the kitten is a potential person. Given the AFP, it then also appears that the kitten should have the same moral status as a person—and would be wronged by the person who did not inject the kitten. But this is absurd.

What can one say in response to these versions of NI? An obvious first move is to table this whole discussion for the moment (it will be addressed below) and point out

\textsuperscript{57} Again, like Singer, Dworkin seems to think that “life” is enough here—but to answer the AFP the analogy much be consistent with \textit{personhood}, and not just ‘life.’

again that a friend of NI must have answers to questions about our moral intuitions regarding the enraged, the extremely intoxicated, the asleep, the insane and the temporarily comatose. It looks as if, because NI requires that a being currently have the relevant personal interests to have moral status, regardless of its potential to have them in the future, the above examples are beings which a friend of NI must claim are without moral status.

Bonnie Steinbock has attempted to respond to this move by claiming that in each example above the being in question has had the relevant interests “in the past.” (Steinbock, 475) This past is relevant because it forms, “the basis for saying that the comatose person wants not to be killed while unconscious.” (Steinbock, 475) Indeed, killing adult humans is different from killing human fetuses or infants “because they have a life they (ordinarily) value and which they would prefer not to lose.” (Steinbock, 475) Apparently, a comatose adult human continues to have such an interest, while a fetus lacks just such an interest.

Dombrowski and Delete argue in a similar way. They point out that “a car mechanic who is not currently fixing cars” can “still legitimately be called a car mechanic.” In the same way, a person who currently does not have interests that are personal can still legitimately be called a person.

What follows are simple forms of the argument being put forth:

1. Joe is not now acting as a car mechanic.
2. Joe has acted as a car mechanic in the past.

59 Bonnie Steinbock, "Why most Abortions are Not Wrong," *Advances in Bioethics* 5 (1999), 245-267.

3. Therefore, Joe can still be considered car mechanic.

1. Joe is not now acting as a person.
2. Joe has acted as a person in the past.
3. Therefore, Joe can still be considered a person.

OK, but what about the following argument:

1. Charlie is not now acting as the third basemen for St. Joseph’s High School.
2. Charlie has acted as the third basemen for St. Joseph’s High School in the past.
3. Therefore, Charlie can still be considered the third basemen for St. Joseph’s High School.

Of course, this conclusion is absurd. I am now many years removed from having been the third basemen at SJHS and I have no potential in the future to ever be so again. My past is wholly irrelevant to the question of whether or not it is legitimate to call me the third basemen at SJHS, and what is relevant is my future potential. The same can be said of Joe. If Joe never again fixes a car, and is now not currently fixing cars, in what sense is it legitimate to still call him a car mechanic?

A thought experiment might help clarify this point. If Michael Tooley can speak of injecting cats with a drug which can turn them into persons, perhaps one can be permitted to speak of a Star Trek “replicater machine.” Let us take Joe, a human being in a temporary coma, and put him into the replicater and throw the switch. Now we have Joe 1 and, his identical ‘clone,’ Joe 2—both comatose, and both exactly the same in every other respect. Before replication, Joe 1 (according to both friend and foe of NI) had interests and moral status and presumably has them after replication. But what about Joe 2? It looks as if those who support the NI must argue that Joe 2 does not have moral status and may be killed without wronging him. After all, Joe 2—like a human infant—has not had personal interests in his past which can be said to be operative while he is
currently comatose. If it is the past that matters, and not the future, then Joe 2 may be
killed without wronging him. But someone that would want to argue that killing Joe 2
(who is in every way other than his past indistinguishable from Joe 1) is wrong would
want to argue that Joe 2’s coma is temporary and that his future potential for personal
interests grants him the moral status of a person. Again, it is the future that matters—not
the past. And it is for this reason that the infant and fetus should be considered to have
moral status.

But perhaps, when faced with this dilemma, one should want to go in the other
direction. Perhaps one might argue, fine, every being that does not have personal
interests cannot have moral status. Therefore, even if counter-intuitive to our moral
sensibilities about the moral status of infants and the temporarily comatose, one needs to
bite the bullet and take the road down which the argument leads. But this need not be the
case. Singer’s interest utilitarianism can be rescued by rethinking our understanding of
interests. Both Singer and Steinbock (and they are not alone) fluctuate back and forth
between talking about interests and preferences61 as if they are the same thing. Clearly,
they are not. What might be in one’s best interests is often not what one prefers. Indeed,
many children would prefer not to go to school, but a parent who allows such a child to
skip school nevertheless violates an interest of theirs—because going to school is in the
child’s best interest. This, then, is the way out for one who wishes to ground moral status
in interests. The enraged, the extremely intoxicated, the asleep, the insane, the

61 We have already noted where Singer did this. Steinbock does this when she flat out admits that
“Our interests also include what is in our interest, whether or not we are interested in [that is, prefer] it,”
(475) and then proceeds, as already noted, to claim that what makes killing an adult human being wrong is
that it (ordinarily) values its life and prefers not to lose it.
temporarily comatose, the human infant, and the human fetus can be described as having certain states of affairs being in their best interests—but, again, it is all based on their future potential.

But a wholly different kind of argument against the AFP, remember, is the following:

If every potential person has moral status, then this leads us into problematic questions about the relationship between probability and possibility. Is any being which has a probability of becoming a person greater than zero a ‘potential person’? If the answer is yes, this may lead us to absurd conclusions about what counts as having moral status. If the answer is no, then we have a problem with deciding at what level of probability of becoming a person we decide grants something ‘potential personhood’—and therefore moral—status. (PP)

Someone who makes an interesting version of the PP is R. Alta Charo in her *Every Cell is Sacred: Logical Consequences of the Argument from Potential in the Age of Cloning.*62 Charo points out that with the advent of human cloning, every single cell is now a potential person—though albeit the probability of a particular cell becoming a person is extremely small. If we are not to get just as worried about killing our skin cells as we are about killing infants or fetuses, we need to deal with the problem of probability. Why does one level of potential personhood ‘count’ morally but another level not? Roy Perrett points out63 that some have tried to figure out a probability marker for moral status. He cites Roman Catholic ethicist John Noonan’s 80% mark—which Noonan believes is the probability a fetus will become a person—as an example. This number appears to contrast with the probability that a body cell will become a person to a degree that makes

---

62 In Paul Lauritzen, *Cloning and the Future of Human Embryo Research* (Oxford ; New York: Oxford University Press, 2001), 291. Her argument is most persuasive as a defense of destruction of human fetuses outside of a mother’s womb, but it is worth bringing up in this context as well.

it acceptable say that the fetus should count as a potential person, and the body cell
should not. But, Perrett argues, this marker will not work for fetuses before week six
gestation because “more recent research has altered our best estimate of the real
probabilities” (Perrett, 189) and before week six a fetus has less than an 80% probability
of becoming a person.\footnote{Indeed, if the research Perrett cites is correct, before week six (but post-implantation) the probability is anywhere from 46\%-60\%.} So, say you have the following:

1. A body cell with a 0.00000000000000000001\% probability of becoming a person.
2. A fetus at 16 weeks gestation with an 80\% probability of becoming a person.
3. A fetus at 5 weeks gestation with a 55\% chance of becoming a person.
4. A fetus at 10 weeks gestation which a doctor, due to complications in the
pregnancy, gives a 10\% chance of becoming a person.

On what basis, those who make Perrett’s claim ask, can one claim that (2), (3) and (4)
above should count as having moral status, but (1) should not?\footnote{Or, alternatively, that (2) and (3) should count as having moral status, but (1) and (4) should not.} Perrett also asks an
important question about implications of the AFP and potentiality in other areas of life:

> Why should the 80\% probability of becoming an X give something the rights of
> an actual X? Even if it is now true that Prince Charles has an 80\% probability of
> becoming king, this does not presently give him the rights of an actual king. Why
> should it be any different for fetuses? (Perrett, 189)

These are important arguments. How can a friend of the AFP respond? One
thing that surely needs to be highlighted here (in both the NI and PP) is what appears to
be a conflation of the concept of potentiality with probability and/or mere possibility.

Reichlin has pointed out that:

> a correct understanding of the embryo’s potentiality shows that by progressively
> acquiring new capacities—including the capacity to perform rational operations—
> the human individual develops and perfects the human nature \footnote{Perhaps one might wonder if one can be faithful to the Singerian project and still speak of such a controversial concept. Indeed one can. He says, “Only a radical change \textit{in human nature} [emphasis}
Reichlin then moves to an Aristotelian distinction between *active* and *passive* potency. A tree, in its passive potency, is a *possible* table—however, this does not mean in any sense that a tree is already a table. Active potencies, by contrast, “are those inherent to the very nature of the being, whose principle of actualization is the very nature of that being.” (Reichlin, 17) In this case no external agent is necessary, and the potentiality is “the capacity to express and actualize inherent potentialities towards which the being in question has a natural tendency—i.e., a tendency which is dependent on its very nature.” (Reichlin, 16) A fertilized acorn, then, is a potential oak tree—but because this potential *is part of its very nature*, this means that the acorn is already, in some sense, an oak tree.

This argument, in addition to answering the PP (which we will get to presently), provides us with another reason to reject some versions of the NI argument. With regard to a move like Singer’s to consider a ‘sperm and egg jointly’ Perrett notes:

> a gamete is not even a potential embryo, but rather depends essentially on external causes. The human sperm does not just need a proper place wherein to develop its inherent potentialities, but needs an external event which is going to change radically its identity and potentialities. [Perrett, 13]

Thus if by ‘potential person’ we mean something with *active* potency for personhood and not merely passive potency, then the moral difference between a fetus and a sperm or ova becomes clear. Like the comatose adult, a fetus has an active potency in its potential personhood, but a gamete has mere passive potency for personhood—making it a *possible* person, but not a potential person. The same can be said of Dworkin’s assemblage of body parts. While it is certainly a possible person, because it would take

---

added]—a decline in acquisitive and self-centered desires—could overcome the tendency for people to find a way around any system that suppresses private enterprise.
“an external event which is going to change radically its identity and potentialities” for it to actually become a person, it is therefore not a potential person in the morally relevant sense. One can also see how this move works with Tooley’s kitten thought experiment. Even if the ‘personhood injection’ existed, kittens have only passive potency for personhood. That is, they are possible persons in the same way a tree is a possible table and a sperm is a possible person. Each would need an outside event, separate from its becoming something inherent to its nature, to become the thing in question. The event of a kitten being injected is akin to the ova being fertilized or the tree being cut down and made into a table—in the process of changing it has lost its original nature and become something else.

We can also see now how this responds to Charo’s and Perrett’s probability questions. Sure, a body cell may (given cloning) have a certain, very low, probability of becoming a person—but this is the wrong question to ask in determining whether or not the cell is a potential person. We need to find out whether a body cell has an active or passive potency for personhood. It seems clear that, because a body cell will not of its own nature turn into person, if would rely on an external outside event in order to do so—thus making it a possible person and not a potential person. Perrett’s Prince Charles example meets the same fate. To use Reichlin’s language, Prince Charles’ becoming king “is in fact dependent on several external causes, such as social conventions and regulations, and in no way implies the kind of necessity shown by a natural

---

67 Charo’s important point is that if one considered the zygote as a subject of stem cell research—outside the womb—it appears that it is only a possible person and not a potential person. She suggests this makes it reasonable to do research on human embryos even given the AFP. I leave this claim unanswered for two reasons. First, it gets into complicated questions about the moral issues in creating IVF embryos that are beyond the scope of the dissertation. Second, again, the focus of this argument is on newborn infants.
development.” (Reichlin, 6) Prince Charles’ 80% probability to become king has nothing to do with his nature—and this is why it makes sense to not treat him as if he were the actual king. But at 16 weeks gestation Prince Charles had an 80% probability of becoming a person, and because this was due to his nature it did make sense to treat him with the moral status of a person.

Thus the arguments against the AFP considered here appear to have been answered. Indeed, as Lee and George nicely summarize it, an entity having moral status (as opposed to having a right to perform a specific action in a given situation) follows from:

an entity’s being the type of thing [original emphasis] (or substantial entity) it is. And so, just as one’s right to life does not come and go with one’s location or situation, so it does not accrue to someone in virtue an acquired (i.e. accidental) property, capacity, skill, or disposition. Rather, this right belongs to the human being at all times that he or she exists, not just during certain stages of his or her existence, or in certain circumstances, or in virtue of additional accidental features. (Cohen, 17)

Of course, much depends on accepting the distinction that Aristotle and Reichlin make between active and passive potency (or between essential and accident properties)—as well as the concept of ‘nature’ inherent in the distinction. But we’ve seen that Singer does accept the concept of a human nature, and the distinction between a tree becoming a table (passive potency) and a fertilized acorn becoming an oak tree (active potency) is convincing and would require significant work to rebut. In addition, we have seen that it is difficult to understand the moral status of those who have temporarily lost actualized personal capacities without reliance on this concept of ‘nature’ used in the AFP.

But perhaps the opponent of the AFP has one more move left to her. What are we to do with human beings who appear not to be potential persons? We have already
mentioned examples of these: those with advanced Alzheimer’s disease, the severely autistic, the permanently comatose, etc. If we accept the AFP, it appears that such individuals cannot have moral status—for, because they can never again be rational nor aware of themselves in time, they are neither persons nor potential persons. If we accept as a brute fact that the above human beings do, in fact, have moral status, then it appears the AFP fails.

The first thing to say in response to this move is that Singer, or any other ethicist that locates moral status in (either potential or actual) personal interests, is going to be stuck with this problem. If they want to defend some kind of moral worth in the above human beings, they appear to be forced to make a Steinbock-like move of distinguishing between moral status on the one hand and moral value on the other. The former would be applied to persons and the later to other beings and things that have a different kind of value. Perhaps those with advanced Alzheimer’s disease, the severely autistic and the permanently comatose are “potent symbols of human life—and for that reason have moral value and deserve respect, even though they lack interests, rights, and (therefore) moral status.” (Steinbock, *Respect for Human Embryos*, 669) The weakness of this move, of course, is that without moral status the lives of such human beings could easily be trumped by the interests of actual or potential persons—and thus allow for ending their lives to serve those interests. Perhaps the responsible thing to do is to kill those with Alzheimer’s and autism to conserve resources to support the interests of actual or potential persons. But this is something that most of us, I think, would find morally

---

repugnant. Maybe we ought to follow our cue from Singer at this point, bite our lips, and just accept our repugnant conclusion. After all, if there truly is (as he would have us believe\textsuperscript{69}) a ‘Copernican revolution’ going on in ethics, why should we expect that the conclusions we come to will be comfortable? And such conclusions would apply not only to mature human beings with these disabilities, but also with regard to the subject of this dissertation: similarly imperiled newborns. Indeed, the vast majority of those who hold the Social Quality of Life Model for treatment of imperiled newborns do so precisely because they believe that they do not have full moral status. It is to this question we now turn.

**The Moral Status of Imperiled Newborns**

To this point, the focus of the chapter (for the most part) has been on the moral status of healthy newborn infants—for if a healthy newborn infant is not a person then it certainly follows that an imperiled newborn is not a person and thus would require far less moral consideration (and, therefore, treatment) than would actual persons. But let us consider the possibility that while healthy newborns are persons, certain imperiled newborns are not. For purposes of this chapter imperiled newborns will fall into four different categories—each with a specific case\textsuperscript{70} to exemplify and reference it:

**Case #1 ‘Ann’ – Very Severe Mental Disability, Terminal**

Annie has been born with anencephaly—this is a non-repairable lesion of the CNS based on a defect of neural tube development. While there are reports of maintaining these children on life support for a few years, it is the rare case when

\textsuperscript{69} Singer, *Rethinking Life and Death : The Collapse of our Traditional Ethics*, 256 and 188.

\textsuperscript{70} I owe of much of this section to Steve Leuthner, MD, MA (bioethics)—a neonatologist at Children’s Hospitals of Wisconsin and head of its ethics committee.
the infant does not get an infection from the typical open skull. Anne has some brainstem activity such as suck and swallow reflexes and may actually feed. She has no cerebral cortex and if there are neurons present they are totally unorganized and not part of a functional organ. She is having seizures, however, which has lead to some palliative medication need. Her prognosis is terminal within the first days to weeks of life.

**Case #2 ‘James’ – Severe Mental Disability, Not Terminal**

Jim has been born with a severe case of Hypoxic-Ischemic Encephaloapthy—brain damage as a result of asphyxia. He is virtually non-responsive, and even on his best days as a child Jim won’t even be able to recognize his mother. Yet, in some HIE children parents can perceive some pleasure/pain experiences. For example they may say the baby groans when near the end of g-tube feeding, or coos some sort of way when they brush their hair. What level of consciousness the child has is difficult to prove. Typically these children are cortically blind, often deaf, not capable of any true speech/language/communication other than guttural sounds. Typically they are close but don’t reach the current definitions of persistent vegetative state. His prognosis is that the HIE will endure, but he is not terminal.

**Case #3 ‘Patrick’ – Moderate Mental Disability, Not Terminal**

Pat has been born with ‘Fragile X’ Syndrome—a mutation of the FMR1 gene on the X chromosome. He is sweet and loving and exhibits a strong desire for social interaction, but is severely learning disabled with an IQ likely in the mid-30s. Patrick will probably be able to communicate, but will need to do so using pictures or sign-language. He will also need a tremendous amount of help with basic things like sleeping, eating, dressing, using the restroom, and hygiene. There is no cure for Fragile X, but it is not a terminal condition.

**Case #4 ‘Christopher’ – No Mental Disability, Not Terminal**

Chris has been born with gastroschesis and has lost all of his intestines from a volvulus (twisting of the intestines until they infarct). There is no reason to suspect any major injury to the brain and therefore to suspect any neurological impairments. The only two options then seem to be either maintain him on total parenteral nutrition (IV) in hopes of him growing big enough to get a bowel transplant before there is the toxicity of liver failure. Typically there will be liver failure, so if he gets big enough, he will need both a liver and bowel transplant. The success of getting to the age to do that is low, as is the success of the transplant itself. And even if successful, Chris (and his parents) will have a life of chronic medical and financial burdens.
How should friends of the Social Quality of Life Model evaluate the cases of these imperiled newborns? We already know from the previous section that Singer would consider them all non-persons simply for being infants, but for the next part of this paper, the views of three ethicists who support ‘strong’ views of the model will be examined: physician-philosopher H. Tristram Engelhardt Jr., philosopher Earl Shelp and theologian Joseph Fletcher. Each takes the strong view, however, because while they admit that healthy newborns are persons (or, for all practical purposes, should be treated as if they are persons)\(^{71}\) they also believe that certain imperiled newborns should be treated as something less than full persons. Thus, they hold the strong view for some imperiled newborns for the same reason Singer holds it for all newborns. This section will first examine the general views of each thinker, apply those views to the four specific cases, and then subject both the views and application to some critical assessment.

**H. Tristram Engelhardt Jr.**

In some ways, Engelhardt is the most like Peter Singer of the three thinkers that will be considered. However, this requires a major caveat: Engelhardt is a Christian and believes he must be committed to the proposition that infanticide is morally wrong as part of his Christian identity,\(^{72}\) but he tries to argue from the point of view of a secular ethic in order to show its limitations. Indeed, he claims:

> When one examines the contrast between traditional Judeo-Christian understandings of the status of embryos, fetuses, infants and reproduction, the difference between what can be established in general secular morality and in

---

\(^{71}\) Engelhardt and Shelp speak of the ‘social’ (as opposed to objective) personhood of healthy newborns, however. More on this distinction to come.

\(^{72}\) Though not necessarily murder.
traditional Judeo-Christian appreciations is most stark. It is impossible to make out the evil not only of abortion but infanticide.  

Under such a secular ethics, Engelhardt argues, only rational, self-conscious and morally autonomous beings are persons in an objective, strict sense. (Engelhardt, 137) This means that some human beings—especially the very young or disabled—do not count as persons in this sense. However, these humans may qualify as persons in a social sense. What this means substantively is not clear, but at a very basic level it refers to entities (usually humans, though based on his definition there is no reason to limit it in this way) on whom a certain level or moral status is conferred “justified in terms of utilitarian and consequentialist reasons” (Engelhardt, 148). Such justifications will be ‘somewhat different’ depending on the situation, but Engelhardt offers us three criteria by which we might consider an entity a person in the social sense:

1. It would support important virtues such a sympathy and care for human life—especially when it is fragile and defenseless
2. It would offer protection against the uncertainties of when exactly humans become persons—as well as those who have various levels of incompetence
3. It would secure the practice of child-rearing through which humans become persons in the strict sense [Engelhardt, 147-148]

For Engelhardt, healthy newborns will generally qualify as persons in the social sense, but for imperiled newborns a set of considerations will often show that they would not qualify. He explains that, “there are secular moral grounds for not imposing undue financial and psychological burdens on those who are persons in the strict sense” as long as they are not violating the interests of innocent persons and judging “that a defective newborn should either be allowed painlessly to die (or even be aided in dying painlessly!)”

That is, such defective newborns do not count as persons in either the strict or social senses.

Though evaluating the benefits against the burdens in these situations is often tricky and much of the time on a case-by-case basis, Engelhardt does come up with some general principles for attempting to think about evaluating in the abstract. The strength of a case to treat an imperiled newborn on the basis of its being a person in the social sense can be determined, roughly, by taking the chance of success of the treatment multiplied by the probable quality and length of life of the child and dividing by the costs of the treatment:

\[
\text{\textbf{\textquoteleft Chance of Treatment Success\textquoteleft} \times \text{\textquoteleft Probable Quality of Life\textquoteleft} \times \text{\textquoteleft Length of Life\textquoteleft}} / \text{Cost}
\]

Armed with this algorithm and his underlying philosophy we can now turn to how Engelhardt would evaluate the cases.

Annie certainly would not qualify as a person in the social sense for Engelhardt. The chance of treatment success is zero. This right here would be enough for a final judgment to be made, but it is also worth noting that the probable quality of life is also zero and the length of life is near zero. Cost may be relatively low, especially considering the length of life, but with a numerator of zero this really is inconsequential in Engelhardt’s scheme.

Treatment of Jim has a good chance of success—that is, simply on a biological level of keeping him physically alive. However, Jim doesn’t have prospects for a quality
of life that are much different from a fairly simple non-human animal—perhaps a chicken or mouse. And though HIE cases usually involve a significantly shorter life-span, it is not necessarily dramatic enough to affect our calculation here. The costs of treating Jim throughout his life, however, are quite dramatic given his limitations—not the least of which will be a full-time caregiver. But how do the overall numbers break down for Jim? Engelhardt is not very clear about how to ‘score’—but one might be justified in giving him a ‘zero’ for quality of life if one needs a quality of life that has some future prospect for rationality, autonomy and self-consciousness. However, even if the quality of life is not zero, it is a very small number, and when pitted against the very high costs associated with keeping him alive it seems that Engelhardt’s view would still prohibit Jim from attaining social personhood.

In some ways, Pat is much like Jim from the standpoint of treatment and lifespan. However, he has significantly better prospects for quality of life. Rather than simply ‘cooing’ and having very basic pleasure/pain experience, Pat is a social creature who can interact with other persons—and even communicate using non-verbal means. Though somewhat less costly than Jim’s—especially long term—the cost for Pat’s care is still very high. Though Pat’s case is more difficult to call than Jim’s, he is not a good prospect for Engelhardt’s social personhood. Certain non-human animals, who are not considered persons, appear to have a similar quality of life—dolphins and primates, for instance, have similar social relationships and communication skills. Couple that with

74 As Singer and others have pointed out, rather than claiming that Patrick is not a person, perhaps we should expand our notion of person and instead grant dolphins, primates and perhaps some other non-human animals full moral status.
the very significant cost of treatment and, though it is a much more difficult call than Jim or Annie, Pat appears to fall short of the mark.

Though Chris does not have a terminal disease in the strict sense,\(^75\) he certainly has other problems. The chance of the treatment’s success is very low—and though there is a prospect for a life that is not overly short, that quality of life will likely be lowered by the medical burdens from future treatment. Also, cost is, again, a significant factor. There seem to be enough low numbers for Chris here that, like Pat, his case is not a slam-dunk, but he does not seem like a good candidate for social personhood.

However, once a family was to accept an infant\(^76\) and “assign her the role of child within a established set of practices, perhaps by accepting social support in various fashion for the child’s care and development” (Engelhardt, 149) things could change. In such a case even the above imperiled newborns might qualify for personhood in the social sense. However, the focus of this chapter is on the moral status of newly born infants—generally before such bonding and assigning take place.\(^77\) Given that situation, it must be admitted that the four examples above are poor cases for social personhood in the Engelhardt model.

\(^{75}\) What counts as a terminal disease is certainly open to question. While anencephaly is a clear-cut case, this case is not—Chris need not necessarily die from the disease, but social factors often play a role in making this determination. If treatment for a disease is not available because of one’s social situation, or simply too burdensome, then one could argue that such a disease is terminal as well.

\(^{76}\) Once again we are reminded of the ancient Greek practice of family acceptance of an infant for moral status to be conferred.

\(^{77}\) Of course, one could certainly argue that one need not wait until after birth (or even birth itself) for such bonding and assigning to take place. Perhaps a mother and/or father would have accepted the child in utero at which point social personhood may have been conferred. However, if this is possible, it leaves us with confusion with regard to what social personhood is substantively. Is it simply whatever a parent decides it is? Or can a parent simply decide when to make the social connections which would bring it into effect? If yes, then social personhood means whatever we want it to mean—and Engelhardt’s point that this confusion is a product of a ‘content-less’ secular ethics is laid bare.
Earl Shelp

Shelp argues, much like Engelhardt, that certain newborn infants are to be considered persons in the social sense rather than in a strict objective sense. An infant qualifies for this status insofar as she can make demands on her parents and community to protect and preserve her life. Such a duty obtains proportionally to an infant’s ability to maintain ‘personal independence’—which is indisputably a “primary end toward which parental activity should be directed.”78 The kinds of characteristics which indicate personal independence, for Shelp, include the newborn’s capacity, “to relate, communicate, ambulate, and perform tasks of basic hygiene, feeding, and dressing.” (Shelp, 48) If a newborn infant has “an incapacity to attain a minimum level of independence” then it is appropriate to take account of the needs of other persons—especially married persons and more mature siblings—and give them priority over that of the neonate. (Shelp, 137) Indeed, Shelp sees it as “intuitively unfair or unjust to sacrifice the opportunity of a healthy child in order to sustain the existence of a severely defective or impaired brother or sister.” (Shelp, 138) The choice in these kinds of situations, “is not between two competing equals” and thus it is not unfair to prefer “the interests of the healthy over the interests of the imperiled.” (Shelp, 76) Indeed, Shelp argues that “parents of severely diseased or defective newborns may reasonably choose not to authorize life-prolonging interventions” when “it is reasonably believed that the infant’s condition is such that the capacities sufficient for a minimal independence or personhood” cannot be attained. (Shelp, 203)

78 Shelp, Born to Die?: Deciding the Fate of Critically Ill Newborns, 46.
Unlike Engelhardt, Shelp does not come up with a calculus for determining social personhood, but rather puts imperiled newborns into three diagnostic categories (Shelp, 126-127):

1. Newborns with medical conditions which cannot be effectively treated. No prospects for attaining a minimum level of independence and thus social personhood.

2. Newborns with medical conditions which could be effectively treated and produce a normal or near-normal quality of life. High probability of attaining independence and thus social personhood.

3. The third category, unlike the first two, presents significant complexity and open-endedness. In these cases therapeutic interventions are available, but the projected quality of life is very poor. In such cases, the family should be given much latitude in weighing this kind of imperiled newborn’s interests against the interests of the family. In general, the interests of persons in the family should take precedence over those infants with a limited capacity to sustain future independence.

How would Shelp evaluate the four cases above? In evaluating the case of Annie, Shelp like Engelhardt would agree that this is not a close call—but, again, rather than using any kind of calculus, he would simply mention that the capacity for a minimal level of personal independence is not present and therefore neither is social personhood. She falls into the first category above.

Jim, an infant who needs to be fed through a g-tube and whose level of consciousness is difficult to prove, doesn’t appear to meet Shelp’s criteria for minimal independence and certainly cannot ‘ambulate and perform tasks of basic hygiene, feeding, and dressing.’ However, because Jim is not terminal, he falls into the third category above where a parent would have to weigh Jim’s interests against the interests

79 By ‘poor’ Shelp apparently means non or minimally autonomous, non or minimally relational, and (interestingly) “a level of life purchased at an incommensurate cost.” (Shelp, 127) Spelling out a version of this last point will be the focus of chapter four of this dissertation.
of those persons who are affected (parents, children, etc.). However, it is clear that Jim’s personhood—if he has it—is merely a function of whatever his parents decide about the relative weight of the interests involved. He is not a person in any objective sense of the word.

Pat, though he may have a dramatically different quality of life than Jim, nevertheless fails to have the kind of personal independence that Shelp requires for social personhood. He has a strong desire for social interaction—but will also need a tremendous amount of help with basic things like sleeping, eating, dressing, using the restroom, and hygiene which precludes a minimum level of independence. Like Jim, Pat’s interests will need to be balanced against the personal interests of his family.

Chris, however, is a case where Engelhardt and Shelp may part company—for Chris, though his treatment is expensive, burdensome, and likely not to be successful, has good prospects for independence if he can beat the odds. The case is complicated, though, by the extreme cost and medical burden that would be a part of Chris’ treatment. It depends on whether or not the medical burdens of Chris’ life were commensurate with the cost of treatment. Again, for Shelp, this would be something which a parent or other family member would need to weigh for themselves.  

Joseph Fletcher

---

80 This dissertation will be at pains to argue that it is not merely a matter for the family, but rather the broader community if we are paying for the infant’s current and/or future healthcare. The question of whether or not it is commensurate cannot be answered without an appeal to the burden of the community—not just the individual or family.
Like the other two thinkers, Fletcher connects his ‘strong’ view of the social quality of life model to the moral status of newborns. Unlike them, he rejects the ‘social’ personhood approach and instead agonizes over what certain objective indicators of personhood might be: minimal intelligence, self-awareness, self-control, a sense of time, a sense of futurity, a sense of past, relational ability, concern for others, curiosity, and neocortical function all played major roles in his exploration. However, he eventually comes to the conclusion that the quality which is most important is that which is “required for the presence of the others” (Fletcher, 5)—namely, neocortical function. He says:

Neocortical function is the key to humanness, the essential trait, the human *sine qua non*. The point is that without the synthesizing function of the cerebral cortex (without thought or mind), whether before it is present or with its end, the person is nonexistent no matter how much the individual’s brain stem and mid-brain may continue to provide feelings and regulate autonomic physical functions. To be truly Homo sapiens we must be sapient, however minimally. Only this trait or capability is necessary to all of the other traits which go into the fullness of humanness. Therefore this indicator, neocortical function, is the first-order requirement and the key to the definition of a human being. (Fletcher, 6)

Fletcher, then, has the least required to ‘count’ a person—and also makes no distinction between a person in the objective sense and one on the social sense.

But how would the individuals in our cases fare under Fletcher’s standard? They are much easier to determine given his simple criteria. Annie does not have a neocortex and so clearly does not count as a person. Jim has a neocortex, but it is damaged to the point where its function does not permit personal ‘indicators’ like self-awareness and relationality—so he also does not count as a person. Pat’s problem is the mutation of a

---

gene—and not brain damage to the neocortex—and thus would qualify. Chris’ problems have nothing whatever to do with the neocortex and this would also qualify. Fletcher’s view then is, by far, the most friendly to imperiled newborns in terms of their moral status.

Critical Evaluation

What can be said in response to the three approaches to the moral status of these imperiled newborns? The first aspect which must be called into question is shared by both Engelhardt and Shelp: the distinction between objectively inherent personhood and socially bestowed personhood. In what sense is what they mean by ‘socially bestowed personhood’ anything like personhood at all? Objectively inherent personhood, though more controversial when specifics are invoked, is, uncontroversially, something which refers to the dignity of the entity bearing the name. Though it certainly obligates others to respect that dignity by taking certain kinds of actions and refraining from others, the focus of the concept is about the dignity of the subject. Socially bestowed personhood, by contrast, and at least in the way that Engelhardt and Shelp use the concept, has nothing to do with anything objectively inherent to the infant—but rather either (1) the social utility of the parent and/or community treating the infant in the certain ways (Engelhardt) or (2) virtually whatever a parent decides about the balance of interests within a family. In this sense, such infants are persons in a very similar way to how a corporation is viewed as a ‘person’ under American law—not because of any objectively

82 It is worth noting here that one could use a concept of ‘socially bestowed personhood’ in a way that coheres with a corresponding objective personhood. This, however, is not what is going on with Engelhardt and Shelp.
inherent dignity the corporation has, but because of the social utility that comes from
treating a corporation in certain ways. Given this ‘willy-nilly’ way of using the term,
virtually anything that, if we treated it in certain respectful ways that resembled how we
treated persons, gave us a net benefit of utility could be considered a person in the social
sense. But this is an evacuation of meaning from the term to the point where another
word should be used—for most people mean something dramatically and categorically
different from this when using the word in its objectively inherent sense.

Furthermore, we need not use such a word. Both Engelhardt and Shelp connect
social personhood directly to the duties of parents and others in the community toward
their infant children. But we can easily speak about the duties of, say, ‘owners to their
animals’ without calling animals persons. If Engelhardt and Shelp mean something very
different from objective personhood, then a different word should be used. In using
‘socially bestowed personhood’ they do not mean personal moral status—indeed, they are
much like Singer in that they do not think that these infants have any objectively inherent
personal moral status at all. And, given this, their arguments ultimately fall in the same
way Singer’s fall. They miss the implication that an infant’s potential, rightly
described, has for her moral status.

Given this limitation of the Social Quality of Life Model, perhaps Shelp could be
rescued by taking his ‘capacity for a minimum level of independence’ and turning it into
an objectively inherent criterion. Indeed, this could be a rival candidate for Singer’s
objective ‘rationality and self-awareness’ criteria used in the previous section of the
chapter. Unfortunately, it does little better. Connecting independence to personhood

83 Please see the argument from potential given in response to Singer pp 29-41.
almost completely misses the empirical reality of human personhood. Shelp notes that ‘no man is an island’ but this is surely radical understatement. No human being has his or her identity as a person from anything other than (mostly dependent) relationships with others: with God, with one’s family, friends, communities and institutions, and so on.84 A defining characteristic of human personhood is not independence, but interrelated interdependence. Especially in today’s globalized reality where small changes in China’s currency, for instance, can send shockwaves through virtually all the economies around the world, it is precisely our radical lack of independence which has been laid bare for all to see.85 Strongly connecting personhood with independence misses the anthropological mark.

But what of Fletcher? He certainly gets it right in searching for an objectively inherent indicator of personhood, but is his choice of ‘neocortial function’ a good one? It would seem that it is not—for lots of other animals have neocortial function who do not have self-awareness and relationality (among other indicators) which, he says, constitute mature human persons. Rather, it is the potential for these other ‘mature’ personal indicators which he really values as morally significant. However, he mistakenly thinks that neocortial function is the ‘that without which’ such traits could never come to be. Human organisms have several such organs which, if they do not develop (or do not develop properly), the mature indicators will never come to be. If he wants something

84 We will see this argument made in some detail in chapters 2 and 3.

85 In addition, for those that believe in a Triune God whose very nature is one of interdependence of three persons in one being, we should hardly be surprised that human persons, made in the image of this Triune God, mirror that kind of relationality in our personal natures. For a nice explication of this connection see, Catherine Mowry LaCugna, God for Us : The Trinity and Christian Life (San Francisco, Calif.: HarperSanFrancisco, 1991), 243-292.
more ‘basic,’ Fletcher would have done better to go back to an even more primitive indicator than development of the neocortex: that of the somatically integrated organism. For it is this entity, and not a cerebral cortex in the abstract, that has the kind of potential for the indicators that Fletcher truly thinks are morally significant.

But now we have returned to the argument of the previous section which refuted Singer’s position. Recall Reichlin pointing out that a human organism’s, “potentiality shows that by progressively acquiring new capacities—including the capacity to perform rational operations—the human individual develops and perfects the human nature it already possesses.” (Reichlin, 12) This potentiality is, “the capacity to express and actualize inherent potentialities towards which the being in question has a natural tendency—i.e., a tendency which is dependent on its very nature.” (Reichlin, 16) And it is “inherent to the very nature of the being, whose principle of actualization is the very nature of that being.” (Reichlin, 17) Existence of a human organism then, with natural potential for personhood, is the true sine qua non indicator for personhood. Indeed, it is simply not the case, as Fletcher argues, that one need be ‘sapient’ in order to be considered homo sapiens—rather, one simply needs to be an organism with a natural potential for personhood.

But, if the previous evaluations of the four cases fail, then how should they be evaluated? How does the concept of personal moral status as being indicated by an organism with a natural potential for personhood ‘work’ in these practical situations? The evaluation will not take long. All four are examples are human organisms with a natural potential for personhood—and thus count as persons in the moral sense. Chris surely counts for he has no serious impairment which would call into question his being a
human organism. Indeed, if the medical treatment he receives is successful he will
develop his natural potential into explicitly personal capacities. Pat also has no
impairment which would cause us to doubt his organismal status. Indeed, if genetic
therapy existed which could cure him of his disease, he would also develop his natural
potential for explicitly personal capacities. Jim is also undoubtedly a human
organism despite his brain-damage. For if we were to find a way to repair the damage—
say, by inserting cultured stem cells from neural tissue into the damaged areas—he would
also express natural potential he had all along as a human organism. Finally, though this
is surely counter-intuitive for some people, Annie is also a human organism with the
natural potential for personhood. Though she is profoundly disabled, she still has all the
potential that every other member of her species has—but that potential has been
frustrated by unfortunate circumstances. No, each of the examples above is an example

86 Some might argue here that Pat’s potential for gaining personal capacities is actually a fiction.
No such treatment exists and thus the potential is zero. However, this is the same mistaken notion of
potential that Charo uses earlier. It is mathematical potential (or ‘probability’) rather than potential of kind
or nature. Such mathematical potential can be influenced by a host of factors which have no moral
relevance—many of them social. Consider that an infant born with bone cancer may have a mathematical
probability of becoming a person of zero given its social situation (say, she is born in the remote areas of a
developing country with no technology to treat such a disease), but that means nothing for her actual moral
status—which in light of her natural potential for personhood. Indeed, such potential would be realized if
she lived in a different social situation. The same is true of Pat (and also Jim and Ann)—if their social
situations were different, their natural potential would be realized and thus should be considered persons.
However, this does not mean that all persons (including all four persons in the cases above) should
therefore be treated. As we will soon see, though it is important to establish the full moral status of
newborn infants from the start, the question of whether or not these persons should receive full medical
treatment is a very different one.

87 For some, this conclusion about anencephaly might be too quick. Might there be important
differences between, say, Jim’s brain damage and Annie’s lack of a neocortex? Perhaps, but one would
then have to make an argument as to what precisely this difference might be. We are currently just as
unable to ‘fix’ the brain of either Jim or Annie—and both are clearly human organisms with a natural
potential for personhood. (Again, this is an argument about moral status only—and the arguments about
treatment for Jim and Annie would be quite different. One might say that while both are persons, treatment
of Jim would be mandatory but for Annie it might be burdensome.)
of human person—and therefore these approaches to the ‘strong’ social quality of life model seem to fail.

**One Final Challenge: The Argument of John Lizza**

But the idea that those who are radically disabled (like an anencephalic infant) are persons in the same sense that more mature humans with a functioning rational and self-aware capacity, is, for some, so counter-intuitive as to seem absurd. John Lizza makes a powerful argument which underpins such a reaction. He argues that the best theoretical framework for thinking about persons is one which considers them “constituted by but not identical to human organisms.” (96) The idea that any human organism at all has the natural potential for personal qualities and therefore counts as a person “invokes the most remote and promiscuous sense of potentiality [emphasis in the original].” (105) For Lizza, a “more sensible, realistic concept of potentiality would support the claims that the life histories of persons and human organism can diverge and that a person can die even though the organism that constituted it may remain alive.”

Indeed, Lizza claims that we can think of many human organisms which have this ‘remote and promiscuous’ sense of potentiality that virtually no one would want to admit are persons. Though some of the examples he uses ask us to suspend disbelief and do a

---


89 Though Lizza is invoked here as a foil for the argument from potential as applied to imperiled newborns, one might wonder how he would talk about indicators of personhood in his own view. He talks about the need for a ‘biological substrate’ (108) being necessary for personhood—rather than simply species membership. However, this kind of argument has already been answered above in the response to Fletcher. Lots of species that aren’t persons have the same biological substrate has humans at the infancy stage—but it is only the natural potential for personal capacities that have moral weight. And this is contained in the organism herself—not in an adult cerebral cortex or embryonic primitive streak.
thought experiment, they are certainly worthy of serious consideration. What about a human body that has experienced whole brain death, but has been artificially sustained? (105) Or how about a human body that has been decapitated, but through futuristic technology, is also artificially sustained? (105) What about dead organisms? After all, sometimes dead butterflies are carefully mounted in museums and advertised as “members of their respective species”—why shouldn’t we think that human cadavers, even after rigor mortis has set in, are also members of our species who, through some futuristic technology, might be brought back to life? (106)

If one thinks that any of the above examples counts as a person, Lizza suggests, then something has gone seriously wrong. For then, “there is no rational basis for determining when such a radical power or potency for intellect and will is present in a thing”—the possibility that anything could become rational or self-aware cannot be ruled out, given advancing states of technology. In addition, he asks “why should we think that the power remains” in any of these beings “as opposed to thinking that the power has left the body at this point?” (106) None of these beings will regain rational capacity “in the natural course of events.” In fact, artificially sustaining or reanimating these bodies “falls outside the natural or normal course of events.” (107) Indeed, if we were to do this, we intervene in the life history of the organism in such a radical way that we create new kinds of beings, and we should recognize that the human being or ‘person’ has died.” (107)
Though Lizza isn’t necessarily making an argument about imperiled newborns, his views play directly into—and provide a direct challenge against—the central argument of this chapter. For, if it is the case that the argument from potential means that entities like decapitated human bodies and even dead human bodies count as persons in the full moral sense then it must be admitted that the view has been reduced to the absurd. Perhaps Annie (and even Jim and Pat), rather than being human organisms who have stopped ‘constituting’ a person (100), are human organisms who have never constituted a person. If this is the case, positions which support of the Social Quality of Life Model based on the arguments of Engelhardt, Shelp and Fletcher would need to be affirmed.

But there is an important response to Lizza’s move here. He himself gives a clue to what it might be when he says that “if we were to do this, we intervene in the life history of the organism in such a radical way that we create new kinds of beings, and we should recognize that the human being or ‘person’ has died.” At this point it is helpful to recall the discussion about Dr. Frankenstein’s assemblage of body parts, Tooley’s personhood-injected kittens, and Charo’s cloned body cell. In each of these cases there was first one ‘kind’ of being—some disorganized tissue, a non-rational organism, and a cell that was part of another organism—that underwent a nature-changing event. The disorganized tissue had its nature changed into that of an artificially animated creature with a personal nature. The kitten had its nature changed into an organism with a personal nature—indeed, it would no longer belong to the species of cat to which it had belonged previously. The body cell had its nature changed into an organism with a

90 Though it is interesting that in arguing for his ‘biological substrate’ model he discusses how anencephalic babies would not qualify. (108)
personal nature as well—instead of being part of another organism, she is now *her own* organism.

Lizza asks us to think about a ‘reverse’ nature-changing event—the death of a person. Aren’t brain dead or decapitated bodies that are artificially sustained, or a body in which rigor mortis has set in, examples of beings which are the result of a nature-changing event? They once constituted beings with a personal nature, but after a nature-changing event (the death of the person) they no longer have such a nature. And if they were, through futuristic technology, to constitute persons again some time in the future, that would also be a nature-changing event. It is not as if they would be persons the entire time.

This seems to be exactly right—and fits with the argument from natural potential leveled against Singer. Recall that the claim was that all those with a natural potential for personhood should count as persons—and that newborns (healthy and imperiled) have this potential based on their biological membership as organisms in the species *homo sapiens*. While it is true that a certain level (perhaps very high) of artificial sustenance is sometimes necessary to keep a human organism alive (artificial heart, ventilator, etc.), it does not follow that *any* human body which has certain physiological functions (like blood circulation and breathing) artificially sustained counts as a organism which is a member of *homo sapiens*. Indeed, it is simply the case that though beings that are obviously dead (like the butterfly) may be corpses that ‘belong to a certain species,’ they are certainly not *organisms*. Indeed, one could argue quite convincingly that the decapitated and whole-brain-dead corpses, artificially sustained, are in fact no longer organisms. Their animation is no longer simply aided or assisted by artificial means, but
rather that artificial means is now *itself responsible* for the animation. There is no longer an organism animating herself (with or without artificial assistance).

Admittedly, as with most binaries (such as alive/dead), there are grey areas which are difficult to distinguish. When does artificially assisted animation by the organism herself end and animation by the artificial means itself begin? Offering a definitive answer about this in the abstract surely gets us into complex questions of philosophy of biology, but it seems one could discuss the cases of Annie, Jim and Pat without having to get too far into those questions. If we were to use artificial means to cure the disease of each of these beings, would they undergo a nature-changing event? Would they go from human organisms without a natural potential for personhood to human organisms with such natural potential? It seems clear that the answer to this question must be in the negative. For whatever therapy would be used to treat their maladies (stem cell injections, gene therapy, etc.), would not create or instill a new natural potential. Instead, it would repair the injuries which are inhibiting the inherent natural potential from becoming actualized. If cured of their disease, these human organisms would then be able to fully animate all aspects of their nature—including their personal capacities. Though Lizza’s argument is a powerful one, and should be taken very seriously when we are thinking about brain dead human bodies that are artificially sustained, it should not cause us to retract the view that all human newborn infants (both healthy and imperiled) are persons in light of their natural potential.

---

Conclusion

History, and even a self-critical look at our present western culture, shows us that the main reason that some ethicists today support the strong version of the Social Quality of Life Model—the view that at least some newborn infants are not full persons in the moral sense—is, far from being ‘too shocking to be taken seriously,’ a proposition which must be carefully considered and responded to. It cannot be dismissed out of hand as absurd or obviously wrong. That said, if the central argument of this chapter is correct, then the justifications for such a proposition (either with respect to all infants or simply certain imperiled ones) have failed to pass muster. This failure is important for two reasons. The first and most obvious reason is that this strong version of the Social Quality of Life Model should be rejected as it relies on a faulty moral anthropology. Second, because all newly born infants have the dignity and worth of persons, at least from a Christian perspective, the good of their lives cannot be directly acted against in infanticide. We will see more about this line-drawing in the next chapter.

However, the direct killing of infanticide needs to be distinguished from the very different questions surrounding whether or not to medically treat an imperiled newborn. For some, the fact that all infants, even the most severely imperiled, are full persons in the moral sense becomes a ‘conversation stopper’ when the issue of factoring in social considerations in treatment decisions is raised. A discussion of this point of view is the focus of chapter two.
CHAPTER TWO

ARGUMENTS AGAINST THE SOCIAL QUALITY OF LIFE MODEL

If we can say of adults (who can and do have obligations) that it is reasonable to expect that they will want a certain good for others and contribute to this good if there is discernible risk, discomfort, or inconvenience, it is not precisely because they are adults that we conclude this, but because they are social human beings.

Richard McCormick

Introduction

For a substantial number of those who share the conclusion of the previous chapter, discussion about whether social factors should be considered in determining whether or not to treat an imperiled newborn should be over. Once we have established the full moral personhood of the infant we know all we need to know. Personal dignity cannot be reduced to their social utility or to a number of dollars that they are ‘worth.’ Such calculations, at a very basic level, deny the dignity of the individual human person. Such radical individual dignity cannot and should not be subsumed within a broad social calculus about what is best for the community.

Indeed, isn’t it the case that the modern discipline of bioethics has arisen as a response to, and safeguard against, precisely this kind of impoverished reasoning? Haven’t foundational documents like the Nuremberg Code (response to the medical abuses of the Nazis who subsumed the good of the community over the dignity of certain
undesirable individuals), the National Research Act of the United States (response to the medical abuses of the federal government who subsumed the dignity of certain African-American individuals in the Tuskegee syphilis studies), and the World Medical Association’s Declaration of Helsinki all claimed, in one way or another, that the autonomy and dignity of the individual cannot be reduced to the good of the community? This kind of reasoning seems to be especially important for physicians whose relationship with their patients is the foundation of medicine. Indeed, the World Medical Association’s Declaration of Geneva makes claims that a physician must, “always act in the patient’s best interest when providing medical care” and to have “the health of my patient” as her first priority. This ‘patient’s best interest’ standard has been interpreted by modern clinical organizations like the American Association of Pediatrics Committee on Bioethics Policy to mean that the only benefits and burdens to be considered by the physicians are those that belong to the child [patient] alone. And this standard has been interpreted still further by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research to “exclude consideration of the negative effects of an impaired child’s life on other persons, including parents, siblings and society.”

These powerful and persuasive positions in today’s modern bioethical culture fly in the face of the central argument of this dissertation—which directly connects the benefit or burden of a treatment to just distribution of resources toward the common


good—and thus deserve careful consideration. This chapter will attempt to address them in the following way. First, the chapter will consider arguments which rule out social considerations—at both theoretical and practical levels of inquiry—when deciding whether or not to treat an imperiled newborn. This view will be answered by a review of the Christian tradition on the distinction between ordinary and extraordinary means which, from the point of view of this dissertation, is clear and convincing about at least the theoretical importance of social factors: due in no small part to the essentially social nature of the individual. Next, the view that while social factors in treatment decisions have some theoretical value, they nevertheless should not be considered in practice—as articulated by Richard McCormick and John Paris—will be examined. These authors will be answered with both an internal critique of their positions as well as an attempt to show that their concerns about abuse are outweighed by claims of distributive justice. Next, the chapter will consider the argument by John Arras that it is *de facto* wrongful discrimination against disabled persons. The response to this argument will be that one need not factor in disability (as defined by Arras) into the calculation at all—but rather only cost (broadly speaking) as it relates to distributive justice. The chapter will then consider the arguments of Michael Panicola and Edmund Pellegrino that the very foundations of medicine are threatened by the social quality of life model in that it forces physicians to consider something other than their patient’s best interests. The response to this argument will be that the concept of a patient’s ‘best interest’—especially when viewed within a lens of Catholic Social Teaching and a relational anthropology—must be broadly construed so as to include the interest of affected others. The chapter will conclude with a recounting of the Ramsey/McCormick debate over whether non-
autonomous children should be held to the same moral standard in this area as are adults—finding McCormick to have the stronger argument.

**Ruling-Out Social Factors on Theoretical and Practical Levels: Paul Ramsey**

James Walter, when attempting to summarize various ethicists’ positions on the central question of this chapter, had the following to say (all emphasis is in the original):

For most of the authors under review, any inclusion of quality-of-life considerations into the decision to forego life-preserving treatment must be directly related to a patient’s best interest…Though the criteria of “best interests” can be somewhat ambiguous, most would define it by reference to an assessment of the proportion of benefits and burdens of the treatment. If the burdens of the treatment considered in itself clearly outweigh any benefits to the patient, then it is morally permissible never to start or to terminate the treatment in question.⁹⁴

Though clearly many (perhaps even a strong majority) bioethicists strictly focus on the patient apart from social factors at both theoretical and practical levels of inquiry, this chapter will focus on a paradigmatic example in its analysis: the ‘medical indications’ model of Protestant Ethicist Paul Ramsey.

One of the important points Ramsey emphasizes is that most of the issues raised in medical ethics are not ‘special’ or ‘unique’—but rather manifestations of ethical issues that arise in personal relations more generally. Ramsey brings important Protestant Christian emphases to this discussion—and one of them is a Christian understanding, revealed in scripture, of covenant. He notes that, “at crucial points in the analysis of medical ethics, I shall not be embarrassed to use as an interpretive principle the biblical

---

norm of *fidelity to covenant*, with the meaning it gives to *righteousness* between man and man [emphasis in the original].”\(^95\) He cites agreement with Karl Barth that covenant-fidelity is the inner meaning and purpose of our creation as human beings, while the whole of creation is the external basis and condition of the possibility of covenant. This means that the conscious acceptance of covenant responsibilities is the inner means of even the “natural” or systematic relations or roles we enter by choice, while this fabric provides the external framework for human fulfillment in explicit covenants among men. The practice of medicine is one such covenant. (Ramsey, xii)

Questions like those being considered in this dissertation involve “the principle task of medical ethics” which is “to reconcile the welfare of the individual with the welfare of mankind.” (Ramsey, xiii) Crucial to this discussion is one’s ‘view of man’ because from this follows “the moral claims upon us in the crucial medical situations and human relations in which some decisions must be made about how to show respect for, protect, preserve and honor the life of fellow man.” (Ramsey, xii) Ramsey describes the principles that follow from these moral claims as ‘Canons of Loyalty’ that exist between human beings generally, but also in specific instances within medicine.

One canon of loyalty for which Ramsey argues implies that, “it is never right to turn against the good of human life. In the case of one’s own life, public policy could go so far as to place that in the area of liberties. But to allow private individuals to turn against the good of another’s life would be to promote injustice.”\(^96\) This position has at its heart the central idea that, “an individual human life is absolutely unique, inviolable, irreplaceable, non-interchangeable, not substitutable, and not meldable with other lives.”

\(^95\) Paul Ramsey, *The Patient as Person; Explorations in Medical Ethics* (New Haven: Yale University Press, 1970), xii.

(Ramsey, xvi) This dignity is something we find in an embodied existence and is an essential, constitutive part of that dignity—and, therefore, when we choose against this embodied good (as we do when we refuse potentially life-saving treatments of another) we violate this dignity in an unacceptably unjust way. To be sure, life-sustaining treatment can be withdrawn or refused—but this needs to be done when faced with a medically-indicated situation where ‘the disease has won.’ The “naked equality of one life with another”97 means that there is a right to equal treatment based on medical criteria without letting non-medical criteria set us in a direction toward wrongful discrimination against those deemed to be too expensive or too burdensome.

Ramsey has applied his medical indications model specifically to treatment and care of imperiled newborns—and specifically in a critique of physicians letting some babies die “not only on the basis of the newborn’s medical condition and prognosis, but on the basis of familial, social and economic factors as well.”98 Regardless of the economic issues at stake, Ramsey maintains that “to deliberately make medical care a function of inequalities that exist at birth is evidently to add injustice to injury and fate.” (Werpehowski, 248) To make decisions based on such social factors is “playing God” and Ramsey would at least hope that if physicians are going to do this they do so “as God plays God.” (Werpehowski, 249) But our God does not factor social considerations into respect for human life. Nor does our God curtail care for us based on these factors. God “cares according to need, not capacity or merit.” (Werpehowski, 251)


decision “to treat or not to treat should be the same for the normal and abnormal alike.”
(Werpehowski, 251) True humanism, Ramsey asserts, leads to an ‘equality of life’
standard based on medical indicators and not social factors.

**Ramsey: Critique**

Much of what Ramsey argues for here is correct and implied in the arguments of
the preceding chapter. Surely one should never turn against the good of human life. That
good is absolutely unique and inviolable and finds itself embodied. The dignity of each
human life is equal and we should not treat the abnormal with injustice compared to the
normal. However, it does not follow from any of these considerations that ‘evidently’ it
is therefore unjust to consider social factors when determining whether or not to treat an
imperiled newborn. Indeed, while it could be consistently argued that human dignity
implies the medical indications model Ramsey offers, it could also be argued that the
dignity and equality which Ramsey wants to defend so strongly are more dynamic and
multi-faceted than his medical indications model is prepared to consider. Indeed, while
embodiment is central to human dignity, so is the *social situation* of that human,
embodied person. Indeed, it is precisely the relationship that the embodied person has
with her God and her community that defines and delimits her dignity. It is certainly not
‘evidently’ clear that, in giving life-saving resources to one person over another, one is
‘turning against the good’ of human life. For several hundred years the Roman Catholic
moral tradition has been developing a fairly systematic way in which one can take
seriously the concept of human dignity, within its total spiritual-social reality, applied to
medical treatment decisions. In attempting to answer Ramsey, it is to this tradition we now turn.

**The Roman Catholic Tradition on Ordinary and Extraordinary Means**

The distinction between a medical treatment that is ordinary and therefore morally required (in a possibly life-saving or life-prolonging situation) and one that is extraordinary and may be refused or withdrawn, while going back to medieval Roman Catholic thinkers, has been adopted (at least in some form) and invoked in the wider secular debate of these issues. However, it is important and appropriate to get perspective on this tradition by briefly locating it in its historical context.99

Many locate the beginning of this tradition’s trajectory with Thomas Aquinas’ thirteenth century attempts to balance one’s abiding respect for human life with some acknowledgement that the duty to sustain such life, a temporal good, is not absolute. God has dominion over human life and responsible stewardship of God’s gifts may mean choosing other goods over those of human biological life. Three centuries later, moralist Francisco de Vitoria started reasoning in a way reminiscent of the current ordinary/extraordinary means tradition. In dealing with the question of a very sick person’s refusal of food, he claimed that if the patient is so depressed that taking food becomes ‘a kind of impossibility’ then the patient is not guilty of the mortal sin of suicide—especially if there is little hope for life. Interestingly, Vitoria adds that even if it would be more nutritious (and thus more likely to yield a healthier state), the sick person

99 Most of the narrative here is owed to Sparks, *To Treat or Not to Treat: Bioethics and the Handicapped Newborn*, 94-100.
is not required to eat the best or most expensive food. Indeed, he broadens out this point in claiming that one is not obliged to sacrifice one whole means of subsistence, nor one’s general lifestyle, nor one’s homeland in order to acquire a cure or maintain optimum health.

Prior to the development of modern anesthetics, surgical procedures not only involved mutilation and disfigurement of the body, but almost always involved virtually unimaginable pain. Also in the 16th century, Domingo Soto, O.P. claimed that such surgeries—and especially amputations—were necessarily optional because of their torturous nature. Even if medically beneficial or even life-saving they could be forgone because the pain was beyond what the ‘common man’ could possibly be forced to bear. Though it appears that another 16th century thinker, Dominican Domingo Banez, was the first to use the terms ‘ordinary’ and ‘extraordinary’ in this medical context, it was Jesuit Gerald Kelly who explored, summarized and gave synthetic expression to the distinction in the mid-20th century. For Kelly, an ordinary treatment was one that was obtained without very great difficulty, while an extraordinary one was one obtained with excessive difficulty—with respect to pain, repugnance, cost, “and so forth.” Of course, such judgments are going to be dependent on one’s social circumstances—a particular treatment in which anesthetic is used (by now available to some communities of Kelly’s time), for instance, now could be considered ordinary whereas in the century previous it would have everywhere been considered extraordinary. Importantly, one extenuating
circumstance which would make any medical means extraordinary would be if there was no reasonable hope for benefit of the patient.\textsuperscript{100}

A few years after Kelly’s work came out, Pope Pius XII delivered an address which, despite it having had appeared in the Roman Catholic moral manuals for centuries, gave the ordinary/extraordinary distinction clear papal confirmation:

Natural reason and Christian morals say that man (and whosoever is entrusted with the task of taking care of his fellowman) has the right and duty in the case of serious illness to take the necessary treatment for the preservation of life and health…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…[And] 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.\textsuperscript{101}

And to return to the first insight which called the Ramsey medical indications approach into question, “Before anything else, the doctor should consider the whole man, in the unity of his person, that is to say, not merely his physical condition but his psychological state as well as his spiritual and moral ideals and his place in society.”\textsuperscript{102}

Based on this history, one can come up with some general principles that characterize the ordinary/extraordinary distinction:

\textsuperscript{100} It is worth noting here that this is the ‘early’ Kelly. Later Kelly retreats from talk about benefit to the patient. The tradition on this distinction is by no means without confusion and grey area—as we will soon see. However, this messiness does not detract from its basic premise: that human goods beyond what can be determined merely by medical indications should indeed be factored into medical treatment decisions.

\textsuperscript{101} Pope Pius XII, "Prolongation of Life," \textit{The Pope Speaks} 4 (1958), 395-396; ibid.

\textsuperscript{102} Pius XII, “Cancer, a Medical and Social Problem as quoted in Sparks, \textit{To Treat Or Not to Treat: Bioethics and the Handicapped Newborn}, 92.
1. Physical life is a basic precious value that one has an obligation to protect and preserve. However, physical life is a limited value subordinated to the pursuit of spiritual ends.

2. One’s moral obligation to prolong life through medical means is evaluated in light of one’s overall medical condition and one’s ability to pursue the spiritual ends of life.

3. One is morally obliged to prolong life with medical means when it offers a reasonable hope of benefit in helping one to pursue the spiritual ends of life without imposing an excessive burden.

4. One is not morally obliged to prolong life with medical means when death is imminent and medical treatment will only prolong the dying process; when medical treatment offers no reasonable hope of benefit in terms of helping one pursue the spiritual ends of life; or when medical treatment imposes an excessive burden on one and profoundly frustrates one’s pursuit of the spiritual ends of life.\(^{103}\)

5. Benefit and burden are understood broadly in the Catholic tradition to refer not just to the physiological dimension of life, but the psychological, social and spiritual dimensions as well.\(^{104}\)

6. Cost to the individual and family are social factors which may be considered when determining whether or not a treatment imposes an excessive burden.

---

\(^{103}\) One might wonder whether this principle still holds in light of the latest document from the Congregation for the Doctrine of the Faith on Responses to Certain Questions of the United States Catholic Conference of Bishops on Nutrition and Hydration (1 August 2007). In response to the question of whether or not food and water must be provided for a PVS patient who is deemed by competent physicians to have no capacity to regain consciousness, it claims, “A patient in a ‘permanent vegetative state’ is a person with fundamental human dignity and must, therefore, receive ordinary and proportionate care which includes, in principle, the administration of water and food even by artificial means.” Though one might ask a legitimate question about whether this answer conforms to previous Church teaching, it still may been seen as consistent with principle 4 above. One might make the claim that giving a patient artificial nutrition and hydration is not medical treatment, but rather a kind of generalized ‘care’ and therefore something that doesn’t fall under the ordinary/extraordinary distinction. One might also see the phrase ‘in principle’ as an opening as well. For it certainly is the case that, in principle, food and water is a proportionate treatment (given the resources of most cultures)—but in some situations with less resources it might be disproportionate treatment. Also, if a PVS patient were to need other kinds of medical treatment (say, cardiac resuscitation) there is nothing in the document which points to this being, in principle, ordinary treatment.

\(^{104}\) The preceding principles are taken from Panicola, *Quality of Life and the Critically Ill Newborn: Life and Death Decision Making in the Neonatal Context*, 218-219.
Much of the debate surrounding ordinary and extraordinary means has to do with complex patient-centered distinctions like those between the benefit/burden of a patient’s treatment vs. the benefit/burden of the patient’s life. While these are interesting and important issues in bioethics, the essential principle for the central issue of this chapter is #6 above. The Catholic approach here differs dramatically from the Ramsey medical indications approach in that it asks the physician to see the patient in the totality of her social reality—and in light of the spiritual and moral ideals which define and delimit her dignity and duties within that reality. These are indications which are far beyond medicine’s ability to assess and imply that physicians and other healthcare providers need to be far more than simply highly educated technicians. If they truly have care of the person—and not just treatment of disease—as their goal, then the medical indications policy falls short.

But what, specifically, does this kind of spiritual-social reasoning mean for treatment of imperiled newborns? Richard Sparks, whose thought will be examined in some detail in chapter three, takes this question very seriously. (Sparks, 107-113) He notes that even non-competent patients like imperiled newborns are not isolated, but rather, social creatures—members of the commonweal who are affected by the decisions of others and who affect others through decisions made with reference to them. As such, their proxy decision-makers may rightly factor familial and other social concerns into the ordinary/extraordinary distinction. As seen above, Pius XII included grave burden for one’s self or another [emphasis added] in his definition of extraordinary

---

105 In this sense, he agrees strongly with McCormick over and against Ramsey regarding social duties of newborns.
means. With regard to the family of the newborn, while care must be given to caution against potential greed and other selfish motives, the excessive emotional and financial strain on parents and fellow siblings is a genuine component of an infant’s life situation and is certainly not inconsequential. Indeed, the psychological and financial resources of a family have limits—and it may be that the strain could be enough so as to threaten the essential functioning of the family unit. In such cases, analogous to the case of the sick person with food or wounded person facing amputation, treatment of the imperiled newborn might be a practical ‘moral impossibility’ and therefore extraordinary treatment. Perhaps one might think that in these situations society at large is under an obligation to provide the treatment if it is ordinary with respect to the benefit of the newborn herself. But then the next logical question—and it is a central question of this dissertation—is, “Could the [short and] long term costs of a handicapped infant’s medical treatments and care ever be judged excessively burdensome even for society, and therefore categorically extraordinary and optional?” In theory at least, the answer appears to be yes. There appears to be no theoretical reason why social factors, if they apply to treatment decisions made by the nuclear family, should not also apply to the treatment decisions the larger family of one’s society at large.\textsuperscript{106} Indeed, just as with the nuclear family, society’s resources are limited and could be strained to the point where its ‘essential functioning’ is threatened. Though physicians can do their best to imitate Ramsey’s God, they must face the fact that we do not have the same resources.

\textsuperscript{106} However, one might indeed have the practical worry about a State being motivated by expediency or corruption rather than a loving commitment to the best interest of the newborn. But this is a worry that one might have about the family as well, and is not a good reason to make a strong disjunctive move between them.
However, to allow this kind of reasoning on such a broad scale would at least allow for the possibility of far more dramatic practical implications than limiting it to nuclear family considerations. One could consistently argue that while certain kinds of social considerations are acceptable to consider in theory, in practice they could lead to such bad consequences that they should ultimately be rejected. It is to this kind of argument we now turn.

**Ruling-Out Social Factors on a Practical Level: Richard McCormick**

Richard McCormick’s thought on these questions is sometimes difficult to follow. On the one hand, he quite often disparages the use of the ordinary/extraordinary distinction. As far back as 1976 McCormick claimed in a Linacre article that he would agree that “the terms ‘ordinary’ and ‘extraordinary’ are not too helpful. They are code words for other judgments.”\(^\text{107}\) And in a Hastings Center report in 1978 McCormick claimed that, “it must be pointed out that the terms ordinary and extraordinary are so relative that they are equally capable of abuse as quality of life language… In sum, then, I would seriously question whether means language protects human life.”\(^\text{108}\) However, if one were to look at his relationship with the substance of the principles of the ordinary/extraordinary distinction, it seems clear he is largely in agreement. Consider each of the principles again and McCormick’s agreement:


\(^{108}\) Richard A. McCormick, "Quality of Life, the Sanctity of Life," *Hastings Center Report* 8 (F, 1978), 35.
1. Physical life is a basic precious value that one has an obligation to protect and preserve. However, physical life is a limited value subordinated to the pursuit of spiritual ends.

“Life is indeed a basic and precious good, but a good to be preserved precisely as the condition of other values.”

2. One’s moral obligation to prolong life through medical means is evaluated in light of one’s overall medical condition and one’s ability to pursue the spiritual ends of life.

“The meaning, substance, and consummation of life is found in human relationships [emphasis in the original]…It is neither inhuman nor unchristian to say that there comes a point where an individual’s [medical] condition itself represents the negation of any truly human—i.e., relational—potential.” (To Save or Let Die, 174 and 175)

3. One is morally obliged to prolong life with medical means when it offers a reasonable hope of benefit in helping one to pursue the spiritual ends of life without imposing an excessive burden.

McCormick spends most of him time arguing about principle number 4 below—taking this principle for granted as uncontroversial. However, regarding those infants diagnosed with mental illness that still leaves room for relational potential he says, “Life-sustaining interventions may not be omitted simply because the baby was retarded [sic].”

4. One is not morally obliged to prolong life with medical means when death is imminent and medical treatment will only prolong the dying process; when medical treatment offers no reasonable hope of benefit in terms of helping one pursue the spiritual ends of life; or when medical treatment imposes an excessive burden on one and profoundly frustrates one’s pursuit of the spiritual ends of life.

---


“Life sustaining intervention may be omitted when there is excessive hardship on the patient, especially when this is combined with poor prognosis.” (McCormick, 358.)

5. Benefit and burden are understood broadly in the Catholic tradition to refer not just to the physiological dimension of life, but the psychological, social and spiritual dimensions as well.

McCormick often builds on the personalism of Vatican Council II which insists that human dignity be “integrally and adequately” considered.111 This “refers to the sum of dimensions of the person that constitute human well-being: bodily health; intellectual and spiritual well-being, which includes the freedom to form one’s own convictions on important moral and religious questions; and social well-being in all its forms: familial, economic, political, international and religious.”112

Despite disparaging the use of the terms ordinary and extraordinary, McCormick quite clearly supports the basic principles of the distinction looked at thus far. However, with regard to the final principle, McCormick is once again difficult to follow.

6. Cost to the individual and family are social factors which may be considered when determining whether or not a treatment imposes an excessive burden.

On the one hand, McCormick clearly supports the consideration of these social factors—at least in theory. Given his theological anthropology of the human person as ‘essentially social’113 and also what has been quoted above, it would be difficult to reject them and avoid inconsistency. Citing Catholic tradition on this question positively, he says “if the


113 Again, this comes right out of Vatican Council II. See the Pastoral Constitution on the Church in the Modern World, nos. 12 and 32.
financial cost of life-preserving care was crushing, that is, if it creates grave hardships for one or one’s family, it was considered extraordinary and nonobligatory.” (McCormick, *To Save or Let Die*, 174-175) In an article he wrote for *Second Opinion*’s neonatal ethics series topic he asked the following, “Do the sometimes staggering costs of neonatal intensive care mean that at some point the economics of care determine the meaning of best interests [of the infant]? We shy away from such considerations, and this is undoubtedly a healthy response. But how long we can sustain it I do not know.” He left the theoretical door open to consider social factors as part of the infant’s good and best interest 12 years previous to this question in the JAMA article, but ultimately, on a practical level, McCormick refuses to walk through it. In an article he wrote with John Paris in 1983 for *America* magazine, he states rather clearly that issues surrounding life-preserving treatment of imperiled newborns, “ought not be framed in terms of emotional or financial burden on the family.” Three years later he is just as, if not more, direct on this question:

First, lifesaving interventions ought not be omitted for institutional or managerial reasons. Included in this specification is the ability of this particular family to cope with a badly disabled baby…it remains an unacceptable erosion of our respect for life to make the gift of life once given depend on the personalities and emotional or financial capacities of the parents alone. No one ought to be allowed

---


115 It remains then only to emphasize that these decisions must be made in terms of the child’s good, this alone. But that good, as fundamentally a relational good, has many dimensions. Pius XII, in speaking of the duty to preserve life, noted that this duty, “derives from well-ordered charity, from submission to the Creator, from social justice, as well as from devotion toward his family.” All of these considerations pertain to that “high, more important good.” If that is the case with the duty to preserve life, then the decision not to preserve life must likewise take all of these into account in determining what is for the child’s good.” (*To Save or Let Die*, 176.)

to die simply because the parents are not up to the task. At this point society has certain responsibilities.¹¹⁷

More will be said later about whether or not this is an inconsistent (or, perhaps, incomplete) position based on commitments McCormick has already made. Before going there, however, we now turn to the arguments of John Paris who makes a similar distinction.

**Ruling Out Social Factors on a Practical Level: John Paris**

John Paris, like Richard McCormick, believes strongly in the principles espoused by the ordinary/extraordinary distinction. While he does believe that physical life is a precious value, our “ultimate goal is the restoration of the fullness of the kingdom. Thus, it is eternal life and not life itself which is ultimate.”¹¹⁸ Medical indications are important, of course, but the chief end of human activity is also to be considered paramount: “simply love, the giving and receiving of love…a love that proves itself in the concrete world of justice, gratitude, forbearance, and charity.” (Paris, 154).

Regarding the distinction between ordinary and extraordinary means, Paris says:

> Ordinary means are those which are not disproportionately costly, burdensome or painful, and—this is the important part—they must also offer substantial hope of benefit to the patient as a person, not simply to his liver, lungs or heart. What we are to be valued for is our personhood, and if the treatment cannot offer substantial benefit to the person, not just to his or her chemistries, it is extraordinary and need not be applied. (Paris, 156)

---


Paris has spilled much ink attempting to respond to the apparent shift in magisterial teaching on artificial nutrition/hydration and ordinary/extraordinary means and he argues almost exclusively using principles of the Catholic tradition making this distinction. Citing the New Jersey Catholic Conference of Bishops, he argues that the limited times in which such artificial nutrition/hydration is able to be withdrawn morally, it “is designed not to hasten the death by starvation or dehydration, but to spare the patient the prolongation of life when the patient can derive no benefit from such prolongation.”¹¹⁹ In backing up his position he refers to the two giants in the history of the ordinary/extraordinary distinction already cited above. Francisco DeVitoria argued that one was not obliged to take food if it was excessively burdensome, and if this was true in his time, then “how much more so today for total parenteral nutrition, feed gastrostomies, nasogastric tubes and other artificial means of providing alimentation?” (Paris, 358) He also cites Gerald Kelly who, after a thorough survey of the prior teachings on the subject, finds that “no remedy is obligatory unless it offers a reasonable hope of checking or curing a disease.” (Paris, 359)

So Paris is largely on board with principles 1-5 detailed above—indeed, he uses them as central supports in his most important arguments. But what of principle 6 that, “Cost to the individual and family are social factors which may be considered when determining whether or not a treatment imposes an excessive burden”? Like McCormick, Paris is difficult to follow on this question. It seems that he does accept them on a theoretical level. We have already seen how one of his criteria for a means to

be ordinary was one that is ‘not disproportionately costly.’ (Paris, *Quality of Life*, 156) In this same article, Paris goes on to specify the way such costs may be taken into account. After citing positively magisterial teaching that ‘excessive expense to the family’ might make a given treatment extraordinary, he ask us to consider the following case of:

a 27 year old woman who fell off a horse, was decerebrate, quadriplegic, and maintained in the community hospital for some 18 years…. [The physicians] noted that the cost of such care would be astronomical, almost beyond belief. Well, if one calculates at a very low rate of $300 a day, and builds in an inflation factor of 12 percent, 18 years of such care comes to $6,104,590. The Vatican reaffirms the duty of physicians to take such factors into account. (Paris, 158)

This is a remarkable point for at least two reasons. First, considering that the article was written over 25 years ago, the number—already astounding—would be that much more dramatic given today’s costs. Second, Paris speaks affirmatively of a duty to take such broad social factors into consideration. This becomes all the more remarkable when one considers other things he has written on this subject.

As we’ve already seen, Paris wrote the article with McCormick which claimed that treatment of imperiled newborns “ought not be framed in terms of the emotional or financial burden on the family.” (Paris and McCormick, *Saving Defective Infants*, 315) In the *Quality of Life* volume, Paris, when considering whether or not the financial or emotional burdens could truncate an infant’s right to life, he answers with “an emphatic ‘no.’” (Paris, 152) He claims that, “although parents may continue to be involved in decision making for their children, they do not have the sole right to demand or refuse medical interventions for infant. It is the child’s best interest, not the parent’s wishes,
that is to govern treatment decisions." He makes the same point even more strongly in a letter to the editors of *Law, Medicine and Healthcare*:

I wish to join those who raise their voice against the theory that children are to be accepted or rejected—to live or be killed—because of their burden on others...It is the interest of the patient, and the harm to the patient, which have been and ought to be the primary focus of medical ethics. To deviate from that norm is to distort if not destroy medicine’s role in society.121

### Ruling-Out Social Factors on a Practical Level: Magisterial Teaching

The reasoning of some members of the Magisterium—and especially that of the United States’ Bishops—mirrors that of McCormick and Paris. The Congregation for the Doctrine of the Faith’s *Declaration on Euthanasia*, for instance, claims that refusal of treatment out of “a desire not to impose excessive expense on the family or the community” is “considered as an acceptance of the human condition.”122 However, while the United States Catholic Conference of Bishops claims that while, “in principle cost can be a valid factor in decisions about life support” (for example, money spent on expensive treatment for one family member may be otherwise needed for food, housing and other necessities),123 they also claim that, while the problem “requires further study and discussion,” what “is best for the individual child should take precedence over any conflicted interests of parents or society”—and the solution to this problem is “increased

---


local, state and federal assistance” to families that find themselves in this situation. The Pennsylvania Catholic Bishops add that, given the society in which we live, the argument that social factors should be considered (at least with regard to the family) is “not convincing” because “resources are available from other sources and these can often be tapped before a family reaches dire financial straits. Such assistance has been and continues to be available.”

McCormick, Paris and Magisterial Teaching: Critical Evaluation

A quick read of McCormick, Paris and the American Bishops on these issues can be difficult to reconcile—and some might even be tempted to call their views self-contradictory. On the one hand, they seem to accept, and accept rather strongly, the principles behind Catholic teaching on ordinary and extraordinary means—including those regarding the application of social issues in making the distinction. On the other hand, each makes very clear that social factors should not determine treatment decisions regarding life-prolonging therapies for imperiled newborns. What is going on here? Richard Sparks attempts to shed some light on this issue by arguing that while in theory “McCormick, Paris, et al. are willing to consider familial and social ‘costs’ in determining the burden component related to prolonging life, ultimately their fears of potential abuse lead to non-inclusion or at least a tendency toward exclusion of such

---


126 It should be noted that the teaching under critical evaluation is that of the United States’ bishops—but not the Roman CDF. The later does not make the theory/practice distinction in the documents cited.
social burden factors.” (Sparks, 179) This seems especially true for McCormick—who seems to fear abuse on two levels, “First he fears that a broad interpretation of social factors can easily lead to the slippery slope of social utilitarianism. This, he understands, can lead to infanticide. Second, McCormick is well aware of the finite and sinful nature of humanity. How does one determine if a family is taking the never-competent patient’s perspective or their own self-interested perspective?” In addition, Sparks wonders if McCormick and Paris don’t take social factors into consideration more than one might think at first glance. He says, “it is not clear whether McCormick and Paris absolutely exclude all social burden factors.” (Sparks, 199) For, in their joint paper in America, they point to the fact that the family shouldn’t be allowed to discontinue because society can absorb the cost [emphasis added]—but then they neglect to speculate on whether the cost of an imperiled newborn’s treatment ever exceeds a society’s duty to treat her. (Sparks, 200)

Though Sparks and Clark are helpful here, this doesn’t get these views off the hook with regard to the charge of inconsistency. Let us take the theory/practice distinction and the worry about potential abuse. First, it is not clear that incorporating social factors, especially when disciplined by the Catholic moral tradition’s principles beyond the ordinary/extraordinary distinction, will indeed lead down a slippery slope toward bad things like social utilitarianism. Indeed, as we will see in some detail later in

---

127 Peter A. Clark, To Treat Or Not to Treat : The Ethical Methodology of Richard A. McCormick, S.J., as Applied to Treatment Decisions for Handicapped Newborns (Omaha, Neb.: Creighton University Press, 2003), 216.

128 The classic distinction between acting directly against the good of human life and letting die as a foreseen and unintended consequence, for instance. Also see Clark on the many other safeguards that exist in this tradition including McCormick’s relational quality-of-life criterion itself. (Clark, 216)
this chapter, one could certainly approach social factor inclusion from the patient’s perspective rather than that of society interests. Also, as we will see in chapter 3, Catholic Social Teaching demands that we approach social factor inclusion with distributive justice in mind—not social utility. Second, it is not clear, even if something like a social calculus were used, that infanticide would be (or even would likely be) the result. As we will see in Chapter 4, we currently use a (poorly conceived) social calculus in determining how community monies are spent in public health programs like Medicare and Medicaid—this kind of reasoning has not led us closer to things like infanticide.¹²⁹ Indeed, whatever arguments lead to the conclusion that infanticide would be the likely result of social quality of life reasoning also lead to the conclusion that infanticide would be the likely the likely result of more traditional quality of life reasoning. For, even when working with a strict ‘best interest’¹³⁰ quality of life model—through which it was determined that the burdens of a particular life-prolonging treatment outweighed the benefits—one could certainly have the worry that infanticide, being more direct, cost-effective, timely, and (arguably) less painful than withdrawal or refusal of treatment, would be the result of slippery-slope reasoning. If a view accepts the Social Quality of Life Model ‘in theory but not practice’ because it might lead to infanticide, it should reason the same way about the strict ‘patient best interest’ quality of life model as well—one which all three above accept.

¹²⁹ Though this goes well beyond the scope of this dissertation, it is worth noting here that it might be the case that a social calculus specifically precludes systematic active euthanasia of imperiled newborns due to the callousness and disrespect for life that would result.

¹³⁰ Later in the chapter, a possible distinction between a ‘strict’ model of best interests (one that would include only the isolated, individual interests of the person) and a ‘broad’ model (one that would include the interests of a patient specifically situated in their social context) will be explored.
But what about Spark’s suggestion that perhaps McCormick and Paris’ model is not that strict after all? Perhaps they offer an opening to consider social factors by claiming that families should not be allowed to discontinue treatment because, in part, society can pick up the tab? Might it be the case that the way society picks up the tab could be subject to the considerations of the Social Quality of Life Model? The central argument of this dissertation is ‘surely yes,’ but that conclusion is difficult to come to given the direct commitment of McCormick to not consider ‘institutional and managerial’ reasons for discontinuing treatment of an imperiled newborns and Paris’ scolding those who support factoring-in the interests of others as contributing to the ‘destruction of the role of medicine in society.’ The USCCB explicitly rejects this move by claiming, “decisions about life-extending care should not be determined by macroeconomic concerns such as national budget priorities and the high cost of healthcare. These social problems are serious, but it is by no means established that they require depriving chronically ill and helpless patients of effective and easily tolerated measures that they need to survive.”131 This might be the way to go as an argument independent of the McCormick, Paris and the American Bishops—but as a matter of internal consistency they appear to be forced to reject it.

In continuing a critique of these positions, it becomes instructive to consider the theological and moral anthropology in play. Each of the three to a certain extent, but McCormick perhaps most dramatically, holds a strong relational anthropology. As we will see later in this chapter, he thinks that the social nature of human beings is present

even in non-volitional newborns. Paris, as we have seen, locates the essential value identity of human life as existing in loving relationships. And, as we will see in great detail in chapter 3, Catholic Social Teaching’s theological anthropology starts with the human person as she exists ‘in social relationship.’ It is difficult to see, then, how each can hold such an anthropology that is so dramatically connected to a social context—and yet rule-out social considerations on a practical level when deciding on how best to respect the dignity of human life in the case of imperiled newborns. As Sparks articulately notes:

McCormick’s absolute declaration that decisions ‘must be made in terms of the child’s good, this alone’ does not itself forestall incorporating some social factors as they related to the infant’s holistic well-being. For that matter, his advocacy of relational potential as the measure of infant’s minimal interest in life-saving treatment is a family-oriented, socially-conscious criterion, at least as viewed from the patient’s perspective.” (Sparks 180)

And:

In their admirable effort to avoid a socially-weighed bias against a patient’s own experience of burden vis-a-vie benefit, I believe the more restrictive quality of life proponents have construed the determination of excessive burden too narrowly. The ultimate decision as to whether treatment is in a given patient’s total best interest ought to incorporate not only medical or individualistic (i.e., experimental) burden factors, but also broader social factors, viewed from the patient’s existentially-contexted vantage point. On this level, the broader interpreters of the quality of the patient’s life echo the best of the ordinary/extraordinary tradition in their insistence that the cost, psychic strain, and degree of inconvenience born by others, a non-competent’s social network, ought rightly to be factored in as part of the patient’s burden, holistically considered. (Sparks, 198)

A final argument for rejecting the theory/practice distinction involves the absolutely overwhelming injustice and need when it comes to medical resources. Though much more will be said about the hard figures and numbers in chapters 3 and 4, suffice to say here that healthcare is the single-most expensive component of our nation’s budget,
that such monies are allocated not primarily on the basis of need or justice, but in large part according to a market profitability scheme, and that the profitability of treating NICU patients dramatically and unjustly skews how community money is spent on the our nation’s poor. That such radical and far-reaching injustice exists is a strong reason to get over concerns about a slippery-slope—especially in light of previous concerns.

Despite what appears to be the US Bishops arguing the contrary, the resources to aid families, under our current healthcare system, simply do not exist—at least if we want to justly allocate resources as a culture. If we truly take Ramsey seriously that medicine is about the ‘good of human beings’ then we must take these numbers seriously and practically—not just theoretically. Recall that Paris himself seems to be arguing this very point when he asked us to calculate the cost of patient’s treatment at, “a very low rate of $300 a day, and builds in an inflation factor of 12 percent, 18 years of such care comes to $6,104,590. The Vatican reaffirms the duty of physicians to take such factors into account.” (Paris, Quality of Life, 158) How can Paris argue what appears to be a self-contradictory position here—namely, that taking into account the cost to others is to distort if not destroy medicine’s role in society and that physicians have a duty to take cost into account?

One route is suggested by Panicola in his treatment of Paris’ position. He says that from reading him “one might get the impression” that “Paris fits better into the narrow social quality of life camp.” This, he claims, “is the wrong impression” because Paris is claiming social considerations may be taken into consideration for a patient only when the “life-sustaining treatment provides no benefit to them [emphasis in the
original], and it is a careless use of resources to sustain their lives when they receive no meaningful benefit. (Panicola, 157)

Does this work for the case Paris gave us to consider where he explicitly argues for taking social considerations into practical account? Well, he does claim that the patient is ‘decerebrate’—which, depending on whether this refers to a neurological state or a bodily posture, could be the kind of human being that Panicola insists that Paris is talking about. At the very least, Paris does not justify his consideration of social factors by arguing that the patient could not have benefited for the treatment anyway. But let us say for the sake of argument that Panicola is correct, does this still keep Paris out of the social quality of life camp?

In answering this question one should consider seriously the arguments of Joseph Boyle in his A Case for Sometimes Tube-Feeding Patients in Persistent Vegetative State.132 In this article, Boyle argues that the claim that treatment of PVS (and like) patients is of no benefit needs to be called into serious question. He admits that “by any estimate, the benefits of keeping a person alive who has no prospect of recovering from…radically impaired consciousness…are small.” (Boyle, 192) However, he argues that such patients “can be harmed by being killed, by being treated as spectacles or sex objects, by being used improperly for experimental purposes and so on.” (Boyle, 193) And, if such indignities are harms, “then actions taken precisely to prevent or remove these indignities must be benefits to them.” (Boyle, 193) But what about the burdens of treatment? “The pain, suffering and interference with the pursuit of valued activities

which often provide reasons for discontinuing treatment are not possible for patient in PVS,” (Boyle, 194) and a good portion of the these kinds of burdens are also not possible for others with similar impaired consciousness. Therefore, Boyle argues, most of the time the burdens involved in the treatment of such patients “must be those imposed on others.” (Boyle, 195) In the case that Paris presents us, the burdens imposed on others are astronomical—and would, given Boyle’s argument, probably be enough to tip the balance in favor of non-treatment. However, the reason behind it would not be the one that Panicola suggests—it is not that treatment of the patient provides no benefit to them, but rather than that treatment’s burden to others is so large that it overrides what little benefit it does give the patient with radically impaired consciousness. But this is precisely the argument of the social quality of life model. Now, in fairness to Panicola, it might be the case that Paris believes that such treatment does not benefit the patient and thus remain consistent. However, if Boyle is correct, the set of those with radically impaired consciousnesses—such that they cannot benefit from treatment—is very small indeed.

Wrongful Discrimination Against the Disabled?

Arguments against the Social Quality of Life Model might take a different track from the ones considered above. One might claim, for instance, that taking into account social factors when deciding whether or not to treat imperiled newborns is de facto wrongful discrimination. Someone who has made this argument quite forcefully is John
Arras. In his *Toward an Ethics of Ambiguity*\(^{133}\) he freely admits that there may be ‘non-medical’ problems which seem attractive, at first glance, to take into consideration when making treatment decisions about newborns. For instance, parents may “face the dilemma of keeping their child at home, where the demands of caring for her disabilities are likely to drain their economic and emotional resources, or handing her over to an institution that is likely to be underfinanced and understaffed.” (Arras, 27) However, despite the fact that “socially induced burdens can join forces with strictly physical disabilities,” Arras claims that nevertheless “we must base our treatment decisions solely on the extent of medical disabilities. To take social factors into account is to act unjustly toward the child.” (Arras, 28) He puts the point more bluntly, “To say that the wealthy child should live (because her anomalies are not so severe as to make life too burdensome) but that the poor child with similar prognosis should die (because of further burdens imposed by her poverty) is to indulge in the rankest kind of discrimination.” (Arras, 28) Indeed, we should avoid “morally dubious justifications based on the well-being of other interested parties, such as parents, siblings, or even of society at large.” (Arras, 26)

J.H.M. Dorscheidt, a Dutch legal scholar, wrote a dissertation\(^{134}\) in which he explored the connection between the Dutch policy of deliberate termination of the lives of certain imperiled newborns and international law prohibiting discrimination against the disabled—and, specifically, discrimination against children with regard to medical care.


\(^{134}\) J. H. M. Dorscheidt, "Levensbeëindiging Bij Gehandicapte Pasgeboren: Strijdig Met Het Non-Discriminatiebeginsel?" Sdu Uitevers.)
Dorscheidt argues that the Dutch policy is, in fact, in violation of both explicit and implicit international law—citing documents like the UN Children’s Rights Convention and the UN Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. The UN Convention on the Rights of Persons with Disabilities\textsuperscript{135} claims, “‘Discrimination on the basis of Disability’ means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” (Article 2) Later, when speaking specifically of “children with disabilities, the best interests of the child shall be a primary consideration.” (Article 8, Section 1) With regard to health, the Convention claims that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability,” and that persons with disabilities should have “the same range, quality and standard of free or affordable health care and programmes as provided to other persons.” (Article 25, Section a) The UN Children’s Rights Convention\textsuperscript{136} also weighs in on this issue, claiming that “a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community” and that States “shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which


application is made as which is appropriate to the child’s condition and to the
circumstances of the parents or others caring for the child.” (Article 23, Sections 1 and 2)
However, if one wishes to convincingly argue that ‘taking into account social factors
when deciding whether or not to treat an imperiled newborn’ is wrongful discrimination
against the disabled demands further clarification; specifically, two concepts need to be
better defined: ‘disability’ and ‘discrimination.’

What does ‘disability’ mean in this context? A disability is any medical or
psychological malady which *substantially limits one or more of the major life activities of
such individual.* 137 Does a supporter of the Social Quality of Life Model necessarily
discriminate on the basis of disability? The answer appears to be ‘no.’ The model is not
concerned with disability in this sense, but rather with how social factors—like financial
(and other) costs to the family and broader community—should be considered in the
determination of whether a treatment is burdensome or beneficial. It surely is the case
that it is often someone with a disability that will have the costs and burdens factored-in
such that social factors will be strong considerations. Indeed, the subjects of each of our
four case studies from chapter one certainly would appear to fall into this category.
However, one could certainly think of a case in which the Social Quality of Life Model
would take social factors into consideration in which the patient was *not* disabled in the
narrow sense. Consider, for instance, someone with significant heart disease such that if
they do not have bypass surgery and take expensive medicines they will likely have a

137 This is the definition of the U.S. Equal Employment Opportunity Commission. United States
disability more broadly as ‘any medical or psychological malady’ at all. But this would seem to violate the
common sense meaning of the term which is generally connected to a malady which impairs one of more
life activities of an individual.
massive heart attack and die. However, until that time his life will be basically normal and he will be able to engage in all the life activities that he wishes. One could certainly argue, using the Social Quality of Life Model, that the social factors surrounding the burden to his family and community should be considered in determining whether or not he should get this treatment—without wrongfully discriminating against a disabled person. If this sense of disability is correct, then the claim that invocation of social factors is ‘the rankest kind of discrimination’ against the disabled is simply false. Indeed, this is why the subject of the dissertation is ‘imperiled’ newborns rather than ‘disabled’ newborns. It is a meaningful and important distinction to make.

But let us suppose that a more broad sense of disability is the correct one. Though it certainly strains common sense to think of disability as any physical or mental malady, without reference to it affecting a life-activity, let us suppose for the sake of argument that all those who are subjects of non-treatment under the Social Quality of Life Model are, in fact, disabled. Does it follow that the social quality of life model is wrongfully discriminating against the disabled? Though this move would put Arras, Dorscheidt and company on stronger ground, the answer is still ‘no.’ The key here is to define precisely what one means by ‘discrimination.’ In a later article, Arras is quite concerned with defining this idea and suggests that, rising from ashes of the political

---

138 Or perhaps one need not think of present disability as the only relevant kind. Perhaps someone who is facing a future death from a heart attack is ‘disabled’ in the sense that he may be dead before he is able to engage in the kind of activities he wants to: witnessing his children’s weddings, grandchildren’s baptisms, etc.

fight over ‘Baby Doe’,\textsuperscript{140} were three possible definitions of ‘discrimination’ in this context:

1. Discrimination is failure to provide customary care. Or the appropriate ‘standard of care’ for newborn infants.
2. Discrimination is failure to provide care to a disabled child that would have been provided to an otherwise normal child.
3. Discrimination is denying medical benefits to a disabled child solely on the basis of the infant’s present or anticipated disability.

The first definition cannot be the correct one because the reason why there is controversy about this topic is that there is no ‘customary’ care or ‘standard of care’ that exists with regard to the controversial cases in question. Or, perhaps better, simply invoking ‘standard of care’ with regard to controversial cases in the grey area has the practical effect of begging the question. If there was agreement about the standard in these cases, we would not be debating this issue at all. (Arras, 24)

The second definition is more convincing—and would seem to work in many cases. It certainly works for the case of Baby Doe in which the infant has a problem with her esophagus and Down Syndrome—and life-saving treatment is rejected for this child, but would not have been if the Down was not present. This does seem by almost everyone to be wrongful discrimination on the basis of disability. However, in this case the disability and the medical problem requiring treatment (blockage of the esophagus) are separable in way that makes this judgment work. It is not always the case. Consider an infant born with a meningomyelocele (failing of the neural tube to develop during fetal

\textsuperscript{140} Arras is primarily concerned in this section of the article in critiquing the senses in which the US Department of Health and Human Services defined ‘disability’ in order to respond to the ‘Baby Doe’ case and make sure disabled infants would not get ‘discriminatory’ medical treatment or non-treatment.
life causing part of the spine to be exposed) accompanied by hydrocephalus (an abnormal buildup of cerebral spinal fluid that, in this case, will likely cause mental retardation). Arras argues that it is meaningless to ask the question, “Apart from the child’s hydrocephalus and possible retardation, would we seal up the spinal column of an ‘otherwise normal’ baby?” He claims that while we may certainly wish to close the spine, we cannot exclude the accompanying difficulties from our consideration. If we choose to operate, we choose to do so based on the best interests of the child—and not because we would perform the operation on an ‘otherwise normal’ child. (Arras, 25)

Arras argues that the third definition, “rather than any well-thought-out moral theory of discrimination” is rather a “philosophical rejection of quality of life reasoning”—and this is evidence that the trappings of nondiscrimination and of civil rights law appear merely to have servered as convenient vehicles for advancing a narrow ‘sanctity of life’ agenda. (Arras, 26-27)

But, if none of these, then what is discrimination in our context? In a general sense, as Arras notes, discrimination is not immoral: it is simply to make distinctions between two or more things or persons. Wrongful discrimination is not merely making distinctions which result in unequal treatment. For, when “a distinction is based on a relevant trait, there is no discrimination; but when people are treated differently sole on the basis of irrelevant criteria, then we have genuine discrimination.” (Arras, 27) What kind of discrimination, then, is the Social Quality of Life Model using? It seems clear that, even if we assume the dubious broad definition of disability, the basis on which the model discriminates has nothing directly to do with disability at all. Rather, the Social Quality of Life Model discriminates on the basis of social cost to the family and
community. Such a model is non-committal about whether or not one could ever
discriminate on the basis of disability: its discrimination takes place with regard to the
treatment cost to a patient’s family and community, not whether or not a patient is
disabled or whether her individual quality of life make it ‘worth living.’ The Social
Quality of Life Model bypasses these questions altogether and does not discriminate on
the basis of disability. It does, of course, discriminate on the basis of a treatment’s
cost to a family or society—and it seems clear that Arras would consider this to be an
‘irrelevant’ basis for discrimination. However, he does not give an argument for this
point of view, and might do well to heed the clause inserted into the point made by the
UN Children’s Rights Convention which subjects our duties to treat disabled children: ‘to
the availability of resources.’ Much more will be said in support of this point in the
following chapters, but for now it suffices to say that the Social Quality of Life Model
does not discriminate wrongfully against the disabled.

The Social Quality of Life Model and ‘The Moral Foundations of Medicine’

Michael Panicola fires another volley at the Social Quality of Life Model by,
again, calling it out for basing treatment decisions on familial and social factors rather
than patient-centered factors. One should not rely on predictions about the cost of
treatment to a family or on the burdens imposed on society—rather, the main concern
should be the newborn’s good and this alone. This means that external factors should be

141 It is worth noting that even if the Social Quality of Life Model is not discrimination against the
disabled in the sense that disability is not the basis by which it discriminates, one might still argue that it is
de facto discrimination against the disabled because a majority of babies not treated have disabilities. This
move gets into complex questions about wrongful discrimination’s relationship to an act’s intention verses
its consequences—but suffice to say here that difficult decisions must be made in a situation where needs
dramatically outstrip resources.
left out of the decision-making process. (Panicola, 162) If they enter explicitly into life-
sustaining treatment decisions for imperiled newborns, he argues (much like Paris) that
this “poses a serious threat to the moral foundations of medicine.” Panicola explains:

Traditionally, the patient-practitioner relationship has focused on the individual
patient in need with a tendency toward excluding external factors. While a fair
amount of latitude has been given to patients in assessing the burdens imposed on
others within this relationship, the main emphasis of the practitioner has always
been on the patient’s best interests. The social quality of life approach would
have practitioners refocus their sights to include the interests of affected others.
This would certainly undermine the sacred trust upon which the patient-
practitioner is founded. Consequently, patients and proxy decision-makers would
be left wondered whose good or interests the practitioner is promoting. (Panicola,
110)

There are at least two things to say in response to this argument. First, someone
could certainly support the Social Quality of Life Model such that social factors were
explicitly considered in treatment decisions of imperiled newborns on the level of
managed care within a particular healthcare financer—like Medicaid or a private
insurance company. This is, as we will see in chapter 4, what is happening already—and
it does not necessarily involve the explicit decision of a practitioner in a specific clinical
setting. Rather, social factors are considered at a prior level and take the form of rules
and regulations over which the practitioner has little or no control. Thus, the physician
would be able to make treatment decisions with the best interests of the patient in mind—
but within a set or rules and regulations that were sensitive to social factors with which
the physician had nothing to do. Second, we need to return to moral anthropology here.
If one accepts that a human person is essentially social, and has her highest good found in
her ability to engage in relationships, then the concept of distinguishing between a
physician having ‘her’ good or the good of ‘affected others’ in mind is a false one. If one
takes the broader Catholic understanding of relational anthropology seriously, there is no
such thing as good ‘for her’ in the individual abstract—without reference to the good of affected others. Indeed, for a physician to pretend otherwise is to engage in anthropological self-deception. One’s good is always connected to the good of affected others—at least if one is living in a community. And a physician is bound to accept this regardless of what the history of medicine has been. A physician should indeed focus on the ‘best interests’ of the individual patient in need—but those interests go far beyond medical indications of an individual person’s biological body. They include that person holistically considered—her spiritual and social realities are to be considered primary indicators when it comes to treatment decisions.

Edmund Pellegrino pushes Panicola’s argument still farther—and in ways which challenge the response given above.\(^{142}\) He claims that the modern age has brought with it tremendous confusion about the role and identity of medicine. He asks, “Is the physician still a helper, healer and caregiver? Or are physicians something else—gatekeepers, guardians of society’s resources and employees, ‘managed’ by gag rules and restrictive clauses, or entrepreneurs and co-investors in commerce of healthcare?” (Pellegrino, 55) Pellegrino suggests that there is something internal to medicine itself, something inherent in its nature as a particular human activity, which does not allow it to be set upon externally by some form of social construction—relative to the values of a culture. On the one hand we have the ‘essential’ ends of medicine—that which gives it an essential character. They grow out of the phenomenology of medicine: “the universal experience of illness.” (Pellegrino, 60) This experience transcends time, place, history and culture—

and identifies objective ends which are to be contrasted with ‘socially constructed’ goals that “open medicine to possible subversion by economics, politics, social ideology or government.” (Pellegrino, 60) Whenever “medicine is used for any purpose or goal—however defined—that distorts, frustrates, or impairs its capacity to achieve its proper ends, it loses its integrity as a craft and its moral status as a human activity…We have socially crucial reasons for maintaining the internally defined ends of medicine. Without ends, there is no source of criticism, no counter to the most malevolent uses of power of medical knowledge and skill by individuals, societies or governments.” (Pellegrino, 64)

But how do these considerations relate to an evaluation of the Social Quality of Life Model? Pellegrino admits that “physicians are members of the moral community” and as such have obligations “to advocate just distribution of physicians, healthcare resources, and facilities. A role of advocacy in distributive justice is a collective moral obligation of physicians.” (Pellegrino, 66) But these fall under the category of societal goals—and, as such, must be ‘second’ to the internal ends of medicine. When a physician is:

serving the end of medicine as medicine, the physician’s focus must be his covenant with his patient. The physician is then bound by a covenant of trust which must not be compromised by other roles of, for example, the physician as gatekeeper, entrepreneur, guardian of social resources, or by the economic pressures to undertreat…The welfare of the patient, jointly determined between physician and patient or patient’s morally valid surrogate must continue to be the end of medicine in the clinical encounter and first in the order of priorities for the physicians role. (Pellegrino, 65)

Though Pellegrino’s argument is intuitively convincing, it is weak on several fronts. The first weakness is one of internal consistency. Pellegrino is at pains to show the internal ends of medicine cannot be trumped by the mere goals of society. But why? There are ‘socially crucial’ reasons for keeping medicine’s internal ends unassailable—
this keeps those who would use the power of medicine for ‘malevolent’ purposes able to be critiqued. But how is one supposed to determine what a ‘malevolent’ purpose is without appealing to the kinds of social ‘goals’ that Pellegrino says are never more basic than the ends of medicine? Sure, the ends of medicine may speak of the covenant between the patient and physician—but this, by itself, is not enough to condemn the Nazi-like practices he invokes. For these the central issue was the moral status of certain human beings and whether or not they counted as patients in such a covenant. In order to condemn such medical practices, one is going to have to appeal to—at least as Pellegrino defines it—mere societal goals like, say, the moral status of human beings. But this is precisely what cannot be in the case if Pellegrino is correct. Supposedly contingent societal goals cannot be the reason for keeping medicine’s ends unassailable, for, if it were, then as these goals shift and change, so would the status of medicine’s ends.

The second weakness is that it has a difficult time dealing with a counter-example to the assertion that the internal ends of medicine are wrongfully distorted when a physician violates the supposed covenant between her and a patient by allowing economic considerations or distributive justice to be considered. What should one think, then, of the battlefield medic? Clearly, her role is to distribute her resources (time used to treat wounded soldiers) in a just way—and this sometimes means meeting, often face-to-face, with patients and then sometimes passing them by, realizing that even though they could be saved by spending significant resources, she could save more lives by moving on to someone else. Here is a clear example of, according to Pellegrino, a supposedly mere societal goal (distributive justice) trumping what is supposedly an internal end of medicine (the patient/physician covenant). Pellegrino, as we have seen, cannot abide
this—but it is unclear where his complaint would be lodged. The medic has done nothing wrong and, to the contrary, she would be *unjust* if she spent undue time on the first patient she met—based on some supposed physician/patient covenant—with the result that several others died who could have otherwise been saved. It is important to note that the battlefield medic can serve as a counter-example without arguing that any current clinical situation is analogous to that of a battlefield. Though chapter 3 will attempt to make the argument that such an analogy is indeed convincing in some important situations, all one needs here for a counter-example is *any* situation in which a physician acts correctly in factoring distributive justice concerns ahead of a supposed physician/patient covenant. Surely the battlefield medic counts as just such a physician—and a heroic one at that.

Third, Pellegrino wrongly considers matters of economic concern and distributive justice to be mere ‘goals’ of society (changeable and malleable) rather than just as fundamentally to, and a legitimate end of, medicine as treatment and care of patients. This builds on the original response given to both Ramsey and Panicola: that of relational anthropology. One’s social relations—and duty to exist in just relationship—are intrinsic aspects of the patient. Indeed, if there is a patient/physician covenant, then it is to the patient *holistically considered* to which a physician has a duty. The ends of medicine surely do include, at a primary level, treatment and care of patients—but built essentially into these ends must be the restriction that treatment and care is just to others that are affected by it; and this cannot be meaningfully considered without taking social factors into consideration.
Can Imperiled Newborns have Duties?

The last paragraph spoke of ‘a duty to exist in just relationship’ being an essential part of what it means to be a human being. But how can this be said of the imperiled newborn? It certainly appears that such non-volitional human beings have no moral duties at all—and thus perhaps duties connected to social relationships should not be considered when it comes to treatment of imperiled newborns. Such is the argument of Paul Ramsey in his article *The Enforcement of Morals: Nontherapeutic Research on Children*. Though the subject of the article is about proxy consent for experimentation on children, the key issue discussed is the same for the issue at hand: moral duties of non-volitional children. Ramsey notes that to impute consent (and, by extension, moral duties) on a child “is to treat a child as not a child…It is to treat him as if he were an adult person.” (Ramsey, 21) With regard to the Social Quality of Life Model, Ramsey would say that it is immoral to assume children have any social duties with regard to distributive justice because they “cannot themselves consent” to such duties and “ought not be presumed to consent.” (Ramsey, 21) The good of living in just relationship may be intrinsic to a volitional adult, but it is not a good for the imperiled newborn. As yet, the imperiled newborn “is not a moral agent, not a bearer of moral obligations, even presumptive ones.” (Ramsey, 25)

Richard McCormick responds to Ramsey in his *Experimentation in Children: Sharing in Sociality*. McCormick asks us to recall the reason why any parental consent

---


for medical treatment for their infant is valid: “precisely insofar as it is a reasonable presumption of the child’s wishes.” (McCormick, 42) He then argues that behind the finding that child ‘would wish’ something is the conviction that the child *ought* to wish it. There are “things that the child *ought* [emphasis in the original], simply as a human being, to choose.” (McCormick, 42) He grants Ramsey’s point that infants have no actual moral obligations, “but the language of *ought* [emphasis in the original] need not imply actual obligations.” (McCormick, 42) Indeed he says [all emphasis in the original]:

If we can say of adults (who can and do have obligations) that it is reasonable to expect that they will want certain goods for others and contribute to these goods if there is discernible risk, discomfort, or inconvenience, it is not precisely because they are adults that we conclude this, but because *they are social human beings*. Being adults we assume that they will understand, acknowledge, and respond to the claims rooted in their sociality, their social nature. And we call the experience of such claims an *ought*. But the claims themselves are rooted in the sociality of our being. They are not primarily rooted in the adult’s capacity or willingness to respond to them as an adult…but in the social nature of human beings. Now this sociality is shared quite as much by infants as by adults. *Ought* language is but an attempt to highlight this. That is, in using such language the focus is sociality, not age. The good of infants is inseparably interlocked and interrelated to the good of others; for they are human beings. Clearly, they cannot experience this or respond to its implications as claims. But we may for them—to the extent that it is reasonable to do so, a reasonableness founded on their common share in our human nature. (McCormick, 42)

McCormick suggests that the root of their disagreement may come from (once again) their differences over theological anthropology—and claims that Ramsey has a ‘narrowly individualistic notion of human nature.’ Certain kinds of moral duties, those at hand being living in just relationship, are not predicated on individualistic ideas about volitionality or consent. Rather, they are predicated on the nature of human beings as intrinsically social and are binding regardless of whether consent is offered or not—or capable of being offered or not.
Ramsey responds to McCormick\textsuperscript{145} somewhat begrudgingly—and with some amazement that McCormick offers the argument he does: “The charge is that I ‘hold a narrowly individualistic notion of human nature’ and believe an incompetent patient to be ‘an unrelated reality.’ ‘Isolationism’ is the verdict. If an ‘individualist’ is one who believes a child is not born with sociality in exercise, then I am one.” (Ramsey, 40) But even here Ramsey misses the point. Sociality is not something that is ‘exercised’—rather, it is something that is an essential part of the nature of all human beings.\textsuperscript{146} We are participating in it regardless of whether or not we are aware of it or choosing it, or capable of being aware of it or choosing it. It is a strange thing for Ramsey to argue against, because at times he appears to be making exactly this kind of argument. In his extended thinking about ‘covenant’ between God and humanity—and between human being—he claims that human beings exist in covenant from the beginning:

A man is never without his fellow man in any such fashion, nor does he reach his neighbor only by choice or contract from which he can as easily withdraw. Instead, because his creatureliness is from the beginning in the form of fellow humanity and because the creation in him is in order to covenant, and because this means he has real being only by with and for fellow man, we have to reckon with this in everything that is said about justice and about the rights of man.\textsuperscript{147}

It appears that he and McCormick are not that far apart after all.

Like the ‘medical indications’ discussion which began this chapter, the key point here is one of theological and moral anthropology. If one is convinced of the intrinsically


\textsuperscript{146} One might wonder how this is possible if we are to take seriously the idea that human infants are persons simply in light of the fact that that are human organisms. But recall the argument from the first chapter: it is not simply being a human organism that carries the moral weight—rather, it is the natural potential of that organism for certain morally relevant capacities: like relationality.

\textsuperscript{147} Werpehowski, William and Stephen D. Crocco, The Essential Paul Ramsey, 115.
relational anthropology, and therefore the intrinsically social nature of human beings, then the arguments like this against the Social Quality of Life Model fall flat.\textsuperscript{148}

A Post-Scrip\textit{t} on Relational Anthropology: A Necessary Ingredient in the Social Quality of Life Model?

Much of this chapter has attempted to show how important a relational anthropology is for responding to the charge that medicine needs to always be in the best interest of the individual patient. It is worth very briefly noting here at the end of the chapter that one need not accept a relational anthropology to, at least in principle, accept the Social Quality of Life Model. For a relational anthropology becomes important in the context of avoiding the charges of undermining individual human dignity or the covenant between physician and patient. If one wants to keep the sole focus on the physician and healthcare system on the individual, and still accept the Social Quality of Life Model, then relational anthropology becomes indispensable. But one could certainly persuasively argue, as James McCartney does, that not all limitations and restrictions of care must needs be based in the infant’s “questionable ability to benefit [broadly conceived] from this treatment, but on the sheer fact that it may cost too much, may involve personnel who are needed elsewhere, [and] may utilize resources that could more readily save many more lives…While I agree that we ought to do all we can to mitigate these factors, when they

\textsuperscript{148} It is worth noting again at this point that this chapter makes no argument about how, precisely, social factors are to be taken into consideration either theoretically (as primary or secondary factors) or practically. These are questions to be answered in chapters 3 and 4.
are irrevocably present I hold that they would provide adequate justification for the foregoing or discontinuance of treatment.”

\[149\]

---

CHAPTER THREE

THE ‘WEAK’ SOCIAL QUALITY OF LIFE MODEL

This concern with family and society is important not so much with a view to its effect on them, but insofar as it reflexively creates a burden on the infant as well.

Richard Sparks

Introduction

To this point in our discussion of the Social Quality of Life Model, we have looked at two kinds of approaches. The first was to accept the model in its ‘strong’ version—that is, a version which claims that social factors should have a primary, rather than secondary, importance when making treatment decisions regarding imperiled newborns. However, that approach was shown to have been founded on a faulty moral anthropology. Even the most imperiled newborn is a person, and because this approach relied on the premise that such newborns are not persons it was found to be unconvincing. The second approach was to attempt to show that, because even the most imperiled newborn is a person, the social quality of life model—in whatever form—violates human dignity in a theoretically and/or practically unacceptable way. However, this approach was also founded on a faulty moral anthropology. Because the concept of human dignity does not and cannot exist apart from social relationship, and therefore
social duty, social factors must play some kind of role in deciding whether or not to treat an imperiled newborn. What we have not explored to this point is just how much weight should be given to social factors and on whom the social factors should focus. This chapter explores a ‘weak’ version of the Social Quality of Life Model—an approach which, while accepting the necessary place social factors play in treatment decisions, sees them as secondary rather than primary considerations and/or factors which apply only to the narrowly considered best interests of the newborn and not to the broader ground of the interests affected others. Arguments to this effect from Raymond Duff and A.G. M. Campbell, Paul Johnson, Anthony Shaw and Richard Sparks will be considered.

In response to this approach, the central argument of the dissertation will be brought to bear—critiquing the ‘weak’ version of the Social Quality of Life Model in light of Catholic Social Teaching. A central flaw will again be found in the moral anthropology of the approach in that it underestimates just how connected human dignity is tied to social considerations—something which cannot be argued for more strongly in the Catholic Social Tradition. They are not essential but merely secondary considerations, but rather essential and primary considerations. In addition, the approach underestimates just how overwhelming the social factors at stake actually are: not just with regard to NICU care, but follow-up care and special education as well. This affects not only the families directly involved, but the resources available for other departments in clinics and hospitals, those under Medicaid and private insurance, and, to a large extent, our national healthcare system. The argument that this is analogous to a ‘triage’ situation—which, by definition, includes social factors with regard to distribution of resources (time, money, etc.) as primary considerations—will be evaluated with
particular reference to Medicaid. Though the chapter’s last section will examine several
good reasons to be skeptical of the triage analogy, it will conclude that, with so much at
stake, the idea that social factors are of secondary, rather than primary, importance in
treatment decisions of imperiled newborns is untenable.

Raymond Duff and A.G.M. Campbell

Duff and Campbell have written several articles (both jointly and individually)
from the ‘weak’ social quality of life perspective. They claim when making treatment
decisions with regard to an imperiled newborns’ best interests the relevant facts and
circumstances that one should consider are the infant’s “future health, development, and
well-being, and the human costs that are likely to accrue with survival.”150 The concept
of ‘human costs’ is, however, rather vague and requires further definition. Duff and
Campbell claim that the “rights of patients to live or die and the rights of family members
and others in the present and future generations must be considered.”151 A choice for
treatment might be “bad” if “the parents have little or no capacity to care for their child;
where the family does not want to be forced to do what they believe should not be done
and where resources to help the child or the family are limited or absent.”152 Though
they are very open about the explicit and direct role that social factors should play, it is

150 A. G. M. Campbell, "Quality of Life as a Decision-Making Criterion I" in Ethics in
Perinatology, ed. Amnon Goldworth, William Silverman, David K. Stevenson, Ernle W. D. Young, and


152 A. G. M. Campbell and R. S. Duff, "Authors’ Response to Richard Sherlock's Commentary,"
Journal of Medical Ethics: The Journal of the Institute of Medical Ethics 5 (S, 1979), 141.
clear they intend to argue that they should be taken into consideration only when it serves the child’s narrowly conceived interests:

Since one cannot prudently ignore the family’s limitations and interests even if considering only the child’s interests, responsible decision makers cannot avoid the ‘tragic choices,’ that is, at times knowingly sacrificing, perhaps unfairly, one person’s good or life in order to protect another’s. With a sense of balance, irony, and tragedy it is understandable, right, and common that the family’s interests are sacrificed to the benefit of the child. With a similar sense, the converse may be true particularly when the child may benefit little even though the family sacrifices much.\textsuperscript{153}

Though social factors are to be considered, it is still the individualistically narrow interests of the infant that are to take precedence—for it is really only when a child cannot directly benefit ‘much’ from a treatment that social factors can trump. Indeed, the only time a parent’s decision for or against treatment can be overridden is when they, “select a course which goes too far toward sacrificing their child’s interests and seeking their own.” (Duff, 28)

\textbf{Anthony Shaw}

Physician Anthony Shaw’s ‘weak’ version of the Social Quality of Life Model comes directly out of his experience as a physician working with imperiled newborns. He says that for years he simply accepted that treatment decisions should be focused on the newborn’s ‘mental and physical capacity,’ but eventually came to the conclusion that if more factors are not considered then something important has been neglected. Indeed, one must consider, “aptitudes, motivation, skills and pleasure, physical and intellectual, which the individual acquires as a result of efforts made on his behalf by his \textit{family} and

\begin{flushright}
\end{flushright}
by society [emphasis in the original].”154 Shaw attempts to give a simple mathematical formula to illustrate how this might be done. (Shaw, 11) Shaw asks us to let

\[ QL = \text{Quality of Life} \]

\[ NE = \text{Infant’s Natural Endowment (physical and mental)} \]

\[ H = \text{support from the infant’s home/family} \]

\[ S = \text{support from society.} \]

He says that his old view—and the view (like Ramsey’s medical indications model) of those who reject even the weak version of the Social Quality of Life Model—is

\[ QL = NE. \]

However, the formula should look like this:

\[ QL = NE(H+S) \]

Considering only the objective natural endowment of the infant misses the fact that such a natural endowment exists, not in a theoretical vacuum, but in a social situation which directly affects quality of life. Even if the natural endowment is well above zero, the quality of life depends, in large measure, on what social resources are available to support an imperiled newborn—enhanced in certain situations where the family or society provides support, and diminished if they do not. Notice that in the case where there is zero social support the objective natural endowment is meaningless and therefore \( QL = 0. \) If this formula is correct, it is a good indicator that the concept of QL in any non-social sense is a misguided one.

Shaw, like Campbell and Duff, makes it clear that what is at stake when considering social factors are the individualistically narrow interests of the newborn—

which should be separated from consideration of the newborn’s impact on the family and society. When applying his formula to a newborn with Down Syndrome, he is at pains to show that the social factors he considers (including the extent to which the parents have the emotional and financial resources to give all the care that is necessary) “all influence the quality of life of the baby [emphasis in the original].” (Shaw, 11) Indeed he makes it clear again and again that proper application of the formula, “excludes potential contributions to or detractions from society and family when considering any individual’s potential quality of life.” (Shaw, 11)

Paul Johnson

Paul Johnson is largely in support of the formula offered by Shaw—and builds directly upon it. He says that we are dealing with a medical culture with a ‘bias toward life.’ And Christians, particularly those who are convinced by the tradition of the ordinary/extraordinary distinction, should be careful about such bias—especially “given the lack of accessibility to sufficient assistance to all families and given the competition for scarce monetary and manpower resources in society.” A bias like this is not necessarily bad, but “such a commitment to life logically should entail commitment to provision of means to support and enhance life.” (Johnson, 496) It is not fair to choose life for a newborn, “and not choose to allocate the resources to make that life livable.” (Johnson, 499) Families who care for these children need the assistance of such services as special education, physical therapies, and family counseling. Financial relief and

---

respite care may be necessary. Institutions for raising such children need to be fully funded and staffed so as to be genuinely compassionate rather than simply give custodial care. Given the enormous costs associated with such a commitment, “Severe strain and dislocation can be brought on families. And minimal provision of resources may not be sufficient to assure extensive and adequate care.” (Johnson, 497) While Johnson admits that ethical and or medical decisions ought not simply reflect often unjust social structures, “neither ought they be made without any reference to them. Recognizing that financial and personnel resources are not inexhaustible, allocation decisions will have to be made and consequences faced honestly.” (Johnson, 499)

Johnson offers us the same warning the previous authors have given above. When considering social factors, “The further one proceeds from the immediate burden placed on the infant…the more caution is called for.” (Johnson, 497) If one starts with the personhood of the infant (as all authors outside of chapter one do), then “Respect for the person should lead to criteria established with the best interest of the infant, not society, in mind.”

Rather than doing a utilitarian calculus, we must give “specific concern primarily to the best interests of the infant.” (Johnson, 103) Johnson acknowledges that “costs have traditionally played some role in the determination of some means of life preservation as extraordinary and therefore elective,” while also arguing that “societal and parental resources are important to the degree that lack thereof affect the future well-being of the infant.” (Johnson, 98) Without this individualistically narrow focus on social factors as they impact the best interests of the infant, he maintains,

---

we are left “open to great abuse” (Johnson, 97) and also “might override the newborn’s right to life.” (Johnson, 103) Interestingly, because of “even currently available societal and family support resources,” Johnson believes that, “quality of life considerations in ordinary-extraordinary analysis is to be more restrictive than permissive of nontreatment.” (Johnson, 107)

With regard to the thinkers considered so far, we can formulate at least three principles common to all:

1. Human beings are indeed intrinsically social creatures.

2. That intrinsic sociality means that one cannot consider the best interests or quality of life of the newborn without considering social factors that impact on her best interests and dignity.

3. However, social factors can only impact treatment decisions based on how those factors impact the newborn’s best interests, considered from an individualistically narrow point of view.

This is certainly a logically consistent way of interpreting both the intrinsic sociality of the human person and the essential place social factors have in considering whether or not a treatment is ordinary or extraordinary—both essential characteristics of the Social Quality of Life Model. However, though the mistake of the above thinkers is not as fundamental as that of the thinkers considered in chapter two, it is cut out of the same cloth. It is a mistake of moral anthropology. We have already seen Richard McCormick’s specific argument for the fundamental sociality of the human person in the context of arguing for the social duties of newborns. But to this point we have only hinted at how this teaching is argued for and developed within Catholic Social Teaching. It is to this topic we now turn in some detail.
Catholic Social Teaching on the Fundamental Sociality of the Human Person

Catholic Social Teaching’s starting point is nicely summarized thusly:

The right to the common use of goods is ‘the first principle of the whole ethical and social order’ and ‘the characteristic principle of Christian social doctrine’…it is innate in individual persons, in every person, and has priority [emphasis in the original] with regard to any human intervention concerning good, to any legal system concerning the same, to any economic or social system or method: ‘All other rights, whatever they are, including property rights and the right of free trade must be subordinated to this norm [the universal destination of goods]; they must not hinder it, but rather expedite its application.’

Todd Whitmore has spent considerable time studying the social encyclicals of the Popes who have contributed to the Church’s social doctrine. In his writings Whitmore has argued that one should start with the common good in Catholic Social Teaching because “of the repeated claim that human beings are fundamentally social.” (Whitmore, 5) The claim that human beings are somehow individually autonomous is a fiction—for “a supportive set of interrelationships is a precondition for human life and concomitant with it.” (Whitmore, 6) This is the point of Pope Leo XIII when he says that man “cannot, if dwelling apart, provide himself with the necessary requirements of life, nor procure the means of developing mental and moral faculties. Hence it is divinely ordained that he should live his life—be it family, or civil—with his fellow man.”

Two generations later, Pope Pius XI confirms both the claim and its theological underpinning. Human persons are, “endowed with a social nature.” Indeed, “God has destined” them for civil

---

157 Pontificium Consilium de Iustitia et Pace, *Compendium of the Social Doctrine of the Church* (Dublin: Veritas, 2005), 82.

158 His chapter ‘Catholic Social Teaching: Starting with the Common Good’ appears in Kathleen Maas Weigert and Alexia K. Kelley, *Living the Catholic Social Tradition: Cases and Commentary* (Lanham, Md.: Rowman & Littlefield Publishers, 2005) and makes many of the following arguments, but I will be using the following unpublished paper which makes the arguments in more detail: Todd David Whitmore, “Catholic Social Teaching: A Synthesis.”

This was true from the first groups of human persons onward, but it has perhaps never been more dramatically true than in the modern globalized world. For “the interdependence of national economies has grown deeper, one becoming progressively more related to the other so that they become, as it were, integral parts of one world economy.” (Whitmore, 7) This was one of the Vatican Council II’s main themes—one of the ‘signs of the times’ being that “a man’s ties with his fellows are constantly being multiplied.” Pope John Paul II would later claim that “the church’s social doctrine focuses especially on man as he is involved in a complex network of social relationships within modern societies.”

In addition to being empirically true, the above claims have a theological underpinning that has been developed far beyond a simplistic claim that ‘God has made it this way.’ Human dignity, even when mistakenly considered in an autonomous fashion, is often tied to the theological claim that human persons are made ‘in the image of God.’ However, “the social documents stress that the imago Dei (“image of God”) doctrine is precisely about imagine of the triune—that is, interrelational, God [emphasis in the original].” (Whitmore, 7) Relationality is an essential aspect of the divine nature—and, insofar as human persons share in this nature, an essential aspect of our nature as well. John Paul II says persons in society are in “the living image of God the Father, redeemed


by the blood of Jesus Christ and placed under permanent action of the Holy Spirit…This supreme model of unity, which is a reflection of the intimate life of God, one God in three Persons, is what Christians mean by the word communion [emphasis in the original].”

Whitmore notes that Vatican Council II reminded us that Jesus prayed to the Father ‘that all may be one…as we are one’ (John 17:21-22) and this implies a certain similarity between the union of the divine persons and the union of human persons. It reveals that man cannot fully find himself except through a sincere gift of himself. (Gaudium et Spes, 24) It means that, as Whitmore puts it, “there is no human dignity apart from the dignity we all have in relation to each other.” (Whitmore, 8)

Whitmore then goes on to argue that this concept of what one might call the ‘social dignity of the human person’ implies a moral and sometimes legal obligation of mutual assistance. As John Paul II reminds us, our fundamental sociality means a duty to the common good which in turn means that, “all really are responsible for all.” (Solicitudo rei socialis, 38) Though Catholic Social Teaching defines the common good variously, one particularly good definition was offered at Vatican Council II. It is “the sum of those conditions of social life which allows social groups and their individual members relatively thorough and ready access to the own fulfillment.” (Gaudium et spes, 25) One primary way that Catholic Social Teaching, and especially when offered by John Paul II, attempts to articulate just how human persons are to live in accord with the common good is by invoking ‘solidarity.’ John Paul II says that solidarity:

is above all a question of interdependence, sensed as a system determining relationships in the contemporary world, in its economic, cultural, political, and

religious elements, and accepted as a moral category. When interdependence becomes recognized in this way, the correlative response as a moral and social attitude, as a ‘virtue,’ is solidarity. This then is not a feeling of vague compassion or shallow distress at the misfortunes of so many peoples, both near and far. On the contrary, it is a firm and persevering determination to commit oneself to the common good. [*Solicitudo rei socialis*, 38]

Solidarity can surely be a benefit for members of the community of human persons, but it also “imposes a duty”¹⁶⁴ on human persons as well. This duty needs to be particularly aware of a “vast and unfair distinction in the distribution of goods” which cannot be “in harmony with the designs of an all-wise creator.” (*Quadragesimo Anno*, 64-65) Distributive injustice is also a major concern for the social teaching of Paul VI and John XXIII who warn us respectively that “imbalance is on the increase” (*Populorum Progressio*, 8) and that when “the wealth and conspicuous consumption of a few stand out” human rights are ineffective and “the fulfillment of duties is compromised.”¹⁶⁵ This kind of inequality denies persons the ability to participate fully, and sometimes at all, in the institutions that constitute the communities of human persons.

In response to this inequality, one’s duty is not simply to treat everyone ‘equally.’ Indeed, under Catholic Social Teaching “equality is not an end in itself, but has value only insofar as it enables groups and person to participate in the life of the community.” (Whitmore, 32) Paul VI says that rather that aim at non-contextualized equality, “the more fortunate should renounce some of their rights so as to place their goods more generously at the service of others.”¹⁶⁶ A duty to what Whitmore calls “solidarity-informed egalitarianism” (Whitmore, 33) means that there exists a “serious obligation

---


which binds each and everyone to lend mutual assistance to others” in their efforts to participate in society. (*Pacem in Terris*, 87)

In fulfilling such a duty, “it is not enough to draw on the surplus goods” (*Centesimus Annus*, 35) when lending assistance to others. Indeed, Catholic Social Teaching claims that one’s ownership of private property, while certainly a right, might need to be given up in light of the ‘universal destination of goods’—the idea that all property is to be used ultimately in service of the common good of all. Indeed, one’s private property is “under ‘social mortgage,’ which means that it has an intrinsically social function, based upon and justified precisely by the principle of the universal destination of goods” (*Solicitudo Rei Socialis*, 42) Whitmore nicely summarizes still more examples:

Leo states, “Man should not consider his outward possessions his own, but as common to all,” and goes on to insist that “it is one thing to have a right to a possession of money, and another to have a right to use money as one pleases.” Pius XI continues this line of thinking, and the Second Vatican Council cites Thomas Aquinas to take it even further. If the “universal destination of created goods” means that material goods at the level of basic need are indeed rights, then what appears to be theft from the rich by the destitute is actually legitimate. “If a person is in extreme necessity, he has the right to take from the riches of others what he himself needs.” Paul VI clarifies this point by quoting the early church father, Ambrose, who insists that such actions are not theft because the goods were properly the poor person’s in the first place. Therefore, when the well-off give to the poor, Paul VI tells the former, “You are not making a gift of your possessions to the poor person. You are handing over to him what is his. For what has been given in common for the use of all, you have arrogated to yourself.” Put another way, “you” are the thief.167 (Whitmore, 45)

Whitmore concludes that there are limits on how much of one’s income and wealth one uses for one’s own living—the rest belongs to the common good. If one has

---

earned wealth one has done so partly due to one’s own initiative and work, but it is also due to a globalized society which has created the conditions for the possibility of such work and has needs which rightly generate strict duties for us to fulfill. Indeed, one has a right to one’s wealth insofar as one has needs which are part of the common good—but one does not have a right to use one’s wealth in a way that violates, or is disproportionate with, to the common good.

But what is the relative status of this duty of which Catholic Social Teaching speaks? Perhaps, though real, it a secondary duty or something that could be easily trumped by other more primary duties? Hardly. Pius XI speaks of this duty as a “grave precept” that goes back to the Church Fathers. (*Quadrageimo Anno*, 50) The World Synod of Bishops declared this duty to be one of “absolute justice.” One of the most striking examples of the gravity of this duty comes from Vatican Council II’s positive citation of the Church Father Gratian who has the following to say about an instance of neglect of this duty, “Feed the dying man of hunger, because if you do not feed him you have killed [emphasis added] him.” (*Gaudium et Spes*, 69) Though Catholic moral theology is sometimes known for making a strong distinction between the gravity of active and passive actions that result in death, this does not appear to be the case where one’s social duty is concerned. Indeed, to call the neglect of it ‘killing’ means it is about as serious as a duty gets.

Recall, then, the third principle espoused by the ‘weak’ Social Quality of Life Model authors:

---

However, social factors can only impact treatment decisions based on how those factors impact the newborn’s best interests, considered from an individualistically narrow point of view.

Can this point of view be sustained in light of what has just been presented? It seems not; for it is not only an empirical fact that human persons are fundamentally and intrinsically social, but this is backed up theologically by the triune, relational image of God that exists in each person. This sociality is so fundamental that one cannot speak of the ‘dignity’ or ‘best interests’ or ‘quality of life’ of a human person except with reference to some kinds of social considerations. But these considerations must not ultimately be forced back to a individualistically narrow moral anthropology—as the authors above try to do. The fundamental sociality of human persons ‘imposes a social duty’ on us as well—a duty to the common good with particular reference to ‘vast and unfair distinction in the distribution of goods.’ Such a duty requires us to limit the use of our financial and other resources such that it is proportionate with the common good. And if we fail in such a duty it is of the utmost seriousness—on a par with taking human life.

**Worries About the Common Good and the Universal Destination of Goods**

One may certainly have legitimate worries about this starting point and emphasis. Indeed, if we start with the common good and universal destination of goods don’t we run the probable risk of subsuming the inherent and irreducible dignity of the human

---

169 Catholic Social Teaching seems more comfortable using ‘human flourishing’ or ‘human goods’ in this context, but more often than not the dissertation will use human interests instead. As mentioned previously, what is in a person’s interest (especially if we take into account the moral anthropology of CST) is going to be something much broader than what one merely prefers—and thus this concept gets at the thick account of flourishing/goods that CST is after. It also has the added advantage of being the term used by several of the proposed interlocutors of this dissertation and thus contributes to the possibility of conservation with them.
person into a social calculus of what is best for the greatest number—say, what will cause the most human flourishing? Although most ethical systems will have questions to answer on where they fall on this scale and why, Catholic Social Teaching’s emphasis on the common good is always disciplined by other moral principles—including that certain acts cannot be ordered to God or the common good because they directly act against an intrinsic good. One cannot for any reason intend to kill an innocent person, for instance, because that acts directly against the intrinsic good of an individual human life. This is different, of course, from justly allocating resources in such a way where one will foresee, but not intend, that human lives will be lost. In the former case, the Church teaches, the object of one’s act is directed against human life, but in the later case the object of one’s act is just distribution of resources.

Another worry might involve the relationship between the private and public spheres in Catholic Social Teaching—especially with regard to safeguarding realm of freedom with regard to one’s private property and one’s social duties. The Church teaches that, “Private property and other forms of private ownership of goods ‘assure a person a highly necessary sphere for the exercise of his personal and family autonomy and ought to be considered as an extension of human freedom.” (Pontifical Council, 84) Indeed, “Private property is an essential [emphasis added] element of an authentically social and democratic economic policy, and it is the guarantee of a correct social order.” (Pontifical Council, 84) If this level of personal freedom with how an individual and family decides to use its resources is ‘highly necessary’ and even ‘essential’ then can Whitmore and this dissertation make the strong claims about the duties present in starting with the common good and the universal destination of goods? The answer is yes:
Christian tradition has never recognized the right to private property as absolute and untouchable. On the contrary, it has always understood this right within the broader context of the right common to all to use the goods of the whole of creation: the right to private property is subordinated to the right to common use, to the fact that goods are meant for everyone. Private Property, in fact, regardless of the concrete form the regulations and juridical norms relative to it, is in its essence only an instrument for respecting the principle of the universal destination of good; in the final analysis, therefore, it is not an end but a means [emphasis in the original]. (Pontifical Council, 84)

Though there is an important right to freedom with regard to one’s private resources, it is only an instrumental right for a more fundamental right: proportionate access to resources available for, and belonging to, the common good.

But the invocation of Veritatis Splendor might awaken us to yet another worry with regard to this kind of emphasis on the common good. Both this document and its predecessor Humanae Vitae seem to emphasize that we are not constrained to limit procreation for purposes of the common good—indeed, if we were to do so it would be upon pain of mortal sin. But with the dramatic effect that overpopulation can have on the common good, it looks problematic, at the very least, to balance the universal destination of goods with a prohibition on limiting procreation. However, this first blush reaction might be resolved by, again, an appeal to the distinction between actions which directly contradict the good of human life and which do not. Both Paul VI and John Paul II argue that artificial contraception, like direct killing, has an object which is directed against the good of human life and therefore cannot be properly ordered to God or the common good. This may or may not in fact be the case, but that is not the point of bringing this to bear on this issue—which is merely to show that the position is internally consistent. Indeed, Paul VI is acutely aware in Populorum Progressio that “the accelerated rate of population growth brings many added difficulties to the problems of development where
the size of the population grows more rapidly than the quantity of available resources to such a degree that things seem to have reached an impasse.” (37) Though he could not see a role for artificial contraception in promoting the common good, he was certainly clear in that measures “in conformity with the dictates of the moral law” (i.e. non-artificial contraception and abstinence) are a perfectly acceptable means for doing so. Though the state has a role play in helping manage population in conformity with the common good, in the final analysis:

it is for parents to take a thorough look at the matter and decide upon the number of their children. This is an obligation they take upon themselves, before their children already born, and before the community to which they belong—following the dictates of their own consciences informed by God's law authentically interpreted, and bolstered by their trust in Him. (37)

Richard Sparks: A Rejoinder

Sparks, as seen previously, has written an entire book explicitly dealing with the above issues: both in a survey of the literature and in forming his own argument. Because his argument is the most developed of the authors considered in the first part of this chapter, and also because his is the closest to the central argument of this dissertation, significantly more space will be given to its explication.

Sparks shares much with Catholic Social Teaching’s understanding of the human person. At several points throughout the book, he is at pains to advocate a ‘holistic concept’ of the human infant patient and of her best interests. He criticizes those who describe the infant’s best interests “too narrowly to the physical reality of a pumping, living human organism.” (Spark, 269) Those who operate under a Social Quality of Life

170 Sparks, To Treat Or Not to Treat : Bioethics and the Handicapped Newborn, 337.
model must widen the scope of a patient’s best interest to include psychological, spiritual and social factors. Indeed, to “isolate a newborn patient as if s/he is a monad wholly unrelated to family, society, and their incarnate limitations is to create an ahistorical, unreal setting for decision making.” (Sparks, 269)

Such a conclusion leads Sparks to be in sympathy with the central argument of this dissertation—at least on one level. He says, “Macro-allocation questions concerning budgetary priorities in light of the limits of global resources lead to valid ethical questions concerning whether any patient, generically-speaking, has a right to soak up an inordinate and unjust share of healthcare dollars, talent and energy. (Sparks, 269) This question, though ‘largely unexplored,’ is one which Sparks supports asking. However, it is one which “prescinds from and prefaces actual medical practice.” (Sparks 271) He claims a subtle but important distinction between socially-weighting the benefit/burden analysis (which, he admits, Catholic teaching on ordinary/extraordinary means supports) on the macro-allocation level of public policy and suggesting the same method for ‘bedside/cribside decision making.’ The former is perfectly legitimate and “may well be the best moral course” (Sparks, 272) for attempting to incorporate distributive justice into healthcare resources allocation decisions. However, once we enter the ‘intra-system’ arena of actual medical practice this kind of socially-weighted benefit/burden calculus “becomes a dangerous threat to the integrity, personhood, and rightful place that has always been reserved for the individual sick or handicapped patient in need.” (Sparks, 273) Sparks points out the Hippocratic Oath mentions that a physician comes to a house ‘for the benefit of the sick’—and no mention is made of the conflicting interests of the patient’s family. He also mentions that the ordinary/extraordinary distinction has
“ushered in the possibility of expanding the notion of the patient-person and of his/her best interests to include such social components as cost and burden to affected others, but always as subsidiary elements [emphasis added] of the patient’s interests, holistically considered, never as distinctive counter-claims.” (Sparks, 273) He is simply adamant that:

the EXCLUSIVE [emphasis in the original] focus in actual medical practice and related decision making has heretofore always been on the best interest(s), however broadly defined. To shift that focus toward a socially-weighted calculus in which the patient’s rightful interests are merely one component among a series of presumably equal counter-claims is to undervalue the primacy of the patient and to potentially discriminate against his/her rights and best interests. (Sparks, 273)

Like the previous authors in support of a ‘weak’ version of the Social Quality of Life Model, Sparks legitimizes attempts to incorporate social factors like familial stress and financial limits “from the patient’s perspective [emphasis in the original].” (Sparks, 274) Anything else opens the door to denigration of neonatal patients in the name of ‘pure social utility’—particularly because these patients are not competent to defend their own interests. If it were so, then the slippery slope will have been greased “toward bias against and abuse of those patients least able to assert their rights and needs in the decision making debate.” (Sparks, 274) In addition, he asserts that those who are all too quick to do a socially weighted calculus for newborns “tend to shun” the same reasoning for competent patients. (Sparks, 275) Because of this double-standard, changing the centuries-old tradition of medicine away from patient cure and care, and the denigration of the inherent personhood and inalienable rights of the disabled and non-competent patients, “one should reject” a socially-weighted calculus model “on the treatment/nontreatment decision-making level.” (Sparks, 276)
Sparks does develop a positive argument about how to proceed at this decision-making level. Provided that one takes respectful caution against too facile a reason, he says that “it seems fair to incorporate financial and emotional costs associated with one’s treatment, at least as a correlative factor [emphasis added] in computing net burden related to the patient’s own well-being.” (Sparks, 298-299) This, of course, is with the proviso that social factors are seen as they impact on the patient’s own objective and experiential best interests, not as factors stacked over and against the patient. The idea that in burdening one’s own family one could also be a burden to one’s self might ‘tip the scales’ in favor of nontreatment.

How would this work in a practical situation? Sparks asks us to consider a severely handicapped non-dying infant with almost no conscious relational potential. If the treatment of such a neonate would totally bankrupt one’s family and/or contribute to a parent’s probable mental breakdown and/or deprive a number of needy patients with far better prognoses of life-saving medical resources, “it is possible that the patient’s total [emphasis in the original] best interests—include psychological, social and spiritual well-being—might be better served by non-treatment.” (Sparks, 301) Such a high cost to one’s caretakers, or fellow NICU residents, may constitute too much burden for too little medical and experiential benefit. Sparks is clear that he is not advocating a socially-weighted calculus “in which the interests of a newborn with a reasonably good prognosis [emphasis added] can be over-ridden by social factors, but rather a patient-centered calculus, in which social factors may compound against an already negative prognosis.” (Sparks, 301)
Sparks, then, gives us two methodological maxims to use when one attempts to incorporate social factors into the treatment of imperiled newborns. First, we can openly adopt a socially-weighted, common-good-oriented calculus on the level of public policy. Based on precise determinations, certain kinds of treatments in certain kinds of situations will be *a priori* excluded as too costly, too futile or too inequitable based on limited resources. Second, all intra-system medical decisions for or against treatment must be centered on the patient’s best interest, (for the most part) narrowly conceived. We can stretch this concept “not only to include familial burden, but one’s social responsibilities,” but this is only acceptable for those without a good prognosis—that is, “given a severely [emphasis added] retarded, intractably pained, or permanently non-conscious infant.” (Sparks, 309) In such cases, “social burden acts as a corroborating, possibly balance-tipping factor in determining patient well-being, but never as a lone criterion placed over and against the total best interests of the non-competent handicapped newborn.” (Sparks, 324)

**Sparks: Critique**

Sparks, then, is largely on-board with the basic direction of the dissertation. He simply has a worry (shared by many previously considered authors, though in a less narrow context) that considering social factors in the benefit/burden calculation at the micro/clinical level has dangers (both theoretical and practical) which make it prohibitive. Recall that he admits Catholic teaching on ordinary and extraordinary means “ushered in the possibility of expanding the notion of the patient-person and of his/her best interests to include such social components as cost and burden to affected others, but
always as *subsidiary elements* [emphasis added] of the patient’s interests, holistically considered, never as distinctive counter-claims.” But this way of thinking about the patient’s interests could benefit from a critique offered in light of the moral anthropology offered by Catholic Social Teaching. The just claims that others in society have on us are not ‘counter’ to, or ‘distinctive’ from, what is in our best interest. In fact, there are no interests of our own that should not always and directly be evaluated in light of the claims of others. The idea that social components such as cost and burden to affected others are ‘subsidiary’ elements of a patient’s interest misses the central point of Catholic moral anthropology outlined above. If physicians have a duty to respect the ‘total best interests’ of their patients, they must do so in light of empirical and theological facts: and this is impossible to evaluate except in terms of one’s fundamental and intrinsic sociality—on the part of the physician and her patient, both of whom have social duties in play.  

Thus, the distinction that Sparks wishes to make between considering social factors as primary on the level of social policy and on the ‘bedside/cribside’ level is a false one. In both cases, policy makers and clinicians are obligated to do what is in the best interests of the newborn, not from an individualistically narrow point of view, but from a truly ‘total best interests’ point of view—which includes the just claims of others to our resources.  

Sparks does seem to accept, in part, the idea that ‘one’s social responsibilities’ could be part of one’s best interests. However, he allows for this to be considered only in situations where treatment is of the most seriously imperiled newborns. That is, situations in which treatment “may constitute too much burden for too little medical and

171 To this point I have spoken in generalities about such a duty and how it would play out in a NICU. The final chapter of this dissertation will deal with these practical and specific questions in some detail.
experiential benefit.” In such cases, social factors only compound ‘an already negative prognosis.’ But again, given the moral anthropology of Catholic Social Teaching, there is no reason to accept this narrow understanding. Indeed, *everyone* is enjoined to refrain from using resources in a way that is disproportionate with the common good. And if one takes seriously the idea that even the most imperiled newborns have the same moral status as an older or more healthy human person, then in limiting this duty to only the sickest newborns Sparks seems to undercut his own goals of avoiding bias against those patients least able to assert their rights and needs in the decision making debate. No, it does seem at least theoretically possible (again, we will get into the practical specifics in chapter four) that even less-seriously-imperiled infants (or, for that matter, *any* imperiled patient) may have a duty to refuse or withdraw treatment that is disproportionate with the common good.

Recall also Sparks’ worry about abuse and a slippery slope leading toward the denigration of the inherent personhood of the infant if, on the bedside or cribside level, we directly considered social factors as primary. He buttresses this claim by pointing out that we seldom force competent patients to adhere to duties of social responsibility when it comes to treatment decisions and this is evidence that, in even making the argument, his opponent is already treating the imperiled newborn as less than a full person. There are at least three things to say in response to this move that go beyond the response given in chapter two to a similar line of argument. First, one needs to reiterate the principle of Catholic Social Teaching that *everyone* is enjoined to refrain from using resources in a way that is disproportionate with the common good. Indeed, though it goes beyond the scope of this dissertation, it is certainly that case that other kinds of treatments designed
for competent adults (cosmetic surgery, certain procedures near the end-of-life, etc.) might also be disproportionate with the common good and ruled out on that basis.

Second, given Sparks’ methodological principles, why would not the same worry apply in the macro or policy level? Indeed, depending on what the policy is (nontreatment of all infants born under 500 grams, for instance), one might ‘denigrate the personhood’ of many more human infants than if one left it to the clinician on a case-by-case basis.

Third, as we will see in some detail in chapter four, one cannot properly evaluate the relative benefits/burdens of treatment—and therefore the socially-aware best interests of the infant—properly by only considering general trends on a policy level. Many judgment calls will have to be made by clinicians on a case-by-case basis and this will require these clinicians to evaluate the infant with regard to the social totality of her best interests.

Sparks is understandably worried that putting a clinician in this role might undermine patient dignity in an unacceptable way. After all, bioethics grew out of a World War II situation in which Nazi physicians did engage in this kind of activity. However, the idea of physicians taking into account social factors in a primary way is not as radical as Sparks makes it seem. Joseph Fins and Curtis Hart argue that cost-cutting measures taken by hospitals and clinics means that “physicians are no longer able to practice in economic isolation. As practitioners in economically strapped hospitals or in HMO’s, physicians often encounter a conflict of interest between satisfying the patient needs and meeting their institution’s demands.”172 And while it is true that the American

Medical Association Code of Ethics explicitly demands that the physician act solely as a patient advocate, interestingly, it also notes that, “Physicians as citizens have a responsibility to participate and to contribute their professional expertise in decisions made at the societal level regarding the allocation of health resources.”173 (Quoted in Fins and Hart, 14) They make the very strong claim that a physician who acts clinically without considering costs and then politically advocates cost containment becomes a victim of an “untenable hypocrisy.” (Fins and Hart, 14)

And cost containment is not the only situation in which physicians do not give a treatment that is disproportionate with the common good. Take the decision whether or not to prescribe an antibiotic. Fins and Hart rightly point out that although “an individual patient might conceivably benefit from a more powerful antibiotic that might marginally improve therapy, the use of the fail-safe drug is limited to well circumscribed situations by the broader needs of the community.” (Fins and Hart, 14) The physician weighs the benefit of giving the drug to the individual with the harm of an increased drug-resistance within a given population. If the treatment is disproportionate with the common good, then the physician often will not prescribe the drug—even though it may well benefit the patient. No, the idea that Sparks is attacking is not so radical after all and certainly does not violate the goods of medicine or the time-honored relationship between physicians and patients.

173 Without a moral anthropology that is cut out of the same cloth as that of Catholic Social Teaching, it looks like that the AMA Code of Ethics has a contradiction here—for if one considers patient’s interests from a narrow point of view, it seems obvious that these will directly conflict with those of the institution in many situations. That the Code includes both is interesting because, if it is not seen as a contradiction, it is an implicit acceptance of at Catholic Social Teaching-like anthropology.
But what, then, are we to make of the part of Sparks’ second methodological claim in which he says that social burden on others should act only as ‘corroborating, possibly balance-tipping factor’ in treatment decisions by clinicians? While the fundamental sociality, and therefore social duties, of the human person has already called this kind of reasoning into serious question, the absolutely overwhelming social consequences in play make one wonder if such a narrow understanding is commensurate with the seriousness of the social situation. Consider how Mary J. McDonough summarizes our current healthcare situation in the United States:

Today the healthcare system in the United States is a mire of rapidly increasing costs and continually declining of insured. Efforts to achieve universal healthcare coverage have chronically failed. Yet healthcare costs are rapidly rising. In 1970, 7.6 percent of the nation’s gross domestic product (GDP) was spent on healthcare. By 2004, that figure had risen to 15 percent, the highest in the world. Moreover, 2003 insurance premiums rose 13.9 percent, greatly outpacing the 2.2 percent inflation rate. That was the third consecutive year of double-digit premium increases and represented the greatest increase since 1990. The number of uninsured people is growing as well. In 2004 approximately 44.5 million people in the United States were uninsured. There is a general agreement on why affordable, fair distribution of healthcare is growing increasingly difficult: the rising number of elderly people as a significant proportion of the population, the impact of new technologies and the intensified use of older ones, and an increasing public demand for better healthcare.174

To get a sense of the kind of numbers we are talking about, consider that 15 percent of the 2004 GDP is approximately one-trillion, six-hundred forty-seven billion dollars.

Neonatal intensive care is already “one of the highest single hospital costs—more than 25% of the country’s entire maternal-newborn budget,” and this cost shows no sign of doing anything other than growing. “The number of neonatalogists has doubled since

1985,”\textsuperscript{175} and profitability and cost of NICU treatments, length of NICU stays, and new NICUs built continue to grow dramatically.\textsuperscript{176} These considerations, dramatic as they are, only constitute a fraction of the total cost of the treatment of imperiled newborns. As Sparks himself notes, the “initial neonatal costs are multiplied many times over if one takes into account the expense of long term care—repeated surgeries, hospitalization, therapy, special education, family support services, and possible institutionalization.” (Sparks, 230) Much more will be said about the specifics of these costs in chapter four, but safe to say at this point that they are even more dramatic when one considers the rapid rise of healthcare costs over the lifetime of the patient.

The dramatic numbers involved when it comes to cost of healthcare resources, and those affected by their distribution, are certainly added reasons to reject Sparks’ claim that social burden should only be a mere ‘balance tipping’ factor in NICU treatment decisions. This becomes even more convincing when one considers that “society bears the brunt of these expenses in terms of Medicaid and insurance payments as well as the cost of maintaining institutional facilities.” (Sparks, 230) One can see this most clearly if one looks at how Medicaid is impacted. Though again much more will be said about the specifics in the following chapter (and much depends and in what socio-economic cliental the unit serves), because a clear majority of NICU infants are funded mostly by Medicaid, decisions about treatment directly affect others whose healthcare resources come from the same Medicaid pool. In a very real way, then, decisions about

\textsuperscript{175} Clark, To Treat Or Not to Treat: The Ethical Methodology of Richard A. McCormick, S.J., as Applied to Treatment Decisions for Handicapped Newborns, 24.

\textsuperscript{176} Lantos and Meadow, Neonatal Bioethics: The Moral Challenges of Medical Innovation, 177, 130-135
Medicaid treatment (both on the levels of policy and clinical treatment) are analogous to decisions made in a battlefield triage situation (both on the levels of policy and decisions by the medic). In both situations the relevant resources (money spent on a patient vs. time spent on a patient) are limited such that difficult and tragic decisions need to be made—for some are going to get inadequate care and are going to die. Decisions not to treat patients that might have survived, on the basis of due proportion with the common good, does not violate the good of medicine on the battlefield or disaster-area and, this dissertation argues, does not violate the good of medicine in the NICU. Indeed, it upholds the duty of medicine to treat the best interests of the patient in a way most authentically aware of the true dignity, best interests, and quality of life of the human person. However, the claimed analogy between a battlefield triage situation and Medicaid treatment is controversial and warrants a more detailed underpinning.

**Medicaid and Triage**

Medicaid is the largest public health insurance program in the United States and provides assistance to more than 50 million Americans at the cost of over $300 billion. The programs are administered and partially funded by individual states, but the federal government provides significant support with the requirement that states fully cover low

---

177 Some might wonder, especially in a dissertation written in sympathy with Catholic Social Teaching, if Medicaid is a good choice here. If one claims to have a preferential option for the poor, how could one be willing to dramatically limited neonatal care for the (largely) impoverished people who qualify for Medicaid? This is an important question—but it is one that must been seen in the context of the full constructive proposal argued for in the final chapter. Here are two preliminary suggestions: first, when changes are made to Medicaid the private insurance companies almost always follow suit—which means that changes to Medicaid will likely trickle down to the rest of the population; second, those who are responsible for making decisions about how Medicaid funds are distributed should do so without reference to factors over which they have no control—like how well their program is funded in relationship to other programs. Their primary concern should be with regard to the things over which they do have control: just and proportional allocation of resources within the Medicaid population.
income children and some pregnant women—after which the state can use monies to cover others. To see the analogy between Medicaid and a triage situation, it is instructive to examine a particular case of a state-run Medicaid program—and this chapter will consider that of Tennessee. The state’s Medicaid program, ‘TennCare,’ was once considered a model for the country. In 1994, the program was financially sound and had helped to drop Tennessee’s uninsured level to one of the lowest in the country. But TennCare ran into problems in 1999 due to several factors: poor management, under-funding and, perhaps most importantly, dramatically rising costs due to medical inflation. Either unable or unwilling to secure more funding, TennCare was forced to drop approximately 120,000 people from the program beginning in August of 2005. And those who remained on the program were subject to one of the strictest prescription drug limits anywhere in the country: adults could only get five drug prescriptions filled per month—three generics and two brand-name drugs. For those who were dropped altogether, there was no safety net in place. 18 months after the cuts began, the State launched a program to help those who were ‘uninsurable’—people who were lucky enough to have had access to private insurance but since been rejected. Such programs were too little too late and served only a fraction of those who had been dropped from TennCare.

---


The best way to understand the dramatic effect this had on the lives of real people is to hear a bit about some of their stories—especially in light of the fact that they are almost never told, while stories about newborns make sexy headlines:

- **Jerry Springfield** (Jackson, TN). Jerry has muscle spasms in his heart—a condition that requires him to take eight pills every day and to see a cardiologist. He has no income other than $157 per month in food stamps and lives with his parents. When he was dropped from TennCare he showed up for a cardiologist appointment and was told that his insurance would not longer pay for the visit. “I couldn’t pay for the appointment without TennCare coverage,” Jerry said, “so I simply didn’t see my doctor that day.” Even with his discount card, his drugs cost $400—which he cannot afford. Recently, he has experienced severe pain in his right arm that prevents him from raising it. “I would have liked to go to the doctor for it, but I couldn’t afford to,” he said. Jerry has tried to get on disability insurance, but his application was denied.

- **Janice Harris** (Nashville, TN) Janice used to work on a regular basis, but after a car accident left her with a severe back injury (requiring four surgeries) she was unable to work—and when she was denied disability her income dropped to zero. The offender in the car accident paid medical bills related to the accident, but her other medical and psychological ailments are not covered: kidney stones, esophagus stretching, and clinical depression. Losing TennCare has forced her into severe indignities and even life-threatening situations. When her esophagus gets inflamed, she has no money to treat it—thus, when it gets bad, “all I can eat is baby food,” she says. She has also been unable to see a doctor about a lump in her breast even though she has a family history of breast cancer.

- **Aaron England** (Crossville, TN) Aaron worked for 23 years, never had health insurance, and luckily has led a healthy life. However, this caught up with him all at once when he developed a triple hernia, a serious and chronic infection, and a cancerous thyroid. Though he originally qualified for TennCare, in the midst of the treatment of these problems, he was removed. He has been surviving because of the free drug samples he gets from his doctor, but he can no longer afford to get his blood drained of excess cells from his infection, so he is at growing risk of having a stroke. Asked what he would tell the governor about the TennCare cuts, he said, “I would say that he is going to kill a lot of innocent people. Believe it or not, there are a lot of people worse off than I am.”

---

180 Knowing the personal stories of those affected will be important later in responding to some anti-triage-analogy arguments.
These tragedies are totally unacceptable given the resources of the country in which these patients live—and one solution to these problems, certainly, would have been to better fund TennCare such that needy people like this would not have been dropped.\textsuperscript{181}

However, when one views Medicaid programs in isolation from this unfortunate (and unjust) under-funding (as one would have to do when making public policy about allocation of Medicaid funds or clinical treatment decisions for those on Medicaid) then one can see how very much like a triage situation it is. Because a Medicaid program has limited resources, and because the medical need in virtually every state dramatically outpaces the capacity of these resources, decisions to spend resources in a particular way necessitates that certain needy others will not get the resources they need: regardless of how the money is allocated. And as we see in the case of TennCare, tragically, this means that some people will die who otherwise would have survived.

This is precisely what is the case in a typical triage situation on the battlefield, disaster area or hospital—except that the social resource in question is not money, but rather time. Consider the classical triage classifications and priority codes:

\textbf{“Emergent”} (or “Red”). Priority 1 is given to critically ill patients who may survive with intervention that does not consume significant resources and personnel, i.e. patients who need immediate surgery to save life or limb, using minimal operation time, and who are expected to have a good quality of survival.

\textbf{“Urgent”} (or “Yellow”). Priority 2 is given to patients who are likely to survive and remain stable for several hours by means of stabilization; i.e., patients who need time-consuming surgery and whose lives will not be jeopardized by delay.

\textbf{“Non-urgent”} (or “Green”) Priority 3 is given to patient who have minor injuries that may be treated by those with minimal training; i.e., patients who can wait until other injured patients have been cared for.

\footnote{181 These kinds of considerations will be taken up in the conclusion of the dissertation.}
“Expectant” (or “Black”) No obvious priority. Patients who have overwhelming injuries with little chance for survival and patients with severe injuries who are not expected to survive unless time-consuming care is almost immediate. The only priority is palliative care and comfort measures to those dying.\(^{182}\)

The key to triage is to apportion the available resources in connection with the common good of the entire community under consideration of the triage physician. The good aimed at might be different depending on the circumstances,\(^{183}\) but in general the idea is to save as many lives as possible. For, as John Kilner points out, the right to life is not a claim to equal resources—rather, the “real claim of each person…is that his life be valued equally with all others—which in turn necessitates that two rather than one be selected”\(^{184}\) in a case where either one or two persons in a group of three could be saved.

Though it is difficult and tragic to admit, patients “with a black card are thought to need too many resources which would deprive more viable patients and who, therefore, may have to be allocated low priority due to limited resources.” (Salo, 156) The variables of number of patients, the severity of the injuries, and the amount of medical resources all help to determine who gets what kind of priority. If the number of patients is high, and the injuries life-threatening, then “the only care that may take place is in the form of rapid life-saving manoeuvres [sic]. When resources are limited—and they nearly always are—in these situations, many patients who might normally receive maximum medical


\(^{183}\) For instance, in a particular battlefield situation one might use ‘reverse triage’ in which soldiers who through medical intervention could be ready to fight again relatively soon might receive first priority whereas those who could benefit from treatment, but who will not fight again (leg amputees, for instance) will receive less priority despite having a more severe injury.

treatment are left to die at the scene because they will consume too much time and resources better allocated to others who have a better chance of surviving.” (Salo, 156)

Calling this ‘triage reasoning’ (or similar phrase) calls to mind an exceptional or uncommon case and therefore it might seem that such reasoning applies only to exceptional and uncommon cases like the battlefield or a disaster area. However, as Kilner makes clear, this kind of reasoning applies in any situation where there are ‘disproportionate resources.’ Again, take the very generic situation in which three people are equally in need of certain scarce life-saving resources. One requires the entire amount available, whereas the other two each require only half. In such a case, all else being equal, “it is right to save the two rather than risking likelihood that only one would be saved.” (Kilner, 263) What this means, then, is that far from limiting this kind of reasoning to exceptional situations, we should broaden it out to any situation in which we are dealing with the three following conditions:

1. A patient population.
2. A significant portion of that population in need of life-saving therapies.
3. Limited medical resources such that, regardless of how we use them, some patients will die who otherwise could have been saved.

If these three conditions are met, then we should use something like triage reasoning in determining how to allocate medical resources. Just as a battlefield or disaster-area medic would not randomly allocate resources by a lottery, or according to the first patient that met her gaze, or by what a market determined, neither should any those factors determine how to allocate the medical resources present in public health programs like Medicaid or any other program that meets the three criteria above. Instead, all physicians—whether in disaster-area, NICU or battlefield—should always be allocating
resources with the patient’s total best interests in mind; that is, with an eye to avoiding treatments that are disproportionate with the common good.

In May of 1990, the state of Oregon attempted to do precisely this with their Medicaid system. Much more will be said about this in chapter four, but it is worth mentioning a bit about the program here to get a glimpse of how this kind of triage reasoning might work in practice. The high cost of healthcare was making it impossible for Oregon to cover all of its poor who had severe medical problems. In response to this problem they created a list of over 1,600 diseases, disorders and conditions and ranked them according to which had the most favorable cost-of-treatment to benefit-of-treatment ratio. At some point on the list, to be determined by the amount of money available to the Medicaid program, a cutoff would kick in and Medicaid would refuse to pay for treatment of the conditions below the cutoff. This was the trade-off for getting all those below the poverty level covered under Oregon Medicaid.

However, the algorithm programmed into a computer to determine the list (which did consider factors like life-expectancy and quality of life) rated ‘headache’ and ‘thumb-sucking’ higher on the list than life-threatening diseases such as viral pneumonia and cystic fibrosis. Subsequently, an 11-member panel called ‘the Oregon Health Commission’ (consisting of five physicians, one social worker, one nurse, and four representatives from patient-advocacy groups) completely recast the list in light of some different, human judgment and values. Esoteric diseases were put toward the bottom of the list, and life-threatening conditions and preventive care were given much higher

---

priority. Not surprisingly, however, there were still life-threatening conditions and diseases which ended up below the line. The new list bottomed out with AIDS—given that the survival rate was less than 10 percent over five years. Interestingly, especially for chapter four of this dissertation, maternity and healthy-baby care ranked very high, but treatment of extremely low birth-weight babies (less than 1.1 lbs or about 500 grams), though able to be saved in some cases, was ranked rather low.\textsuperscript{186}

It seems clear that in any situation in which the above three criteria are met, regardless of how the resources are distributed, we are going to have people die. The reasoning of the advocates of the Oregon Medicaid plan, and the reasoning of this dissertation, is that people are already dying as a result of how we allocate resources—but in a largely unregulated, unsystematic and definitely unjust way. This is a tragic and unavoidable situation. But seen through the lens of those who have no control over the amount of resources at the disposal of programs like Medicaid, and yet still have to make resources allocation and/or treatment decisions, how much better to make choices systematically in proportion with the common good of one’s patient population?

**Medicaid and Triage: Some Understandable Concerns**

There are many who object to using triage as analogy for Medicaid—or as an analogy for any other kind of medical program. And they have convincing reasons for doing so. One who makes a particularly strong case is Benjamin Freedman who, though

\textsuperscript{186} As we will see in chapter four, having a blanket criteria like ‘gram weight’ is not enough when coming up with NICU policies that respect treatments only insofar as they are in due proportion with the common good. Sparks could be happy with something like the Oregon plan because it is on the macro or policy level (though it is still unclear how it denigrates, say, AIDS patients any less than if the decision not to treat was made at the micro level), but he could not accept what will be required of the neonatologist insofar as she is forced to make a determination ‘at the cribside.’
his main worry is that we preference the treatment of the sick over preventive care of the healthy, gives us several reasons to be skeptical of the triage analogy.\textsuperscript{187} He grants the truth of the claim that something like triage medicine yields the best ‘return on the dollar’—but only if one accepts that return being concerned with producing ‘better mortality and morbidity rates.’ (Freedman, 31) Freedman suggests this kind of return on the dollar should not be our number one priority. He reviews the arguments of several thinkers who have written on allocation of scarce resources who agree “on just this principle: that man should be prevented from deciding the fate of men.” (Freedman, 33)

He quotes Paul Ramsey who makes the claim that in allocation of sparse medical resources among equally needy persons, “an extension of God’s indiscriminate care into human affairs requires random selection and forbids godlike judgments that one man is worth more than another.”\textsuperscript{188} We should not be prepared to adopt a policy, Freedman argues, that will make it apparent that the claims of lives in dire need can be adjudicated by human beings. And this is precisely what the triage analogy asks us to do.

Another argument Freedman convincingly uses against the claim that ‘we should save as many lives as we can’ invokes a significant distinction between mere statistics and the worth of a known, individual life. In fact, he claims this is how we already do things, uncontroversially, in other contexts. Consider that “society seems to have taken advantage of the psychosymbolic advantage of showing commitment to the dignity and worth of the individual life (while neglecting, sometimes woefully, the good of the ‘faceless statistic’).” (Freedman, 34) Indeed, we mandate the use of only relatively cheap

\begin{footnotes}
\item 187 Benjamin Freedman, "Case for Medical Care, Inefficient Or Not," Hastings Center Report 7, no. 2 (Ap, 1977), 31-39
\item 188 Ramsey, The Patient as Person; Explorations in Medical Ethics, 259.
\end{footnotes}
and therefore relatively limited safety features on our cars, etc., even though we know that, statistically, more people will die than if we had mandated more expensive and better features. However, in contrast, we spare no expense in order to save the coal mine disaster victim. What is going on here? Freedman suggests that we have a (good and healthy) bias in favor of attention of the individual over and against the mere statistic. For it appears to be the case that, “No one seems to be making the decisions to take human lives and, therefore, no blatant infringement of the commitment to human life as sacred occurs.” (Freedman, 34) In a triage-like situation, by contrast, a human person is directly choosing not to save a particular life, in favor of another life or lives, and this infringes on human dignity. It is a problem inherent in “dealing with statistics, with large numbers of people as an undifferentiated mass, thus excluding individuation of treatment.” (Freedman, 443) Rather, we should err on the side of policy that supports ‘freedom and individualism’ rather than the ‘opposite’ that a more statistics-based approach produces.

James Burtchaell also communicates some convincing worries about the triage analogy.189 To begin with, even if triage reasoning seems justified, “it has a way of consuming a person. For a doctor, the fibers of whose self are braided into lifelines of generous concern, it snarls the soul, not simply to lose a patient to death, but to mark him or her for death. It may require uncommonly high and durable virtue to perform this task without making a vice out of a necessity.” (Burtchaell, 506) This worry is magnified in that triage seems to be too easily invoked in ethical reasoning. For, “in a world where

189 Lammers and Verhey, On Moral Medicine: Theological Perspectives in Medical Ethics, 503-511.
medical resources are never likely to satisfy medical needs, is not every day one of triage?” (Burtchaell, 507) Do we really want all physicians who deal with life-threatening illnesses to ‘snarl their soul’ in calculating the relative value of their patients?

Burtchaell acknowledges that if we ‘grant the battle exists’ then triage and battlefield reasoning seems to be a kind of necessary evil. But he asks, ‘Why grant the battle in the first place?’ Why participate in the evil structures which force us into such tragically person-consuming situations? He cites an example of a Nazi program once proposed to Adolf Eichmann:

There is an imminent danger that not all the Jews can be supplied with food in the coming winter. We must seriously consider if it would not be more humane to finish off the Jews, insofar as they are not fit for labor mobilization, with some quick-acting means. In any case this would be more agreeable than to let them die of hunger. (Cited in Burtchaell, 507)

There is no triage, Burtchaell argues, when the same people who offer the most humane or just solution in a tragic situation are participating themselves in—or even the direct cause of—the social structures that forced the tragedy in the first place.

Burtchaell concludes with the now familiar ‘slippery slope’ argument—or what he calls ‘the possibility of great mischief.’ He is worried that any kind of shift away from a physician focusing on the (narrowly considered) best interests of the patient in front of them will lead us down a path we do not want to take. He against cites a Nazi example in support of his claim. In attempting to get the Dutch physicians on board with what German doctors were doing, they were not told to ‘send your chronic patients to death factories’ or that you ‘must give lethal injections at Government request in your offices.’

Rather, the Reich Commissioner of the Netherlands territories gave the following order:

It is the duty of the doctor, through advice and effort, conscientiously and to the best of his ability, to assist as helper the person entrusted to his care in the
maintenance, improvement and re-establishment of his vitality, physical efficiency and health. The accomplishment of this duty is a public task. (Cited in Burtchaell, 507)

The Dutch physicians unanimously rejected the order, because they knew the slippery-slope down which it would lead—"namely, the concentration of their efforts on mere rehabilitation of the sick for useful labor, and the abolition of medical secrecy."

(Burtchaell, 507) It is the first, slight step away from an essential principle that is the most important one. Because they did not step away from their principles, "not a single euthanasia or non-therapeutic sterilization was recommended or participated in by any Dutch physician." (Burtchaell, 508)

So while it is true that death is not the ultimate enemy, he suggests that "perhaps abandonment is." (Burtchaell, 508) Triage-like reasoning forces us to abandon patients on some level—so what is left to stop this reasoning from mushrooming out to other, less comfortable, levels? This, after all, is what happened in Nazi Germany and was only avoided by the Dutch physicians by refusing to take even one step down that road. If we use a kind of reasoning which demands that we abandon patients within Medicaid, and then specifically for imperiled newborns within Medicaid, will we really be able to hang onto the truth that "that stunted, afflicted fellow human of [ours] is already as invaluably valuable as he or she ever will or would be"? (Burtchaell, 508) Or will we slide down the slippery slope to something that no one advocating the first step ever intended?

A Response to the Concerns

Both Freedman and Burtchaell make powerful arguments—worthy of a considered and careful response. What of Freedman’s claim that ‘men should not be
deciding the fate of men’? That, in a case of limited resources, we should imitate God’s ‘indiscriminate’ giving of resources and randomly select those who get them? There are at least two important responses to this move. First, we should remind ourselves that it is already the case that human beings are deciding the fate of other human beings. All one need do is look at Medicaid in Tennessee or Oregon or any number of other states to realize that non-random choices are being made as to who is ‘in’ and who is ‘out’ when it comes to who receives the limited number of community resources. The primary argument of this dissertation is not that ‘we should use Catholic Social Teaching as guide for deciding the fate of other human beings rather than using a random method’—instead, the argument is that ‘we should use Catholic Social Teaching as a guide for deciding the fate of other human beings rather than the current methods: market-driven decisions, bias in favor of the newly born, etc.190

But perhaps this response would not be satisfying to Freeman—he could grant that a method based on Catholic Social Teaching is better than what we are currently doing, but it is still not the ideal. Again, we should imitate God rather than human beings—and humbly submit to a truly random distribution. However, if one takes the principles of Catholic Social Teaching seriously, this simply will not do. For God, from the perspective of this tradition, is certainly not indiscriminate in giving attention and concern for humanity. Catholic Social Teaching has articulated this as a ‘preferential option for the poor.’ Pope Leo XIII said, “When it comes to protecting the rights of

190 Much more will be said about how these methods work in practice in the first part of chapter four.
individuals, the poor and the helpless have a claim to special consideration.”  

John Paul II also invokes “the option or love of preference for the poor. This is an option, or a special form of primacy in the exercise of Christian charity, to which the whole tradition of the Church bears witness. It affects the life of each Christian inasmuch as he or she seeks to imitate the life of Christ, but it applies equally to our social responsibilities and hence to our manner of living, and to the logical decisions to be made concerning the ownership and use of goods.” (Sollicitudo rei socialis, 42)  Charles Curran notes that we normally think, especially in the West, of preference or bias as a negative thing. However, this is not what our faith teaches us. Our God has a bias in favor of the poor and the lowly. And it is precisely this bias that strengthens the common good of all.  

Those poor who are unjustly being dropped from Medicaid have a special claim to our attention—and cannot be dismissed in a random distribution process.  

Recall also Freedman refers to the ‘faceless statistic’ in almost disparaging terms. A ‘statistics-based’ approach like triage puts more value on ‘undifferentiated mass’ than on the individual dignity of the person right in front of you. Indeed, we as a culture do seem to care more about making automobiles affordable than about the ‘faceless statistics’ that would be saved by making them safer and more expensive. If Freedman’s point here is simply about what is the case, rather than about what should be the case, then he certainly has a strong argument. It surely is the case that when someone is a ‘faceless statistic’ that their dignity often comes second to the dignity of others who are ‘known’ to the person making choices which affect them all. But from the point of view

---

191 Pope Leo XIII) and Leo, Rerum Novarum. (New York: Paulist Press, 1900), 29.
of Catholic Social Teaching—which claims that ‘all really are responsible for all’ and that we should have a preferential option for the poor—this is definitely not a good thing. Recall Catholic Social Teaching’s insight about the ‘multiplied ties’ of human persons in today’s globalized world—and Whitmore’s insistence that this means we are all part of a world community. It follows from this that our social responsibilities go well beyond those that are ‘known’ to us; rather, the so-called ‘faceless statistic’ is a human person toward whom we have a strong social duty as fellow members of a world community. Indeed, Freedman’s argument helps remind us that part of this duty includes making the ‘undifferentiated mass’ of needy poor known to us and others so more will be moved to engage their social duties toward them. This is precisely why it is so important to tell the stories of people like those who were kicked out of Medicaid—they cease to become faceless statistics and get closer to becoming our sisters and brothers calling out for our aid. But whatever the case about their relative levels of familiarity, the poor should still be the focus for our duties as members of a world community.

Let us move to Burtchaell’s claims. Recall that he allows for triage reasoning ‘if we grant the battle’—and then calls into question doing precisely that. But say we grant this move—how would it play out practically for a battlefield or disaster-area medic? Let us suppose that the medic comes across the first wounded person and determines that their life could be saved, but it will take her undivided attention for the next hour. Let us also suppose that, based on her previous experience and training, she determines that she

193 Perhaps this kind of reasoning is also an indictment of what Freedman also notes ‘is the case’—the preference of cheaper automobiles over saving the lives of faceless statistics. If we were made aware of the mangled bodies that resulted from these choices, and the wailing of their friends and family members that followed, perhaps we would take a different approach. Whether or not the lives actually are more than faceless statistics to us, however, is not the point. All human beings are part of one world community—and we have social duties toward all.
could instead use the time to save five other people who otherwise would die. If she chooses to save the first person she comes across, what should she say in response to the parents of the other wounded persons who died because she chose to help the first person? That she ‘refuses to grant the battle’? Aside from the inappropriateness of this answer with reference to disaster-area (perhaps after a hurricane or some such event where there is no military battle), it is wholly unsatisfactory with regard to justice considerations. The parents of those who died could rightly complain that the medic spent resources on one patient in a way that was disproportionate with the common good of the patient population of which their daughter or son was a part. There will always be mitigating factors that make a particular treatment decision more or less difficult, but one should never retreat from one’s duty to the common good simply because the circumstances force one into a difficult situation.

But perhaps Burtchaell could make a version of the common good argument here. Like many others, he invokes the ‘slippery slope’ of any reasoning which forces us to abandon a patient. With this worry in mind, perhaps he could argue that a treatment which is disproportionate with the common good is in fact the one that opens the door to other more serious kinds of patient abandonment: something like what happened in Nazi Germany, for instance. Surely the risk of that kind of thing happening is a more serious threat to the common good than the alternative. But the response to Burtchaell here must be, again, that patients are already being abandoned either way. If the medic ‘refuses to grant the battle’ and stops to help the first patient for an hour, then she has abandoned the other patients—even though they might be over the next hill and she never has to look them in the face. The same is true within a given Medicaid population. If we ‘refuse to
grant the battle’ then we leave market, political and other forces to abandon patients—like those from TennCare described above. The question is what kind of abandonment are we going to practice?194 Are we simply going to ignore the wounded soldiers over the hill and tend to the person in front of us? Or, coming upon the first soldier, will we give him a loving smile, a shot of morphine, briefly hold his hand, and then move onto another patient whose treatment would not be disproportionate with the common good?

But is not this last move horribly difficult? It is one thing to abandon someone that one never meets, but how could one look into the eyes of a dying patient, someone that could be saved, and then leave them to die? Would not repeated instances of this, as Burtchaell says, ‘snarl one’s soul’ and ultimately consume the humanity of anyone who practiced it? No doubt it would take the virtue of fortitude to undertake these kinds of difficult decisions, but fortitude is something that good physicians who deal with life and death issues possess in abundance already. How strong must one be to be called from a family holiday gathering to do hours of emergency surgery? How strong must one be to abandon the life-saving treatment of a patient who has determined that further interventions are too burdensome? How strong must one be to break the news to a pregnant woman that she has uterine cancer? In addition, Fins and Hart remind us that the kind of explicit rationing that goes on in triage situations “might be a less bitter pill” to swallow than the elixir of tens-of-millions totally uninsured—and countless more under-insured. (Indeed, how strong must one be—how snarled is one’s soul—in

194 This is true at least in the first stage of this battle for justice in health care. Admittedly, it does appear to be wrong and dangerous to be content with a situation which forces us to abandon patients in this way—especially given the resources that exist in our society. Though this dissertation limits itself to arguments within a two-tiered system (which shows no signs of going away in the foreseeable future), the conclusion to this dissertation makes explicit the idea our current structure is not ideal and ought to have more systematic changes.
accepting that one’s choices are contributing to *that* utterly tragic state of affairs?)

Accepting “at the outset that our resources for healthcare are limited” provides the proper context for use of those resources in a systematic manner. (Fins and Hart, 15) The constraints imposed by the Social Quality of Life Model “may ultimately lead to improved medical care” by forcing us to examine critically our use of resources—and thus it would be far more likely to be “moral, logical, nonarbitrary and scientifically based.” (Fins and Hart, 16) Allocating scarce resources is not the first challenge to the dialectical relationship of medicine’s obligations with a patient’s expectations—nor will it be the last. However, by “acknowledging the true breadth of responsibility to the individual and to society, physicians could instill into the relationship a greater sense of community. This added dimension could deepen and define the fiduciary obligation and secure the relationship that binds us.” (Fins and Hart, 18)
CHAPTER FOUR

A CONSTRUCTIVE PROPOSAL FOR REFORMING THE TREATMENT AND CARE OF IMPERILED NEWBORNS

There is now much broader public awareness of the need for difficult choices to be made by the providers of national healthcare. We have discussed the difficult economic issues which have to be managed in neonatal medicine because more babies are able to survive than in the past...Consequently, this has caused questioning of whether funds spent on resuscitating or prolonging the life of babies where the prognosis is very poor are spent appropriately.

Nuffield Council

Introduction

Recall that to this point we have seen three general approaches to the social quality of life model: one which supports a strong version of the model, one which rejects the model, and a third which supports a weak version of the model. Each of them has been found to be inadequate—and most obviously with regard to their anthropology. It is difficult, however, to imagine another alternative: are there logical pathways still open to us? The answer is yes, and the key is to remember the reason why the strong version of the model was rejected in chapter one. Those who support a strong version of the social quality of life model almost always do so when arguing from the less-than-full personhood of the newborn. If the arguments of the preceding chapters are correct, one need not accept this understanding of the moral status of neonates in order to support a
strong version of the social quality of life model. Indeed, when a military or disaster medic uses the strong version of this model with respect to allocation of her resources, she is not making any claims about the moral status of those whom she chooses to treat and those she does not. In fact, it is presumed that each of her potential patients has the same moral status and therefore an equal right to her medical consideration. As seen in previous chapters, however, it does not follow from this moral status that all persons have a right to be treated, even if the treatment is necessary to preserve life and even if they are currently the patient ‘in front of’ the physician, in a sense that is disproportionate with the common good. All one is entitled to is equal consideration with others in due proportion with the common good. In tragic situations, this may mean that life-saving treatment may be justifiably withheld from some persons.

But how should this play out practically when it comes to the subject of this dissertation: the treatment and care of imperiled newborns? This is the central question of the final chapter. It will begin by exploring in some detail the facts of, and attitudes toward, treatment of such newborns in today’s neonatal intensive units (NICUs). What kinds of outcomes can one expect based on a particular diagnosis? How reliable are such diagnoses? What sorts of economic considerations impact treatment in the NICU? The second part of the chapter will offer a critique of this current situation using a strong version of the social quality of life model in light of Catholic Social Teaching. It also will deal with a major objection that such a critique is best leveled at single-payer systems by raising the example of Medicaid, its relationship to the funding of NICU

195 It will focus mainly on the United States, but practices from other developed countries (the UK and the Netherlands, for instance) will be brought in for the sake of comparison.
treatments, and how it serves as a favorable ‘test case’ for the social quality of life model with respect to imperiled newborns. Perhaps the most prominent moral feature of certain NICU treatments funded by Medicaid is their disproportionality with other medical treatments funded by Medicaid. Having found the current situation wanting, and dramatically so, the chapter will make several arguments for changing how resources are distributed in the NICU—first considering past models for rationing such as Oregon’s ‘generic health states’ list and the ‘quality-adjusted life-year.’ Appropriating workable and attractive aspects from these models, the chapter will then make constructive proposals with regard to the following: combating a general ‘culture of treatment’ in the NICU, refusing to treat reliably diagnosed terminal cases, and rationing Medicaid NICU care. The chapter will offer and respond to several objections to the constructive proposals—including an internal critique based on the charge that the proposal is antithetical to the preferential option for the poor.

Basic Facts about Treatment of Imperiled Newborns in the NICU

Before making a constructive proposal in applying the Social Quality of Life Model to the treatment of imperiled newborns, it is important to get a far more detailed picture of the facts, practices and attitudes of the modern day NICU. Neonatal treatment takes place within 28 days of birth—infant mortality, however, “is defined as death before 1 year of age.” (Lantos, 13) Three groups of babies are generally admitted to the NICU. (1) Full-Term Babies with Acute Illnesses. According to Lantos, these are

196 The information in this section of the chapter is taken from Lantos, Neonatal Bioethics: The Moral Challenges of Medical Innovation.
usually the least ethically controversial cases as the problems that arise in decision-making are similar to the problems of other high-risk patients at any age. These babies generally either get better quickly or die quickly and the major ethical problems arise when treatment is only partially successful and the babies survive but with long term complications from their acute illnesses. (2) Babies with Congenital Anomalies. These babies were the subject of many dramatic cases in the 1970s and 80s—and in particular those born with syndromes like trisomy 21 and spina bifida. These cases are often complex, however, because the life-threatening disease or malformation is often something unrelated to the congenital anomaly—for instance, a baby with trisomy 21 might also have an intestinal or cardiac malformation. In such cases the life can often be saved, but nothing can be done to treat the underlying anomaly: and thus the choice is to either save a life full of significant impairment or let ‘nature take its course.’ The decision forces one to deal with difficult issues surrounding quality of life that go beyond mere medical indications for survival.197 (3) Babies with Extreme Prematurity. These babies include all of the considerations of the other two groups, but add another: long-term prognostic uncertainty. For any given baby, “the potential outcomes range from early death to late death to survival with severe, moderate, or mild disabilities, to survival with no long-term medical or neurodevelopmental problems. Furthermore, the disabilities associated with the ‘disease’ can be cognitive, pulmonary, intestinal, or cardiac or involve virtually any other organ system.” (Lantos, 16) Since these babies will

197 The paradigmatic case here is that of ‘Baby Doe’ in the 1980s. This was a pivotal case for a host of reasons—including a dramatic shift to a ‘culture of treatment’ in the NICU that will be explored later in the chapter.
be a major focus of the Social Quality of Life Model in this dissertation, much more will be said about this uncertainty later in the chapter.

Due in no small part to improvements in treating babies in the three groups above (along with improved nutrition and sanitation), infant mortality dropped dramatically in the 20th century United States: from 55/1000 in 1900 to 9/1000 in 2000. More recently, neonatal mortality has plummeted from 19/1000 in 1960 to 4/1000 in 2000. However, Lantos argues that progress in improving birthweight-specific rates of survival came to a halt in the mid-1990s. Breakthroughs in treatment like the use of surfactant and antenatal steroids came into regular use at this time, and it does not look as if there are new treatments on the horizon.198

Though the innovation of neonatal care has brought about significant burdens—many of which are the subject of this dissertation—there is no question that the benefits brought about have been absolutely remarkable. Before 1965, most of the babies weighing less than 1500 grams at birth died. Today, more than 90% of them survive: and a conservative estimate is that 20,000 neonates per year now survive who otherwise would have died. If one were to assume a life-expectancy of about 80 years, this means that neonatal intensive care creates 1.6 million years of life—years that would have otherwise been lost—every year in the United States today. In addition, studies have shown that 1 in 8 births in the United States are premature—with the trend increasing and

198 Some work is being done on improving outcomes from respiratory failure (a major problem in extremely premature infants): liquid ventilation, high frequency oscillatory ventilation, new drugs to treat under-developed lungs, and even the prospect of an artificial placenta that could be attached to the umbilical cord after birth. However, the lag time on research and development is so long (surfactant and antenatal steroids had clinical trials as early as the 1970s) that—for the foreseeable future at least—we will not have any new neonatal treatments.
showing no sign of stopping.\textsuperscript{199} This means that the NICU will likely become even more important and add more life-years in the foreseeable future. Though from many perspectives this benefit is surely enough to overwhelm any burden, this dissertation (and this chapter in particular) means to call such perspectives into serious question.

**Outcomes\textsuperscript{200} and Predictions**

Lantos goes so far as to argue that accurate predictions are “the basis for ethical decision making in the NICU.” (Lantos, 88) For instance, if we can predict accurately that a particular treatment will be beneficial (and, of course, the previous two chapters have attempted to show that what this means can be complex) it may be morally obligatory to continue or to initiate treatment—and if we know a treatment will fail it may be morally permitted (or even obligatory\textsuperscript{201}) to refuse or discontinue treatment. The harder cases, of course, come when the predictions are not so certain—in a kind of ‘grey area’ of neonatal decision-making. The grey area, described in terms of gestational age, is between 22 and 26 weeks; and in terms of gram weight it is between 500 and 850 grams. Below the low numbers almost no baby survives, and above the high numbers almost every baby lives. It stands to reason, then, not to treat babies below the low numbers and to treat the babies above the high numbers—but even if this correct (and, all

\textsuperscript{199} \url{http://www.cnn.com/2008/HEALTH/conditions/06/20/premature.babies.ap/index.html} (accessed June 20th 2008)

\textsuperscript{200} This section of the chapter will consider only short-term outcomes. Later in the chapter, and especially in response to a strong opposing argument that compares the costs of NICU care to other kinds of care, longer-term outcomes will be considered.

\textsuperscript{201} One of the arguments this chapter will consider claim that some kinds of treatment always wrong to administer.
by itself, it may very well not be), what should be done in the grey area? The 1983 President’s Commission on Bioethics suggested that parental preferences should determine treatment decisions. However, clinical research over the last two decades has significantly narrowed the grey area (or at least made it less grey) such that (1) parents are now given much more accurate predictions with which to make ethical decisions and (2) not all decisions by parents should be seen as having ethical defensibility in light of the data.

The most important factor to consider at birth, Lantos argues, is birth-weight. In general, the heavier the baby, the better the chance of survival. However, another major factor to consider, more recent clinical research has found, is the ‘initial response’ of the newborn child. Lantos found that, at least with regard to the babies in the University of Chicago Hospital NICU (and this has been backed up by other studies), “more than half of the premature babies who ultimately died would die in the first three days of life, regardless of the treatment they received.” (Lantos, 90) Prior to day 4 of post-natal life, the best predictor of outcomes is birth-weight—but for babies who survive past this time birth-weight virtually disappears as a relevant predictor of survival. Indeed, the “600-gram babies who survive for three days do just as well as the 1000-gram babies who survive for three days.” (Lantos, 92) Not so long ago, it was presumed that the best time to make a decision about treatment was in the delivery room—and also that once a treatment decision was made it was largely irreversible. Lantos convincingly argues that

this is not the case. Of all babies weighing 750 grams at birth, half will live and half will
die, and it is impossible to tell from the gram weight alone which will do what. Lantos
argues that, “One way to determine more accurately to which group a particular baby
belongs is to treat all of the babies. The sickest babies then ‘declare themselves’ by
dying in spite of medical treatment. The less sick babies also ‘declare themselves’ by
improving over the first few days.” (Lantos, 92)

But what to do after 72 hours? There are other predictive indicators to use at this
point, but they are not well-understood, need more study, and are very complex. One
widely used metric is the SNAP score (score for neonatal acute physiology) which
incorporates 37 physiological and biochemical markers: everything from heart-rate to
glucose level to oxygenation index. SNAP scores have been moderately helpful as
predictors because the scores are significantly different for the babies who go on to die
compared to those who go on to survive. However, SNAP has weaknesses too. One is
that the scores are, again, most indicative of outcomes during the first three days of post-
natal life. Later, “when the predictive value of birthweight decreases, and the SNAP
score could potentially be a more clinically useful predictor, the differences between the
SNAP scores of the two groups narrow.” (Lantos, 93) Add to this the fact that (though
its predictions of survival are fairly accurate) a high/dangerous SNAP score is less than
50% accurate as a predictor of death, the score might be “more useful as an
epidemiological measure of outcomes for large groups of babies than…as a clinical guide
to treatment decisions for an individual baby.” (Lantos, 95)

Rather skeptical of quantitative measures like this, Lantos finally considers an
interesting predictive option: the clinical intuitions of NICU workers. He conducted a
study in which 333 very sick infants (each was less than <1000 grams or on mechanical ventilation) in which these professionals were asked whether each baby would live or die. For 231 of these babies, every physician on every day predicted that they would live: and, remarkably, they all did live. However, for the other 102 NICU babies, the clinicians were neither uniformly optimistic nor uniformly accurate. About half of these babies were predicted by all care-givers on each day to die—and they were again all correct. However, there were also times when the clinicians intuitions were not the same. Babies who every clinician predicted to die, on at least one day, often did not die. In addition, of the babies who had at least one day on which two or more clinicians predicted death, a full one-third of such babies survived. Also surviving were one-fourth of the babies who, on at least one day, were predicted by all the clinicians to die. Though perhaps more helpful than one might suppose, clinical intuition certainly has its predictive limits.

However, there are other important predictive factors to take into account which neither Lantos nor the SNAP score considers. A study203 commissioned by the National Institute of Child Health and Human Development Neonatal Research Network found that factoring-in things like sex, exposure or non-exposure to antenatal corticosteroids, and single or multiple gestation can make outcome predictions significantly more accurate. Remarkably, “In multivariable models of infants who received intensive care, female sex, exposure to antenatal corticosteroid therapy, singleton birth, and increased birth weight (per 100-g increment) were each associated with benefits similar to those of

an increase in gestational age of approximately 1 week.” (Tyson, 1679) This usually means a very significant decrease in mortality, morbidity and use of resources.

Of particular interest is the role that sex plays in predicting outcomes. The study found that babies at 23 weeks gestation, weighing between 401 and 500 grams, survived at a remarkably different rate depending on whether or not a baby was male or female. If male, he had an 8% observed rate of survival without profound impairment. But if female, she had a 19% observed rate of survival without profound impairment. A 50% improvement in outcomes is unique to this specific age and weight-class, but multiple studies have found a broad trend of females doing 10-20% better than males across the board.

Especially in light of the amazing story of Amelia Sonja Taylor—a female and black pre-term baby who survived after being born at 21 weeks 6 days gestation (cited in the introduction to this dissertation)—much has been made of the role race plays as a predictive factor as well. Despite many studies with data to the contrary, the Tyson study interestingly found that, “In bivariable analyses as well as analyses adjusted for the center and the factors described above, race or ethnic group had no significant association with outcomes.” (Tyson, et al, 1679) This flies in the face of the data of several other groups who have studied the issue, including the Morse study cited below. Though they admit that the issue of black race conferring a survival advantage has been debated, they find that:

black race conferred a significant survival advantage at 1 year of age across all gestational ages among ELBW infants. The steepest part of the survival curves in Figs 2 and 3 occurred among the lower birth weights and gestational ages, indicating increasing advantage of black race as the degree of prematurity increases. In addition, the OR for black versus white survival was 1.3 (95% CI:1.1–1.5), favoring black race. Our results suggest that race plays an important role in estimates of survival rates and therefore may affect treatment decisions. (Morse, et al, e111)

As dramatic as these numbers are—they show that being black is an even better boon to a NICU baby than being female—they are nothing compared to when one combines race and sex. The Morse study found that when, “Combining race and gender, the largest advantage was seen among black female infants, compared with white male infants, with a 2.1 (95% CI: 1.7–2.6) increased odds of survival.” (Morse, et al, e110) In light of these numbers, (1) it is hardly surprising that baby Taylor was the first to break into the 21-week survivor category, and (2) race and gender should at least be candidates for factors to use when predicting NICU outcomes. This will become important in determining the final constructive proposal of dissertation.

Before leaving the section on predicting short-term outcomes, it is worth noting here that, though certainly there are some bases on which to make these predictions, it is important to be humble with regard to their accuracy and careful with regard to their use. Steve Leuthner and this author have argued this elsewhere—and especially in light of the fact that postnatal assessment is often worse than prenatal when it comes to certainty of gestational age measure. We point out that that standard metric used for postnatal gestational age assessment—the ‘New Ballard Exam’ is has a margin of error of plus-or-minus four weeks. By contrast, measuring crown/rump length of the fetus at 5-10 weeks

———

205 Leuthner, Steve and Charles Camosy. ‘Problems with the ‘Emergency Exception’ and Consent in the Delivery Room’ (Currently under peer-review at Pediatrics.)
gestation has a margin of error of plus-or-minus three days. In addition, maternal dating based on the last menstrual period is rarely under-estimated. This chapter will later argue that it is important to take some of these post-natal predictors into consideration, but, again, it is important to keep in mind their limitations. This, as we will see below, requires us to be cautious in making hard judgments and recommendations in light of this uncertainty, and shows the need for further study on outcomes for imperiled newborns.

The ‘Culture’ of the NICU

All of this discussion cannot, however, neglect the social context in which NICU treatment decisions take place. One might think that the place to start in exploring the culture of the NICU would be with the attitude and practice of physicians and other clinicians. While this section of the chapter will look at those issues in some detail, it seems clear that—especially in light of the shift to patient and parental autonomy of the 20th century—that we should first briefly look at attitudes and practices of parents if we want a comprehensive understanding of the culture of the NICU.

If should first be said that the overwhelming majority of parents in the NICU want their babies to survive and will often demand that ‘everything be done’ to save their children. This is true for a number of reasons. First it just seems that parents, happily, simply have an innate love for their children and want to see them survive so that they can continue to love them. Second, a good number of babies in the NICU are there precisely due to ‘multiple birth’ complications—and these are often the result of IVF and implantation. Such parents are often quite desperate to have a child: both from a psychological and financial point of view. Third, many parents bring a religious view
into the NICU that God requires them to ‘do everything they can’ for their baby
otherwise they are ‘killing’ her. Since only God can be the author of life and death, they
have a strict duty as parents to err on the side of life and put the rest into God’s hands.206
Speaking with virtually any neonatalogist confirms this generalization. An article in the
Boston Globe exploring parental attitudes toward NICU treatments, for instance, claimed
the following:

But mostly the doctor’s warnings are met with blank stares, or even anger, and
expectant parents choose to hold on to the hope that they will hit the prematurity
jackpot and take home a relatively normal baby. “I have come to the conclusion,”
admits Fiascone [a Tufts Medical Center neonatalogist], “that even when you
explain to parents that the chance of survival without major injury is a very low
percentage, most of them still want you to do everything you can to resuscitate
their baby.”207

That these attitudes of the parents contribute to a ‘culture of the treatment’ in the
NICU is borne out by the sociological literature. For instance, Guillemín and Holmstrom
argue that, “Parents’ sheer determination coupled with their commitment of the survival
of their infant…contributed to the aggressiveness of treatment in the n.i.c.u.”208

But the ‘culture of treatment’ in the NICU is not simply the result of parental
attitude and decisions. Physicians play a major role as well. Guillemín and Holmstrom
argue that, perhaps due to the social structures of the clinical setting where ‘doctors are
suppose to act like doctors,’ the most fundamental decision which contributes to the
culture of the NICU—whether or not to go all out—“was easily was easily and routinely

206 It is certainly worth noting here that, if one accepts the Christian tradition on ordinary and
extraordinary means detailed in Chapter Two, that the this view is fundamentally mistaken.
208 Jean Harley Guillemin and Lynda Lyle Holmstrom, Mixed Blessings: Intensive Care for
made, and the answer was in the affirmative.” (Gulliemin and Holmstrom, 114) They note that, “the decision to be aggressive did not involve long discussion, reflection, or emotional agonizing. On the contrary, such decisions were virtually automatic.” (Gulliemin and Holmstrom, 114-115)

In addition to the ridged and isolated roles and structure of the NICU, another reason physician attitudes and practices contribute to a culture of treatment in the NICU is because a significant number of neonatologists will err on the side of performing the tasks for which they have been trained—especially when success would mean prestige for them among their colleagues. William Silverman, one of the ‘grandfathers’ of neonatology, described precisely this attitude in himself. As a young physician in the 1940’s, Silverman was given the opportunity to treat a ELBW infant about whom he admitted the following: almost no babies of this age ever survived, if the baby did somehow survive he had no idea about the long-term outlook for the child, and if she had been born in another building she would been considered ‘pre-viable’ and simply would have been allowed to die. Nevertheless, Silverman—without getting consent from the baby’s parents—gave the child aggressive treatment. He not only used the standard procedures, but even went so far as to transfuse his own blood into his patient in order to overcome a defect of blood gas transport. Of this move Silverman says the following:

This optimistic suggestion for an untried treatment was just the kind of bold action I was looking for. I began to transfuse infant daily with a few millimeters of my own blood. I quickly became convinced that it was my carbonic-anhydrase-rich blood that was keeping this baby alive—and I was not unmindful of the fact that she was setting a new hospital record for longevity! Now, was this overtreatment [original emphasis]…? The question never entered my head! And

---

it never seem to occur to my teachers. The baby was presented at grand rounds as a triumph of mechanism-guided treatment, and I was made to feel like a hero. My rescue fantasy was fulfilled. (Silverman, 971)

Modern-day grand rounds in research hospitals with a NICU suggest that little has changed with regard to these kinds of stories today.

But a third factor most certainly contributes to the attitude and practices of physicians in the NICU: the law. Or, perhaps better, clinical perception or fear of the law. Prior to the 1980s, claims Norm Fost,\(^\text{210}\) courts were generally supportive of decisions to remove life-sustaining and curative treatment of neonates who had Down syndrome and spina bifida. This was true even “when it was implausible that withholding treatment was in the child’s interests.” (Fost, 2041) This all changed with the case of ‘Baby Doe’—an infant with Down syndrome and esophageal atresia who was refused curative treatment because the parents decided that the baby’s life was not worth living. The Regan administration, spurred on by disability rights and pro-life groups, cracked down on states receiving federal funding by, with limited exceptions,\(^\text{211}\) demanding that NICUs provide medically necessary treatment regardless of mental disability. Otherwise clinicians and hospitals would be subject to prosecution under federal child abuse statutes and loss of federal support. Some NICUs even had red phones in them that had direct lines to federal authorities to be used to report any ‘Baby Doe’ type situations being considered and executed.


\(^{211}\) Exceptions were allowed for infants in irreversible coma, for treatments that were futile, and for treatments that were “inhumane,” although the definition of that term has been the subject of continuing controversy.
The result of this shift, says Fost, is that a “prolonged history of what is now perceived as serious undertreatment of infants with reasonable prospects for living a meaningful life was replaced by an era of serious overtreatment. One form of child abuse, neglect, was replaced by a form of medical battering.” (Fost, 2041) John Lantos suggests that the legal situation is such that doctors today simply don’t want to risk “what a judge might say” and thus might say to a child’s parents, for instance, “It is considered child abuse not to operate on your baby’s intestinal blockage, even though the baby has Down syndrome.” Most parents do not want to be charged with child abuse and to face a legal proceeding they know they will lose, so they agree to the surgery without the need for going to court. In such cases, the law has an effect even though the effect is not measurable through the frequency of its use. (Lantos, 82-83) Indeed, the law seems to have had an effect even beyond what it actually was intended to do. In a study called ‘The Appleton Consensus’—convened by an international group of physicians, ethicists and medical economists—it was found that:

U.S. neonatologists widely agree that the [Baby Doe] law is believed to require overtreatment of infants, and this results in practice in many terminally ill infants receiving inappropriately aggressive care for long periods. This is an inaccurate interpretation of what the law requires. Current U.S. Federal law simply mandates that states that wish to receive Federal grants for child abuse and neglect services must have in place a mechanism to review suspected cases of "medical neglect." No treatment of infants is mandated by that law and no penalties against physicians, parents, or hospitals for non-treatment are contained within the law…If U.S. neonatologists employ overly aggressive treatment, they cannot blame it on the current state of U.S. law. (Stanley, 18)

Lantos also notes something essential about Baby Doe and the NICU ‘culture’ (legal and otherwise) for the context of this discussion:

---

After the Baby Doe controversy, in which the federal government tried to mandate the treatment of almost all newborns, it became difficult to imagine a public policy in the United States that would allow care to be systematically limited. Instead, the opposite happened. Public policies were enacted that generously reimbursed NICUs. (Lantos, 129)

This fact will become especially important when considering the economics of the NICU.

In addition, it is worth noting that this ‘culture of treatment’ is not something which exists uniformly around the world, but is especially strong—and perhaps unique—in the United States. In another international study, this time about neonatologists’ attitudes and practices in Europe, it was found that while making a decision to withhold or withdraw life-sustaining treatment based on ‘poor neurological prognosis’ grounds “raises issues of discrimination against the disabled, as the American ‘Baby Doe’ regulations clearly point out,” this was not a significant moral distinction in the majority of European countries studied. Indeed, “the proportion of physicians involved, at least once in the course of their professional life, in decisions to forego treatment because of poor neurological prognosis is very close to that for fatal and terminal conditions.”

This section of the chapter has attempted to give evidence for a very strong ‘culture of treatment’ in the American NICU. The next will attempt to show how this culture has a direct economic impact on both the NICU and the wider healthcare system in the United States—and that such an impact is open to serious critique from Catholic Social Teaching.

**Economic Considerations**

---

Finding out how much we spend in the NICU in the United States is not an easy business. Private insurance companies (who have no public reporting requirements) pay for a large share of the care, but (as we will see later in the chapter in some detail) so does Medicaid—and because Medicaid is administered by states with their own rules and regulations it is difficult to estimate total costs even with public reporting. Lantos attempts to estimate it by taking a study of 25 NICUs from 1993-94 and adjusting for modern-day numbers.\textsuperscript{214} He suggests that “the direct cost of NICUs in the United States in 2004 could be estimated at about $21 billion.” (Lantos, 124)

But what about more specific cost information relevant to this dissertation? A 2005 study which looked at data from several hundred thousand live births in California found that “costs increase dramatically with decreasing birth-weight. Average total hospital costs for infants who weighed 2000-2499 g at birth were ~$1200 compared with average hospital costs of nearly $119,000 for infants who weighed 1000 to 1249 g at birth.”\textsuperscript{215} This was due in part to “increasing use of advanced medical technologies and complex medical and surgical procedures” but it also was affected by longer hospital stays in general. For babies with a birthweight between 750 and 999 grams, their median length of stay was 71.0 days. For babies with a birthweight over 2500 grams, the median length of stay was 2.0 days. The median daily cost for those in the former category was $2380 and a median total cost per stay of $165,248. By contrast, the median daily cost

\textsuperscript{214} In his adjustment he simply assumes that the numbers of NICU admissions are about the same 10 years later—but gives us no reason to accept this assumption. Given the increase in IVF, multiple births and the corresponding ELBW babies—to say nothing of the dramatic increase in NICUs (which he himself cites a few pages later)—this is very little reason to accept it. And there is very good reason to think that the total cost is higher, and perhaps substantially so.

for those in the latter category was $316 and a median total cost per stay of $570. (Schmitt, 157) These costs for low birthweight babies ‘make up a hugely disproportionate share’ of the total hospital costs on infants. Consider that very low birthweight infants accounted for only 0.9% of the cases, but for a whopping 35.7% of the costs. Low birthweight infants account for only 5.9% of the cases, but a dramatic 56.6% of the costs. It is simply remarkable that only about 7% of the cases account for over 90% of the total costs.

The California study is self-consciously aware that it is dealing only with premature deliveries, but also notes that “congenital anomalies are another significant cause of neonatal costs, and most of these infants are term deliveries…[And] in a simple classification of the cases with major congenital anomalies, they represent a similar disproportionate share of neonatal hospital costs.” (Schmitt, 159) A report from the Centers for Disease Control and Prevention have outlined some of the NICU data with respect to specific birth defects in some detail.216 The average length of stay was longest for those babies with surgically repaired gastroschisis: 41.0 days. Other numbers of note included spina bifida: 15.1, pulmonary valve stenosis: 22.8, esophageal atresia: 31.3, down syndrome: 11.1, trisomy 13/18: 7.7/10.2. The most expensive NICU charges were for two congenital heart defects: hypoplastic left heart at $199,597 and common truncus ateriousus at $192,781. Other cost numbers of interest included: spina bifida: $65,342, pulmonary valve stenosis: $80,814, esophageal atresia: $136,631, down syndrome: $38,745, and trisomy 13/18: $30,021/$39,547. (CDC, 28)

216 Center for Disease Control and Prevention, "Hospital Stays, Hospital Charges, and in-Hospital Deaths among Infants with Selected Birth Defects- United States, 2003," (2007).
These numbers have the power to produce strong reactions all by themselves. But, of course, they do not exist in a contextless socio-economic vacuum—and locating in that context makes them even more powerful. Though not necessarily the same as today’s context,\textsuperscript{217} MH Shearer provided the context for such numbers at the beginning of the 1980s.\textsuperscript{218} She points out that even though the nursery and labor/delivery unit had traditionally been loss leaders in hospital accounting, the reimbursement rates of Medicaid, Handicapped Children’s Services, and Blue-Cross/Blue-Shield in the NICU are much higher and actually make the NICU a profit center for a hospital. One result of this was an 18\% increase in the number of NICUs with concomitant reduction in newborn nursery space. Another result is that in order to match the professionally required occupancy rate for NICU beds mildly sick or even healthy newborns are being admitted. (Shearer, 234) Lantos also cites numbers from the 1980s which confirm this. The NICU at Stanford University, for instance, though it only made up 3.7\% of the total hospital beds, generated 4.7\% of the revenue for the hospital. In addition, 82\% of the faculty-generated revenue for patient care in the department of Pediatrics came from the NICU—subsidizing the entire department and, to some extent, the entire hospital. (Lantos, 130)

Lantos argues that these trends continue today in part because the NICU is one of the few areas where in which inpatient activity is increasing rather than decreasing. (Recall the numbers with regard to average hospital stays cited above.) Indeed, he goes even father and makes the following dramatic claim:

\textsuperscript{217} Though it will become clear later that it is much the same.  

\textsuperscript{218} M. H. Shearer, "The Economics of Intensive-Care for the Full-Term Newborn," \textit{Birth} 7, no. 4 (1980).
The NICU has become the economic engine that keeps our children’s hospitals running. The survival of hospital-based pediatrics as we know it is increasingly dependent on continued commitment to the technologies and the personnel that enable the survival of extremely premature babies. (Lantos, 131)

In support of this claim he cites his own University of Chicago Hospital which he claims, though it only accounted for 4% of the patients in the hospital in 2002, accounted for a whopping 10% of the revenue. Put another way, “the total operating margin of UCH in that year was $23.8 million. Of that, $11.4 million, or 48%, came from the NICU.” (Lantos, 131)

Another trend that continues today is NICU-building in relationship to hospital strategic planning. In an effort to boost profitability, NICU building continues at a rapid pace. Lantos notes that his own UCH, due in part to NICU profitability, was able to build a brand new children’s hospital in 2005—with, of course, 10% more NICU beds. He also cites a hospital in Boston which on August 30th 2002 had its bond rating downgraded ‘due to the hospitals declining operating performance.’ On November 20, 2002 it was reported that the hospital was building a 10-bed NICU—making it the first non-teaching hospital in the state to do so. (Lantos, 31)

A third trend that continues is the number of NICU beds outpacing need and questionable practices in order to deal with this problem. Lantos cites a study which showed that from 1980-1995 the number of hospitals grew by 99%, the number of NICU beds by 138% and the number of neonatologists by 268%. By contrast, the growth in needed NICU bed days was only 84%. A study appearing in a 2007 issue of Pediatrics found that when the NICU census “was in the highest quintile, patients were

---

32% more likely to be discharged when compared with all of the other quintiles of unit census.” However, when the NICU census “was in the lowest quintile, patients were 20% less likely to be discharged when compared with all of the other quintiles of unit census.” (Profit, 314)

International comparisons also suggest that “proliferation of NICUs in the United States, driven by their profitability, is leading to profligate overuse of NICU technology.” (Lantos, 134) For instance, the United States has 6.1 neonatologists per 1000 live births. By way of comparison, Australia, Canada and the UK have 3.7, 3.3, and 2.7, respectively. Better results, however, have not been produced in the United States. The relative risk, with United States as a reference, of neonatal mortality for infants less than 1000 grams was 0.84 for Australia, 1.12 for Canada, and 0.99 for the UK. With respect to infants 1000 to 2499 grams, the relative risk was 0.97 for Australia, 1.26 for Canada, and 0.95 for the UK. (Lantos, 134)

This first part of the chapter attempted to highlight prevailing practices and attitudes with regard to neonatal treatment in the United States. Many of these practices and attitudes—especially with regard to the ‘culture’ of the NICU and the resulting economic considerations—are in need of serious critique. The second part of the chapter attempts to level just such a critique in light of Catholic Social Teaching.

**NICU Attitudes and Practices: A Critique**

The first part of this chapter marshaled evidence that there is a ‘culture of treatment’ in American neonatal intensive care units. Let us review the major factors contributing to this culture:
1. The attitude and perspective of parents who most often ‘want everything done.’ (Sometimes based on a misunderstanding of the Christian tradition on withdrawal and refusal of treatment.)

2. The institutionalization of NICU treatments. ‘Doctors act like doctors.’ ‘Nurses act like nurses.’ And so on. Healthcare professionals simply treat illness. They are neither trained nor encouraged to take broader goods into consideration.

3. The prestige and ego factor. Some neonatologists admit that this is a motivation in some cases of overtreatment.

4. The law: both in its indirect perception and its direct application. Many clinicians (wrongly) believe that the Baby Doe regulation and what has followed demand that they engage in treatment behaviors which contribute to a NICU culture of treatment.

5. NICU treatment profitability. The market helps to contribute to the culture of treatment as well.

   This culture of treatment has led to:

6. NICU treatment that is disproportionate with the rest of the healthcare in the United States. This is especially true when one considers the share of resources allotted to low birthweight babies and babies with congenital anomalies. Also of note is the dramatic increase in new NICUs and the number of neonatology specialists.

   Of course, chapters two and three already gave us one direct critique of this situation. Even when we are considering the ‘individualistically narrow’ best interests of the imperiled newborn, the culture of treatment in the NICU sometimes (and perhaps often) loses those considerations in favor of some of the considerations mentioned above.

   And the Christian tradition on ordinary/extraordinary means supports such a critique.

   But what Chapter Three of the dissertation attempted to show was that this critique can and should go wider and deeper—with a much broader understanding of what it means to talk about what is it someone’s ‘best interests.’ It is to this broader critique we now turn.

Catholic Social Teaching and the ‘Culture of Treatment’ in the NICU
The first thing that Catholic Social Teaching will demand of us is that we look at the NICU culture of treatment in the broader healthcare context in which it takes place.\textsuperscript{220} Though some of this context was mentioned in chapter three, it is worth reviewing here again. The United States, despite spending nearly 2 trillion dollars on health care annually (far and away the highest in the world—even as a percentage of GDP), has 45-50 million of its citizens without health insurance at all and has anywhere from 15-49 million more that are under-insured: those with medical needs not covered by their insurance, medical needs that are covered but with high co-payments that force beneficiaries to forego or delay treatment, or significant out-of-pocket healthcare expenditures in excess of 10% of one’s income. Programs designed to help the poor in this regard—primarily state-run Medicaid programs—are not solvent and (as we saw with TennCare in Chapter Three) are often forced to drop even those with life-threatening conditions. Those without health insurance, or who are forced to delay treatment, are four times more likely to require avoidable hospitalization and emergency room treatment for conditions like diabetes, asthma, hypertension and pneumonia—as well as being far more likely to be diagnosed with late-stage cancer. All this culminates the United States lagging far behind other countries—many of which spend dramatically less on healthcare—on important health metrics like life-expectancy, infant morality, obesity, and other morbidity rates.\textsuperscript{221}

\textsuperscript{220} Of course, it will also demand that we look at other social contexts: worldwide healthcare problems, other resources allocation contexts, etc. However, despite these being important questions, they go beyond the scope of this dissertation. It is certainly an area for future work and study.

\textsuperscript{221} The Catholic Health Association of the United States. “Continuing the Commitment: A Pathway to Health Care Reform.” (April 2000)
We have already seen at the end of Chapter Two, and much of Chapter Three, that the anthropology of Catholic Social Teaching is such that a human person is fundamentally and intrinsically social. This can be described in theologically ‘thick’ ways (such as by appealing to human beings having been made in the image of an essentially relational, Triune God) or with simple appeals to the empirical fact of our multiplied social interconnections—especially in light of a globalized world. John Paul II reminds us that our fundamental sociality implies a duty of solidarity in which ‘all really are responsible for all.’ And on what should this duty focus? Recall the ‘first principle’ of CST:

The right to the common use of goods is ‘the first principle of the whole ethical and social order’ and ‘the characteristic principle of Christian social doctrine’…it is innate in individual persons, in every persons, and has priority [emphasis in the original] with regard to any human intervention concerning good, to any legal system concerning the same, to any economic or social system or method: ‘All other rights, whatever they are, including property rights and the right of free trade must be subordinated to this norm [the universal destination of goods]; they must not hinder it, but rather expedite its application.

But, of course, what one means by a duty to promote the common use of goods is in need of further explanation. Drew Christiansen has argued that “the common good, as John XXIII understands it, demands keeping broad inequalities in check.”

But also recall that one’s response to inequality cannot simply be to distribute goods equally without social context. No, the concept of equality—at least since the social teaching of Paul VI—is directly connected to participation. He says:

---

222 Pontificium Consilium de Iustitia et Pace, *Compendium of the Social Doctrine of the Church*, 82.

223 Kenneth R. Himes, *Modern Catholic Social Teaching: Commentaries and Interpretations* (Washington: Georgetown University, 2005), 228.
While scientific and technological progress continues to overturn man’s surroundings, his patterns of knowledge, work, consumption, and relation, two aspirations persistently make themselves felt in these new contexts, and they stronger to the extent that he becomes better informed and better educated: the aspiration to equality and the aspiration to participation, two forms of man’s dignity and freedom.224

The US Bishops would build on Paul VI’s understanding of the relationship between equality and participation by claiming that justice demands “the establishment of minimum levels of participation in the life the human community for all persons,” and that “social institutions be ordered in a way that guarantees all persons the ability to participate actively in the economic, political, and cultural life of society.”225

In determining whether attitudes and practices in the American NICU are proportionate with the common good, then, we have to ask about its relationship to the ability of all persons to ‘actively participate’—and in this context, to actively participate (at a minimum level, at least) in the life of the health care community. The ‘Culture of Treatment’ in the NICU—when looked at as a whole—certainly has produced lots of participation: 1.6 million life-years added each year. However, when we look at more specific aspects of NICU treatments, its relationship to participation becomes much cloudier—especially if we look at NICU babies with extremely low birthweights and with certain kinds of congenital anomalies. Such babies, as described above, make up a very small proportion of a hospital patient census but require a shockingly disproportionate share of medical resources. Indeed, this is true simply on the level of


individual payments considered at a particular point in time—but it is even more worryingly disproportionate when one considered the economic results that such treatments produce. Namely, a dramatic and disproportionate shift of limited healthcare resources to imperiled newborns and away from others who are without even a ‘basic minimum’ level of participation in the American healthcare system.

A major reason why such a ‘Culture of Treatment’ in the NICU exists at such variance with the common good is because of the kinds of social structures which underlie such treatment: the individualistically narrow roles of neonatal clinicians, technological idolization, hiring and promotion of medical researchers and professors, stacked legal rulings and the culture of health care litigiousness, and the market forces involved in healthcare. The United States Bishops, when talking specifically about healthcare, have this issue at the center of their discussion. Our duty of solidarity requires us to “correct any unjust social, political and economic structures and institutions which are the causes of suffering.” John Paul II goes so far as to call such structures *sinful*:

If the present situation can be attributed to difficulties of various kinds, it is not out of place to speak of ‘structures of sin’ which… are rooted in personal sin and thus always linked to the concrete acts of individuals who introduce these structures, consolidate them, and make them difficult to remove. And thus they grow stronger, spread, and become the source of other sins, and so influence people's behavior. ‘Sin’ and ‘structures of sin’ are categories which are seldom applied to the situation of the contemporary world. However, one cannot easily gain a profound understanding of the reality that confronts us unless we give a name to the root of the evils which afflict us.

---


227 Pope John Paul II, *Sollicitudo Rei Socialis*, 36.
Catholic Social Teaching is particularly aware of two kinds of sinful social structures—both of which are related to each other—the ‘technological imperative’ and the unrestrained free market. It is supremely aware that:

The present historical period has placed at the disposal of society new goods that were completely unknown until recent times. This calls for a fresh reading of the principle of the universal destination of goods of the earth and makes it necessary to extend this principle so that it includes the latest developments brought about by economic and technological progress…New technological and scientific knowledge must be placed at the service and mankind’s primary needs, gradually increasing humanity’s common patrimony. (Pontifical Council for Justice and Peace, 179)

Catholic Social Teaching warns that any social structure where use of technology is an ‘end in itself’ (Pontifical Council, 554) is sinful because it does not take into account the ultimate end of these and all goods. Technologies, “like all goods, have a universal destination [original emphasis]; they too much be placed in a context of legal norms and social rules that guarantee that they will be used according to the criteria of justice, equity and respect of human rights.” (Pontifical Council, 283) Insofar as NICU treatments drive a technological imperative that is unaware of—or even antithetical to—a universal destination of goods aimed at equality of participation in the healthcare community, they are part of a sinful social structure that works against the common good.

Catholic Social Teaching is also aware of another sinful social structure—one that no doubt drives some of the technological imperative—that of a free market without due regulation. While private property is a ‘highly necessary’ sphere and ‘ought to be considered part an extension of human freedom,’ it is “in its essence only an instrument for respecting the principle of the universal destination of goods; in the final analysis therefore, it is not an end but a means.” (Pontifical Council, 176-177) The market’s regulation of such property is an ‘irreplaceable instrument’ for an economic system, but
most certainly needs to be disciplined by ‘ethical objectives.’ In order to do this, one must be aware that the market alone cannot be entrusted with the task of supplying every category of goods—for some goods, by their very nature, are not and cannot be mere commodities. This is easily seen “in [the market’s] proven inability to satisfy important human needs.” (Pontifical Council, 349) One of these needs, most certainly, is the need for healthcare. And in this context one can see quite clearly how the sinful social structure of the improperly regulated market works in the culture of treatment in the NICU: the profitability of such treatments drive resources toward imperiled newborns—and away from other needy patients—in a way that is disproportionate with the common good.

**Catholic Social Teaching on Solutions to the Problem**

If it is indeed the case that NICU treatments of certain imperiled newborns are disproportionate with the common good, then what suggestions does Catholic Social Teaching have for dealing with this problem? The first thing to mention is that it self-consciously aware of its limitations with regard to technical solutions and therefore does not “propose or establish systems or models of social organization.” (Pontifical Council, 68) However, it does give some broad outlines and principles to use in dealing with these kinds of problems. At a most basic level, the market and State are to act in concert and compliment each other: with the State organized in such a manner as it gives an ethical direction to economic development. Because equality, and therefore participation, should

---

228 And the dissertation is a long way from having shown this—more counter arguments will be dealt with later in this chapter.
be at the heart of such direction, it becomes necessary for the State to regulate ‘certain sectors of the market’ which are ‘not able to guarantee an equitable distribution of goods and services that are essential for the human growth of its citizens.’ (Pontifical Council, 353) The public authorities, in this context, are “called to carry out substantial reforms of economic, political, cultural and technological structures and the necessary changes in institutions.” (Pontifical Council, 197) For, “If it is true that everyone is born with the right to use the goods of the earth, it is likewise true that, in order to ensure that this right is exercised in an equitable and orderly fashion, regulated interventions are necessary, interventions that are the result of national…agreements.” Equality and Solidarity are explicitly invoked in this context as essential principles for informing ‘redistribution of resources’ and ‘public spending.’ (Pontifical Council, 173 and 355)

In the case of the disproportionate treatments resulting from a Culture of Treatment in the NICU, then, Catholic Social Teaching proscribes regulation by the public authorities aimed at the common good, equality and participation. This becomes even more morally urgent given the health care crisis described above. As Joseph Boyle argues, in cases of “systematic scarcity [which is certainly the case with currently available health care resources in the United States] someone in authority in a community or institutional system must decide that some resources will be directed to meeting certain needs of community members, and as a result become unavailable to meet other needs of all of some in the community.” Indeed, “One purpose of authority in Catholic Social Teaching is to coordinate the actions of individuals so they can cooperate for common goods. The need for the kind of social choice authority makes possible is especially urgent when moral problems emerge that cannot possibly be solved by the
uncoordinated actions of even the most conscientious individuals and small communities.”

These hard choices need to take place in a realistic context—a context which understands that human needs, whether medical or otherwise, will always out-strip resources. This is the nature of the finite beings we are and the finite world in which we live. As Mark Cherry argues, all health care—and not just NICU treatment—“is provided with in the conditions of human finitude. It is false to assume that all can be provided equal care, the very best of care, with physician and patient choice, without rationing, while still managing to control costs…such a view, however prevalent, fails to face the economic, medical and moral realities of healthcare. It represents an ideology, a false consciousness, which all economic indicators and empirical experiences show to be false, but the reality of which few are willing to openly confront.” (Engelhardt and Cherry, 20) This dissertation attempts to use the resources of Catholic Social Teaching to openly confront the sinful social structures of the Culture of the Treatment in the NICU—and the uncomfortable conclusions which may follow from addressing them. Indeed, in attempting to change such structures to allow ‘basic minimum’ participation for all persons in the healthcare community of the United States, we may find that—as John Paul II warned us—it may not be enough to draw upon our ‘surplus’ goods. We may need to make dramatically uncomfortable sacrifices toward this end.

An ‘Asked and Answered’ Rejoinder?

If one had simply read this chapter in isolation from chapters two and three one might take this conclusion to be absurd on its face. Surely the duty of medical personnel in the NICU—or anywhere else—cannot be to have such broad considerations of economic justice in mind; surely their duty is to the patient in front of them. Limiting neonatal treatment will force clinicians to abandon patients in a way that flies in the face of the very foundation of medicine and is a clear affront to human dignity.

But recall the response to these worries in chapters two and three. Clinicians, if they are really acting in the best interests of their patients, cannot treat patients in social isolation—as if one’s good could be socially separated from the good of others. No, part of what it means to act in the best interests of a patient is to offer treatments consistent with the common good and refuse treatments which are disproportionate with it. Hardly an affront to human dignity or the foundations of medicine, this is exactly the kind of reasoning in the case of triage medicine—when medical need most clearly and directly outstrips resources. In such a case, the choice is not between ‘abandoning’ and ‘not abandoning’—but rather how and on what basis persons (with full moral status) will be (tragically) abandoned. Given the problems of accessibility to our healthcare system mentioned above, it is simply a ‘hard truth’ that—in the absence of sweeping healthcare reform\(^\text{230}\)—we are in a tragic triage situation right now. We are abandoning patients right now. The question is, “Are we going to continue to abandon them in a way that our sinful social structures demand—or are we going to abandon them in the way that the common good demands?” As mentioned in Chapter Three, these are difficult questions,

\(^{230}\) At the time of the writing of this chapter, even the most comprehensive healthcare reform that has a chance of passing does not appear to get around these problems. More to come on this question in the conclusion to the dissertation.
but that is no reason for not openly confronting them. The participation of tens of millions in our healthcare community depends on it.

But perhaps one reason why some fail to see the applicability of triage reasoning with regard to our healthcare system is because the analogy fails. In a real triage situation, the resources (whether time, hospital beds, ventilators, vaccines, etc.) in play are all being used for the needy patient community in question: a battlefield, disaster-area, etc. When resources are limited for some patients in the community, it is because they will go directly to the other needy patients. Perhaps this is analogous to single-payer healthcare systems in Europe with fixed budgets, but it is less clear that this applies to the ‘fee for service’ private system in the United States. If a battlefield medic passes over one patient, it is because her resources will be better used to serve the common good elsewhere. But if the US federal government were to limit neonatal treatment, say, by having a system like the Netherlands where no babies under 25 weeks will be treated, it isn’t at all certain that the resources would then go to places which better serve the common good. Indeed, if the patient was covered by private insurance, the resources could go any number of medical uses which the insurance company covers: hip replacements, Viagra, acid reflux, and hundreds of other maladies which would not proportionally serve the common good.\(^{231}\) If the US healthcare system isn’t analogous to a triage situation, why use triage reasoning to back up proposed reforms?

The first thing to say in response to this question is that not all of the proposed reforms that will follow in the final part of this chapter are dependent on the triage

---

\(^{231}\) It is also a distinct possibility that much of the saved resources would go into the pockets of the insurance company’s shareholders.
analogy. Even if the analogy does not work, the sinful social structures still exist in the system and some practical remedies will be suggested that have nothing whatever to do with triage reasoning. But the second thing is that we do have something like a single-payer system, often with a fixed budget, with regard to healthcare delivery: Medicaid. Though it was described a bit in chapter three, let us take a more detailed look at the program to see if the triage analogy—and resulting critique—does, in fact, follow.

**Medicaid**

The largest growth in an entitlement program in the United States during the last part of the 20th century was to be found in Medicaid. In 1984 the Medicaid program spent $38 billion, 4.4% of the federal budget, 0.97% of GDP and covered 22 million persons. By 1999, the program spent 172 billion, 9.7% of the federal budget, 1.9% of GDP and covered 38 million persons. This growth is even more remarkable given a nearly parallel rise in the numbers of non-elderly persons without health insurance—the major part of the population Medicaid was designed to serve.

Medicaid is actually four public insurance programs in one that serves four groups of needy patients. It provides:

1. Coverage of most medical expenses for low-income women and children families.
2. Supplemental portions of medical expenditures not covered by Medicare for the low-income elderly.
3. Coverage of most medical expenses for low-income disabled.

---

4. Payment of the nursing home expenditures for many of the institutionalized elderly.

The first function encompasses about 2/3 of the program’s enrollees, while the last three functions encompass about 1/3. (Gruber, 1)

Though the federal government puts significant resources into Medicaid, each State administers their own program with some discretion to be balanced against federal regulation and oversight by the Health Care Financing Administration and the Department of Health and Human Services. But in general the program is designed to provide healthcare to the very poor in the groups mentioned above, though the states have significant leeway when determining eligibility criteria—which is usually based on some baseline related to a federally or state-determined poverty level.

Though states have some significant freedom to determine eligibility, they have much less discretion when it comes to covered services. Generally, all enrollees are mandatorily entitled to the following:

- inpatient hospital services
- outpatient hospital services
- rural health clinic services
- federally qualified health center services
- other laboratory and x-ray services
- nursing facility services for individuals 21 or older
- EPSDT services for individuals under age 21
- family planning services
- physicians’ services
- home health services for any individual entitled to nursing facility care
- nurse-midwife services
- services of certified nurse practitioners and certified family nurse practitioners

(Gruber, 11)

According to the Balanced Budget Act of 1997, however, states have full discretion to determine their own reimbursement plans for such services so long as they provide public
notice of their proposed rates and the methods for determining those rates. Most states use:

a purely prospective system of rates that either pay a fixed amount per day, or for the entire stay for a given diagnosis, while some states use a hybrid of retrospective and prospective reimbursement. Some states also negotiate rates with hospitals through a bidding process, whereby the states restrict enrollees’ choice of hospital, and negotiate with hospitals for the right to provide services to Medicaid enrollees. In 1990, the American Hospital Association estimated that, on average, Medicaid reimburses hospitals for roughly 80% of their costs. (Gruber, 13)

All providers are required to accept Medicaid payment rates as payment in full. And when one combines the dramatic rise in Medicaid enrollment and spending growth with the fact that Medicaid reimburses at a significantly lesser rate than does private insurance, “providers are often reluctant to treat Medicaid patients, thus reducing the value of their coverage.” (Gruber, 28) Indeed, the Physician Payment Review Commission found that 38 states identified low fee reimbursement as the major cause of low physician participation rates. For instance, a large body of research suggests that, “increasing the ratio of Medicaid fees relative to private sector fees will increase physician participation in the program.” (Gruber, 54)

Indeed, it appears that this kind of increase would have a direct impact on something of interest to this dissertation: infant mortality. When projecting based on data gathered over a period from 1979-1992, it appears that “doubling the fee ratio would lower infant mortality by 5.2-7%.” (Gruber, 55) In addition to reimbursement rates, Medicaid eligibility expansions also had a significant effect. For instance, during that 1979-1992 period there was a 30% rise in eligibility which was associated with an 8.5%

233 Which, importantly, is dominated by home health expenses and in particular home nursing. (Gruber, 22)
decline in the infant mortality rate. Furthermore, one could consider ‘targeted
expansions’ of Medicaid reimbursement which would deal with treatment and care
directly related to imperiled newborns rather than of all Medicaid treatments.
Interestingly, it appears that targeted expansions work much better—at least with regard
to infant mortality—than expansions that are more broad: an 11.5% decline in infant
morality associated with the former and only 2.9% with the latter. In addition, and again
quite important for this dissertation, there is also “a very sizeable reduction in the
incidence of low birthweight associated with targeted expansions (7.8% lower for a 30
percentage point eligibility increase), but there is no effect on low birthweight from the
broad expansions.” (Gruber, 51-52)

In terms of priorities when talking about reform going forward, Gruber suggests
that though Medicaid eligibility expansion gets most of the attention (the SCHIP debates
being the most obvious example of this), two other areas of reform are necessary. First is
‘long-term care’—the largest share of Medicaid program spending. But second is
Medicaid reimbursement policy. Work on physician reimbursement suggests that more
generous fee schedules can lead to more access to physicians and Medicaid patients, and
ultimately to better health outcomes.234 (Gruber, 71-72)

Medicaid and Triage

234 Gruber expresses frustration that more work has not been done in this area—especially given
the literature that exists on Medicare reimbursement. He says that, “Variations across states, and within
states over time, in Medicaid reimbursement policies offers the potential for rich investigations of how
hospitals respond to reimbursement differences. Moreover, there is no work on the health impact of these
hospital responses. While the state reimbursement rules may be difficult to obtain, this is clearly an
interesting area for further work.” (72)
We can now see how the triage analogy would work with Medicaid. Each state has a single pool of money with which to work—or, perhaps in certain situations, has to view it as if it were a single pool in terms of controlling costs. Making tough fiscal choices is essential now more than ever because—due to the dramatic increase in Medicaid costs, significantly less funding from the federal government, and mismanagement by the states—“The integrity of the Medicaid program is threatened as Medicaid budget shortfalls have occurred in more than half the states, and [were] anticipated to occur in 40 states in 2006.”

Due to these shortfalls Medicaid budgets have to be severely limited, and therefore each state has to make triage-like decisions about who will be eligible for the program and then at what rate they will reimburse for treatment to control how much is spent.

Having a relatively high reimbursement rate for NICU care (which we will see in more detail later in the chapter)—especially when it comes to the very expensive treatment of Medicaid ELBW babies and those with congenital anomalies—means that a significant number of resources are being used that then cannot be used elsewhere for other Medicaid payments. And, just as in a more traditional triage situation, if NICU treatments were somehow limited then those resources would then be available to for other Medicaid payments—either in the form of higher reimbursement rates for existing enrollees or in the form of an increased threshold for eligibility in the program. Either way, as Gruber shows, health outcomes would improve.

---

And we could look at the patient population which is the subject of our triage reasoning as at least two different groups. First, we could look at treatment in proportion to the entire Medicaid population. In this case, in doing our proportional analysis of a particular NICU treatment we would compare the good of the treatment itself with the good it could do with regard to all Medicaid enrollees—at least in the particular state we in question. So let’s say Medicaid reimburses a hospital $467,567 for a 675 gram baby treated in the NICU. That means there will be 467,567 fewer dollars for use, not only for poor babies and their mothers, but also the low-income disabled and elderly and those in nursing homes—often for far less expensive treatments. Mostly obviously, this affects a state’s eligibility threshold in deciding who could be a part of the program. Recall chapter three’s discussion of Tennessee’s Medicaid program which had to drop 120,000 people (many with life-threatening illnesses) from Medicaid due to budget shortfalls.

This, all by itself, would be enough to rethink how we apportion money in Medicaid, but there is another factor to consider: the quality of the care for those who are eligible. As we have seen from Gruber above, a major contributor to substandard care comes from the relatively low rates of physician and hospital reimbursement—but this just another reality faced by states finding it necessary to control costs. An article from the Journal of the American Medical Association found that quality is lacking in Medicaid’s care—and especially in the 60% of enrollees in managed care plans.236 Just to give a few of many examples where the level of care fell short:

- Blood pressure control for hypertension control achieved: 58.4% for Commercial Plans, 53.5% for Medicaid

---

• Timely Prenatal Care: 86.9% for Commercial Plans, 69.4% for Medicaid
• Postpartum Care: 77.2% for Commercial Plans, 40.7 for Medicaid
• Recommended Breast Cancer Screening: 75.1% for Commercial Plans, 52.6% for Medicaid
• Glycated Hemoglobin tested in diabetes patients: 82.6% for Commercial Plans, 73.4% for Medicaid
• Glucose Controlled in diabetes patients: 66.3% for Commercial Plans, 47.4% for Medicaid
• Childhood immunization rate: 68.7% for Commercial Plans, 54.0% for Medicaid

In addition to these startling numbers, one must also focus on the hit that the elderly—and especially those in nursing homes—take from substandard Medicaid care. A study published in the *Journal of the American Geriatrics Society* found, for instance, that “State Medicaid reimbursement rates appear to affect clinical decisions regarding the need for hospital admission and thresholds for nursing home use.”\(^{237}\) It also directly affects mortality rates for those in nursing homes. Jennifer Troyer has found that the “overall mortality rate for Medicaid residents was 14.8% points higher than the death rate for privately funded residents. When considering death within 1 year and 2 years, Medicaid residents’ deaths were 4.2% and 7.8% higher, respectively.”\(^{238}\) She suggests that one possible reason for this is that Medicaid residents are segregated into lower quality facilities—something that makes perfect sense in the context of dramatic attempts to cut costs.

Children also suffer from the lack of quality Medicaid care. For instance, Medicaid-covered children are more likely to receive care in institutions with higher


mortality than their commercially insured counterparts. In addition, Medicaid recipients have higher death rates within groups of institutions that had similar overall mortality rates. Thus, even when Medicaid recipients were cared for at institutions demonstrating the lowest mortality, their overall odds of dying were more than twice that of commercial recipients. Consider specifically, for instance, that in addition to poor children naturally having a higher risk of Type 1 diabetes, they are significantly more likely to get substandard care as Medicaid enrollees. Low continuity of primary care for children on Medicaid contributed to disproportionately exacerbated conditions like diabetic ketocidosis. And who could forget the February 2007 story of 12-year-old Deamonte Driver’s death as a result for complications from an infected tooth. In addition to the fact that his Medicaid coverage had lapsed due to paperwork issues (it probably was mailed to a homeless shelter where his family was no longer staying), another complication was even finding a dentist to see in the first place. Though the federal government requires Medicaid programs to cover dental needs for children, the low Medicaid reimbursement rates make it difficult to find a dentist who will see such patients—particularly in rural areas.

But we could also look at our patient population in a more narrow sense when using the triage analogy. Perhaps we could look at treatment of imperiled newborns in proportion to the good of the whole NICU patient population. Coming at it this way, in


doing our proportional analysis of a particular NICU treatment we would compare the
good of the treatment itself with the good it could do for all NICU babies in the particular
state in question. So if Medicaid reimburses a hospital, again, $467,567 for a 675 gram
baby treated in the NICU, this is 467,567 less dollars to use to either for improving the
fee ratio and/or for targeted eligibility expansion. And, as Gruber argues above, both
would (1) significantly improve health outcomes for NICU babies (especially with regard
to mortality rates) and (2) significantly lower incidence of ELBW in the first place.

**Final Thoughts on the Medicaid-Triage Analogy**

Recall, then, John Lantos’ quote from the introduction to this dissertation:

> Before the advent of neonatology, it was inconceivable to spend hundreds of
> thousands of dollars to save a baby’s life. Today it has become routine and
> routinely disturbing. (Lantos, 6)

Can we be so ‘routine’ about how we spend these resources\(^{242}\) on Medicaid
babies in the NICU? Not at all. The way we spend Medicaid dollars is, from the
perspective of Catholic Social Teaching, something close to unconscionable. What do
we say to Janice Harris about her kidney stones or to Aaron England about his cancerous
thyroid or to Jerry Springfield about his heart spasms? What do we say to Deamonte
Driver’s mother? How do we explain the millions of dollars we often spend to save four
imperiled newborn lives, while their significantly less expensive treatment is denied these
four needy patients?

\(^{242}\) And, as we will soon see in some detail in the final part of the chapter, the actual cost of NICU
treatments—when factored over the person’s lifetime—are dramatically higher than this.
The answer is that we cannot—and that something needs to change. The final section of the chapter makes two kinds of arguments for how we should change our attitudes and practices with regard to treatment of imperiled newborns: first with regard to some general reforms and second reforms specific to Medicaid.

**General Reforms**

Though the idea of limiting neonatal care in the interest of proportionate use of medical resources has barely reached the social consciousness of the United States (with the exception of Oregon, as we will soon see) the central question asked in this dissertation has been debated for some time now in Europe. In particular, the prestigious Nuffield Council on Bioethics in the UK put together a working party in 2005 to deal with thorny issues in neonatal treatment and a central issue was that of resource distribution:

> The limitation of resources for healthcare is a major topic of debate in the UK, especially where the lives of babies are at stake. There is now much broader public awareness of the need for difficult choices to be made by the providers of national healthcare. We have discussed the difficult economic issues which have to be managed in neonatal medicine because more babies are able to survive than in the past…Consequently, this has caused questioning of whether funds spent on resuscitating or prolonging the life of babies where the prognosis is very poor are spent appropriately.\(^{243}\)

As we have also seen in the previous section of this chapter with Medicaid, the Council notes that comprehensive coverage of NICU treatment may not be possible “without cuts to other services so that, for example, spending more on the very young

\(^{243}\) Nuffield Council on Bioethics, "Critical Care Decisions in Fetal and Neonatal Medicine" (2006), 164. Interestingly, the next question the Council asks is, “Can this be reconciled with the aim of healthcare professionals to ‘treat the baby in front of them’?” If one accepts that relational anthropology of Catholic Social Teaching and of a physicians duty to treat the whole person—as was argued for in Chapter Three—then the answer to this question is ‘yes.’
may reduce the amount available to help the elderly.” (Nuffield, 164) In the United States, however, we are far less likely to even consider, much less make, such difficult choices. Indeed, in a 2007 study that studied physician preferences when it came to resuscitation in the ‘grey zone’ of viability found that “neonatologists place great emphasis on patient-orientated outcome variables (futility, viability, and morbidity), deemphasizing societal or personal concerns (resources, religion, and lawsuits)”244 But if the central argument of this dissertation is correct, the United States had better take a cue from the Nuffield Council here and start looking at making some difficult decisions in the interest of proportionate use health care resources. What follows are two sets of arguments and suggestions in this regard.

Make illegal245 the using of resources for treatment of imperiled newborns that cannot possibly benefit from the treatment. Millions of dollars are spent each year in the NICU on babies who cannot possibly benefit from the treatment.246 These kinds of cases are the easiest of all, because invoking the Social Quality of Life Model is not even necessary to make the critique (treatment is not indicated even if one is looking at it from the individualistically narrow point of view)—though doing so certainly does strengthen the case. The fact that we spend these kinds of resources right down the drain, especially in light of our healthcare crisis, is totally unacceptable and ought to be prohibited regardless of the source: Medicaid, private insurance, and even cash.

---


245 Perhaps it would be seen as, as Norm Fost calls it, a kind of neonatal ‘battery.’

246 For instance, according to the MMWR report cited earlier, on 290 terminal cases of anencephaly in 2003 we spent $1,090,270.
Steve Leuthner has written extensively about what kinds of diagnoses and prognoses can, with certainty, be called ‘terminal.’\textsuperscript{247} In one group of terminal ailments we have both diagnostic and prognostic certainty:

- Trisomy 13, 15 or 18
- Triploidy
- Anencephaly/Acранia
- Holoprosencephaly
- Large Eencephaloceles
- Acardia
- Inoperable Heart Anomalies
- Severe Clotting Disorders
- Birth without Pulmonary Veins
- Potter’s Syndrome/Renal Agenesis
- Multicystic/Dysplastic Kidneys
- Polycystic Kidney Disease

Another group, however, has prognostic certainty without diagnostic certainty:

- Thanatophoric Dwarfism or lethal forms of Ostenogenesis Imperfecta
- Potter’s Syndrome with unknown etiology
- Hydranencephaly
- Congenital severe Hydrocephalus with absent or minimal brain growth

Though aggressive medical treatment should not be given—even at a parent’s request or demand—forgoing such treatment does not constitute an abandoning of the child.

Indeed, with proper palliative care this is not abandonment but rather doing what it is clearly in her best interest: even conceived from an individualistically narrow point of view. Given that many of these diagnoses and prognoses can be made \textit{in utero}, it may be the case that early delivery of the baby is called for. This is especially true if there is a reasonably good chance that the child will die before birth and a parent wants the chance to hold and cuddle the child before she dies, there are medical complications possibly associated with a normal birth, the constant moving of the baby reminds the mother of

\textsuperscript{247} Steven R. Leuthner, \textit{Fetal Palliative Care.}, Vol. 31 (Philadelphia,: Elsevier, 2004), 649.
her impending death, persons who are not aware of the diagnosis/prognosis are asking about the coming birth of the baby, etc. In such cases labor could be induced, or a caesarian section done, and palliative care could be administered.

One might anticipate that two objections would be forthcoming here. First, one could certainly press the idea of ‘reliable’ diagnoses and prognoses here. There is always straight-up human error to consider—should we really be making so dramatic and final conclusions in light of this reality? Even something as supposedly obvious as anencephaly has had its share of misdiagnoses. Second, even if we are sure about the diagnoses and prognoses, do we really want to do literally no aggressive treatment of such newborns? Today’s terminal conditions become tomorrow’s treatable ones because some do choose to aggressively treat.

These are certainly objections worthy of consideration. While taking into account human error becomes that much more important when life and death issues are at stake, it is not something that is avoidable—and certainly not unique to the NICU. Individuals and families (and, indeed, some physicians) must make similarly dramatic decisions in other intensive care situations for older persons. Given human error there is virtually no case that one can predict with literally 100% certainty, but even it one accepts this one could still accept as terminal cases where the accuracy approaches 100%. Indeed, one often finds that ‘human error’ often has an easily correctable cause: many of the more widely discussed misdiagnoses of anencephaly, for instance, were the result of deliberately shoddy work in order to make such babies available for cardiac donation.248

With regard to the second objection, it seems that in certain cases where advances in disease treatment are foreseeable there does need to be a separate legal route for clinical trials. Such cases should have a funding path separate from Medicaid, private insurance or private cash from the family of the baby. Rather, treatment should be funded just like any other clinical trial (perhaps by the NIH or other like body) and should have the normal IRB oversight.

*Take dramatic steps to limit the ‘Culture of Treatment’ in the NICU.* From an explicitly monotheistic perspective, the NICU is perhaps one of the best places on earth to see a problematic ‘idolization’ of biological life. Even if one were to reject such a thick theological point of view, one can also see quite clearly humanity’s problematic refusal to accept her own finitude and that of her resources. Several reforms need to take place with respect to this fact.

1. *Merge Medicaid reimbursement rates in the NICU with other kinds of reimbursement.* Although it certainly does depend on the socio-economic areas the hospital is in, NICUs generally have a high percentage of patients funded by Medicaid. It usually varies anywhere from 50-80% of a given census, with an average number\(^\text{249}\) of babies on Medicaid being about 65%. Starting in the 1980s after Baby Doe, and continuing today, Medicaid reimburses for NICU care at a significantly higher rate than it does for other kinds of care. Especially when one considers the connection between pubic and private insurance (specifically, the latter generally taking the lead from the

\(^{249}\) This is about the average for the NICU at Memorial Hospital in South Bend, IN. In an interview with the head neonatalist there, Dr. Robert White, the author discovered that this generally reflects the average of the country as a whole.
former—more on this to come at the end of this chapter) it is important that Medicaid not reimburse at a higher rate for NICU treatment than for other kinds of treatment.

2. **Legal reform and education.** As was seen above, there have been times in the past where neonatal clinicians—especially after the Baby Doe case—were unclear about what the law was and how it would be enforced. Laws supporting the culture of the treatment in the NICU (whether federal or state) need to be repealed and an educational campaign should be started to make both clinicians and hospital attorneys of what the legal realities are.

3. **Regulate new NICU building and expansion.** The dramatic move toward building of new NICUs since the late 1970s certainly, as seen above, has contributed to a culture of treatment which has produced overtreatment. Lantos suggests that, “From a public policy perspective, the solution to this problem of the over-supply is straightforward; stronger regulation could eliminate smaller NICUs or at least make it less profitable for a small hospital to build and operate a NICU.” (Lantos, 134) Profitability would have already been reduced by the reforms made above, but an additional safeguard could be that, perhaps, a certain number of NICU beds could only be built relative to a given population.

4. **Change Medicaid requirements to reflect a proportionate distribution of resources.** This will not only better distribute resources within Medicaid, but will also help spur reform of how private insurers reimburse for neonatal care. It is, of course, one thing to show that resources are disproportionately distributed within Medicaid, but it is quite another to make an argument for what a proportionate distribution might look like.
Happily, we can look to some models that already exist for guidance and insight. It is to this key and complex discussion that we now turn.

**The Oregon Model**

During the 1980s the United States had a similar crisis with Medicaid in comparison to today’s issues. Even then, Medicaid spending had:

increased dramatically and the program consumed a growing share of state budgets. In response, many state lowered eligibility standards for Medicaid to an income level well below the federal poverty line (FPL) and cut coverage for optional enrollee categories such as the medically needy. By the end of the decade, the health insurance program for poor Americans covered only 42 percent of the poor; in order to qualify for Medicaid, AFDC recipients typically needed to live on incomes that were only 50 percent of the FPL...In addition, those who were not “categorically eligible,” such as low-income adults without children, were excluded from Medicaid in most states.250

Oregon bucked this trend in 1989 by passing the Oregon Basis Health Services Act. Instead of ratcheting down coverage based on eligibility, “Oregon proposed to extend Medicaid coverage to all persons living below the poverty line, regardless of traditional eligibility categories.” (Jacobs, 163) Put simply, “Oregon said it intended to pay for enlarged Medicaid enrollment by covering fewer services.” (Jacobs, 164) If there was a budget shortfall, the state legislature could not cut eligibility to Medicaid, but rather had to ration care for those that were eligible. Essentially, a certain number of treatments would be covered by Oregon’s Medicaid program, and the rest would not. But determining how to create such a list, as one might imagine, turned out to be a tricky business.

In creating the initial list, Oregon created a ‘health services commission’ which used cost-effectiveness as its primary consideration—such that even very beneficial treatments might be rejected if the costs were high and/or only a few people could benefit from them. The commission did a cost-effectiveness analysis of over 1600 health services, but ended up with a list that was highly counter-intuitive. For instance, office visits for thumb-sucking were covered, but life-saving surgeries—such as appendectomies—were not. At least in part due to negative public reaction to the list, but also due to negotiations with federal authorities who needed to approve federal funding assistance, the commission abandoned cost-effectiveness as the primary consideration and made a new list. Cost was still a factor, but other factors took more of priority including benefit to the patient, benefit to society, and degree of ‘necessity.’ Intuition also played a significant factor as even after the list was created, commissioners moved treatments ‘by hand’ when seemingly very important services ended up low on the list.\footnote{David C. Hadorn, “The Oregon Priority-Setting Exercise: Quality of Life and Public Policy.” \textit{Hastings Center Report} Vol. 21 (1991), 11-12.}

The program was formally implemented in Oregon in 1994 and the eligible population grew dramatically: from 10,000 in March 1994 to nearly 100,000 by December 1994—far exceeding expectations. Because of these numbers, the state budget could not remain solvent without cutting treatments that everyone agreed counted as a ‘decent minimum’ of coverage. And so, even though this was exactly what Oregon wanted to avoid, eligibility had to be cut anyway: assets tests were initiated and all full-time students were eliminated. To add insult to injury, cost-cutting also included
removing coverage for many procedures including incapacitating hernias, tonsillectomy and adenoidectomy.\textsuperscript{252}

Interestingly, during the first stage of commission deliberations—the one that focused on ‘cost-effectiveness’—the very last two lines on the list with which they came up referred to extremely low birthweight babies (under 23 weeks gestation or under 500 grams) and anencephalic babies.\textsuperscript{253} This meant that they were well beyond services likely to be treated. Indeed, the Oregon state legislature initially approved the list and then “approved funding up to and including line 587, leaving life support for ELBW babies and anencephalic babies (lines 708 and 709) well beyond the funding limit. If this list had been implemented, parents of such babies would have been confronted with the fact that Medicaid would not pay for life-supporting services for their infants.” (Merkens, 266) However, when the second list came out these life-supporting services no longer existed on their own—but rather as parts of more general kinds of treatments for newborns including ‘life support for neuromuscular dysfunctions.’ Such treatments were high enough on the list to be funded. (Merkens, 268) But let us suppose that the dramatic move away from cost-effectiveness in the second list was a mistake. Let us consider that, perhaps, one way to proportionately distribute resources within Medicaid—especially with respect to treatment of imperiled newborns—would be create a similar list with disproportionate NICU treatments toward the bottom. Perhaps federal authorities could mandate that, in order to receive federal funds for Medicaid support (without which

\begin{itemize}
\item\textsuperscript{252} Tom L. Beauchamp and James F. Childress, \textit{Principles of Biomedical Ethics}, 5th ed. (New York, N.Y.: Oxford University Press, 2001), 256.
\item\textsuperscript{253} Merkens, Mark J. and Micheal J. Garland. “The Oregon Health Plan and the Ethics of Care for Marginally Viable Newborns.” \textit{Journal of Clinical Ethics} 12 (Fall 2001), 266-273
\end{itemize}
virtually no state Medicaid program could function), each state much create just such a list.

But there are good reasons to reject a model like Oregon’s which uses a list of ‘generic health states.’ In order to get a list that was manageable, the commission was forced to describe such states very broadly. For example, the ‘trouble talking’ health state incorporated everything from a slight lisp to being totally mute. Similarly, all stages of esophageal stricture were placed in one category despite degrees of stricture varying widely with regard to severity and cost. The same was true of renal failure and a host of other diseases. (Shannon, 430 and 534) Anyone attempting to come up with a similarly manageable list today would be faced with the same problem. Interestingly, the issue with this model is similar to the ‘medical indications’ model considered in Chapter Two. In both cases the disease is unhelpfully abstracted from the broadly considered medical benefit, or best interests, of the patient. Beauchamp and Childress also bring to our attention the financial problems which need to be highlighted when considering such a model:

A basic question has haunted the Oregon Plan: How high can the cutoff line be set and still constitute a decent minimum package in accordance with the demands of social justice? The history of the plan demonstrates that the priority list may be an inadequate way to manage budget shortfalls, which have occurred in every year. (257)

Still, there are positive things to highlight about the plan. It makes an honest effort to balance the severe tension between trying to provide (as Catholic Social Teaching demands) a ‘decent minimum’ of health services to the most vulnerable members of our society and controlling costs (even by considering refusal to cover treatment of ELBW babies) such that the state budget can remain solvent. It
acknowledges the reality that we are rationing resources already and attempts to find a rational and morally defensible basis for doing so. As Paul Schotsmans points out, our culture needs to be more critical about the ‘hidden’ priorities in the status quo of our healthcare system. The value of the Oregon plan was the promotion of public concern for, and participation in, public-policy-making procedures in this regard. And toward this end it is therefore necessary that a more systematic study be done on medical treatments and their various outcomes—and that the relevant healthcare data become public. Both information and policy transparency will help make people more alert and help them to discuss on a more open level the priorities of various healthcare systems. (Engelhardt and Cherry, 133) These strengths of the Oregon plan in mind, let us consider another model for proportionately distributing resources within Medicaid.

**Quality-Adjusted Life-Year**

Rather than looking at a list of generic health states, perhaps we could look at more specific and individual treatments as a basis for controlling costs. One way to do this would be to use something called the ‘Quality-Adjusted Life-Year’ (QALY)—a concept devised by health economists as a means of assessing the relative cost-effectiveness of different treatments. Eric Matthews explains the basics quite well:

The idea is that we can judge different treatments in terms of the number years of extra life enjoyed by a successfully treated patient, multiplied by the quality of each of those years, as measured on a scale from 0 to 1. Thus, if a treated patient has 10 more years of life, each of which measured 0.5 on the quality scale, that treatment would have generated 5 QALYs. We can arrive at a ‘cost per QALY’ for that treatment: suppose the treatment cost £1500, then the cost per QALY would be £300. Finally, we can compare this treatment with others in terms of their relative cost per QALY: if another treatment cost only £1000, but generated
only 2 QALYs, then its cost per QALY, at £500, would greater than that of the first treatment. It would be less cost-effective.\textsuperscript{254}

With the QALY, then, we have an attempt to balance two aspects of the good of health care: its capacity for life-extension and also for life-enhancement. The assumption here is that the trade-off between quantity and quality is accounted for in the multiplication of the two numbers. And, in point of fact, these kinds of trade-offs are balanced every day in medical decision-making.

But determining the trade-off between quantity and quality is one thing—determining the ‘quality-index’ of a certain treatment in the first place is something else. What those who favor this approach do, especially in macro-allocation context, “is take a checklist of factors that are likely to affect the perceived quality of life of normal people, and assign weightings to them…[and] the factors and their associated weightings are mostly so chosen as to reflect the feelings and considered judgments which the average or representative patient is likely to evince in practice, when faced with various forms of disability or discomfort, either in prospect or, better, having actually experienced them.”\textsuperscript{255}

Some might think that this would discriminate wrongfully against those with a disability which brings about a low quality of life. But as Paul Menzel points point, this is not necessarily the case and ‘a common misperception.’ The reason is that medical treatments which do not save lives, but improve a low quality of life, “get more weight in any competition with lifesaving measures than they otherwise would have.” (Matthews,

\begin{flushright}

\end{flushright}
Consider a patient with renal failure and a quality of life index of 0.6. If dialysis treatment would give her 10 years of life, at the cost of $30,000/year, the resulting $50,000/QALY price-tag would undoubtedly place her treatment in a relatively low priority position for rationing. In this case, having a low quality of life hurt the patient in the QALY rationing system. But consider another scenario where, instead of dialysis, her care-givers are considering a kidney transplant which would raise her quality of life from 0.6 to 0.8 for 10 years—producing 2.0 QALYs beyond dialysis. Let’s say the transplant plus the subsequent treatments cost $60,000. Her roughly $30,000/QALY gain “puts her claim for a transplant in better stead against other services than if we ignored her jump in QOL.” (Matthews, 65)

The main advantage of the QALY over the Oregon generic list of health-states is that it allows for a more complete picture of the context to be considered. One part of that picture certainly is life-years added—something which the Oregon system could not directly take into account for individuals. In addition, instead of having to decide whether or not to treat or not treat anyone with renal failure, Medicaid funds could be more nimbly allocated where they do the most good with respect to quality of life. One could refuse dialysis to a Medicaid enrollee who happens to be in a persistent vegetative state (where the quality of life index is zero or even negative), but offer dialysis to other patients who, though they might live just as long, would have a greater quality of life. Medicaid, after thorough research, could come up with threshold of ‘dollars-per-QALY added.’ Treatments under that threshold would be covered, but treatments over it would not. This would have particular reference to the NICU where, as we have seen already,
treatments are very expensive and often have questionable length and quality of life outcomes.

However, though an improvement over the Oregon system, at least two important problems with the QALY make it a questionable model: (1) problems with balancing length of life and quality of life and (2) problems with determining and measuring quality of life. With regard to the former, David Hadorn points out that the QALY method “assumes that people see no difference between, say, one year of normal-quality life and ten years of life at one-tenth quality (whatever that is). The QALY approach assumes that a short, good life is of equal value to a long, ailing one. This assumption seems unlikely to be valid.” (Shannon, 424) Indeed, the relationship between the value of quantity and quality of life seems far more complicated than simply multiplying quantity by a quality index of some kind.

But the latter problem is simply determining quality of life to begin with. As Hadorn asks, what does it even mean to speak of someone with a 0.1 quality of life index? How can we “quantify a quality [original emphasis], especially one so amorphous and ill-defined as quality of life?” (Shannon, 425) Furthermore, how could we possibly compare quality of life for one individual with that of another? Matthews, for instance, asks how we can “precisely compare the moral worth of saving the life of a heart patient by means of transplant surgery with that of enhancing the mobility of an old person by means of a hip replacement. How can we even place these two things on the same scales? Any comparisons between them must be based on qualitative judgments, not on

256 Another problem, not mentioned below, is one of calculation and data-gathering. But because this is a problem that will also be associated with the ultimate argument of the author it will not be dealt with here.
simple mechanical conceptions of cost-effectiveness.” (Matthews, 42) In addition, such judgments are almost totally subjective—with different answers given by healthy persons compared to those with disabilities. Indeed, a person with sight might consider blindness to significantly lower quality of life, whereas a blind person often does share this judgment.\textsuperscript{257}

In addition, QALYs suffer from a limitation shared by the Oregon generic health-states: limitation based on manageability. Recall that Oregon’s system could not get as specific with diseases as it should have because they needed a list that was practically manageable. The QALY needs to define quality of life in a similarly limited way—usually with appeals to ‘disability and distress’ (Matthews, 57)—and for the same practical reasons. But quality of life is often dependent on many factors beyond these which are beyond the capacity of any practical model to capture. Michael Lockwood points out that quality of life includes at least the following: where one lives, one’s social circumstances, what sort of job one has (if any), living alone or with a family, one’s temperament and psychological makeup, the character of one’s relationship with others, the authenticity of one’s actions compared to one’s principles, a sense of security and being in command of one’s life, freedom to pursue life projects, degree of stress or boredom or frustration, sense of satisfaction and fulfillment in day-to-day living…and many, many other things the sum of which cannot possibly be captured by any kind of practical quantitative model. (Kuhse, 456)

\textsuperscript{257} The most striking evidence of this is the recent controversy over blind or deaf parents choosing embryos to be implanted who are also likely to be blind or deaf. They claim that their quality of life, far from being low, is actually a very rich (and perhaps even richer) kind of existence.
A final problem with defining quality of life in a medical treatment context is that many treatments than can be offered in clinics and by health care providers can improve quality of life but not minister to any medical need at all. Cosmetic surgery, for instance, could certainly improve one’s quality of life—especially if one’s employment or social status was largely based on one’s physical appearance. Lockwood suggests, for instance, that (depending on the circumstances) a facelift or hair transplant might produce more QALYs per unit cost than a hip replacement operation. But “would anyone really think that was sufficient reason for switching resources from hip replacements towards such cosmetic surgery? Surely not.” (Kuhse, 458)

QALYs, then, have too many problems to be accepted in their entirely as a model for proportionately distributing health care resources within Medicaid. However, as with Oregon, we can take away positive lessons from its consideration. One basic lesson is that we need to see treatments in a more individual and specific context—not just with regard to a generic treatment or disease/health state. And though it certainly seems that coming up with a quality of life index is hopelessly complex and problematic, it does not follow that we ought to completely abandon quality of life considerations altogether. Indeed, recall the original example of the kidney dialysis machine being used on the PVS patient and the non-PVS patient. Is there a way to capture the intuitively obvious case to be made that resources should be used on the latter patient rather than the former? Perhaps instead of using a vague and broad concept like ‘quality of life’ we instead used a concept like ‘relational capacity.’ Using this more narrow concept in determining which patient to treat above would give us the intuitive result without forcing us to justify
other, much more difficult, quality of life judgments.\textsuperscript{258} Also, \textit{length} of life does seem to be a legitimate factor to consider when making proportional distribution of resources decisions and ought to be an aspect of QALYs that is used in Medicaid distribution.

\textbf{Why Pick on the NICU?}

The central argument of this dissertation is about treatment of imperiled newborns in the NICU. However, especially if one accepts the length of life criteria of the QALY model in a cost-benefit analysis, one might argue that the proportionate distribution critique ought not to be brought first—or even at all—to the NICU. Consider first the actual dollars that might be saved by limiting such treatment. While the figures cited earlier in the chapter might seem high in the abstract, when compared to the total NICU expenses they are relatively small. In the mid-1990s Jeffery Stolz and Marie McCormick conducted in study published in \textit{Pediatrics} in which they found that, “Policies denying care to infants born at < 500, 600, or 700 g would lead to a total NICU care savings of 0.8\%, 3.2\%, and 10.3\%, respectively.” When applying the local survival rates for such birth weights, it would mean the death of “136, 575, and 2689 potential survivors annually.”\textsuperscript{259} The money saved seems relatively small compared to the lives that would be lost.

In addition, when one sees the expenses in the context of a comparison with other ICUs, treatment of imperiled newborns appears to look to be an even better bet. John Lantos and William Meadow have led several studies and something bordering on a

\textsuperscript{258} More will follow on how this would work practically below.

public campaign to show precisely this. In a 1993 study comparing costs and outcomes in the neonatal and medical ICUs—with respect to imperiled newborns and elderly patients—they found that, “To the extent that allocation decisions are driven by concerns about distributive justice and the efficient use of scarce resources, it would be more justifiable to ration intensive care for the very old than the very young.”260 Their rationale was based on the following. NICU babies were more likely to die early and then have their chances of survival improve with each passing day. But precisely the opposite trend occurred with the elderly in the MICU in which the population was increasingly likely to die the longer they stayed. Because imperiled newborns tend to die quickly, “most of the bed-days in the NICU are devoted to patients who ultimately survive. Because adults who die tend to have more prolonged courses in the ICU before succumbing, a much higher percentage of ICU bed-days are allocated to patients who ultimately die.” (Lantos and Meadow, 186) They suggest that proportionate resource distribution discussion “might be better framed in terms of number of ICU bed-days (a proxy for dollars) utilized by survivors (or nonsurvivors) divided by the total number of ICU patients bed-days/dollars expended.” (Lantos and Meadow, 187) The conclusion being that, “although survival for infants of extremely low birth weight may be very unlikely, the cost to society for the care of nonsurvivors is relatively low.” (Lantos and Meadow, 187) This is especially true when one thinks about the number of life-years added in the NICU vs. the MICU.

Neonatal care has changed since 1993, however. Technology has improved such that even more lives are saved at the earliest stages of viability, but this has also meant that imperiled newborns who die take longer to do so. Indeed, in a study that was conducted on imperiled newborns from 1991 through 2001, Lantos and Meadow found “a steady rise in the medical length of survival for doomed infants of approximately one-half day per year, from a median DOL [days of life] 2 to DOL 10. The average LOS [length of stay] for nonsurvivors paralleled this trend, rising from 5 to 17 days over the study period.” And if this is the case, it calls their original argument—that the vast majority of NICU bed-days are devoted to NICU survivors—into serious question. However, Meadow and Lantos believe that their argument still stands because, during the same time period, overall survival for imperiled newborns improved. This trend balanced the other such that, “Nonsurvivors occupied a constant (and extremely small) fraction of NICU bed-days (<10% in every year and 7% for the decade overall).” (Meadow and Lantos, 1228-29) This paved the way for them to reiterate their central claim from the previous article—one which challenges the fundamental position of this dissertation:

Several ethical consequences emerge from these observations. For infants with BWs >1000 g, BW-specific survival is so good that there are no ethically supportable claims for nonsupport as a function of either likelihood of death or of excess cost based on BW alone. Over the past decade, BW-specific survival for infants with BWs of 800 to 1000 g has improved to the point at which the same ethical rubric probably applies. For the tiniest ELBW infants (BW 450 to 600 g) considered at the time of their birth, they remain unlikely to survive. However, because at least half of these nonsurvivors will expire within 10 days, survival for

the population of these infants who reach DOL 10 increases to at least 70% [which makes the treatment quite cost-effective]. (Meadow and Lantos, 1229)

If Meadow and Lantos are correct, then the central focus of this dissertation—with its particular emphasis on treatment of imperiled newborns—is wrongheaded. However, there are good reasons to doubt the claim that ‘there are no ethically supportable claims’ for restricting neonatal care in the interests of proportionate distribution of Medicaid resources—based, at least in part, on complications and medical costs resulting from low birth-weight.

Let’s start with short-term costs. It isn’t clear why one should think that bed-days with respect to survivors/non-survivors would be the best way to evaluate costs and benefits of ICU treatment. Why not use actual dollars spent? And even if that yielded a similar result, one would still need to properly account for Lantos’ own point about various indirect costs: including contributing to a culture of treatment in the NICU that peels off needed dollars from other more neglected areas of medicine. Also with regard to short term costs, why should we think that a savings of 14.3% of the NICU budget is not significant—and, if redistributed to other areas of Medicaid, not a more proportionate use of resources? Using Lantos’ 2004 estimated figures as a baseline, let’s conservatively estimate that total NICU expenditures is $26 billion in 2009. Giving comfort care to ELBW babies below 700 g would still produce a substantial savings of $3,718,000,000 per year.

But even if one were to dismiss the response made above to the short-term NICU costs and benefits (and there is good reason not to), the most powerful response to Lantos and Meadow is to point out that Medicaid and other community resources spent on imperiled newborns are almost never limited to what is spent in the NICU. As the
Nuffield Council points out, “Economic studies of premature birth and low birthweight have tended to overlook the costs, for example, of day-care services and respite care, as well as those borne by the local authorities, voluntary organizations and by families as a result of modifications of their everyday activities.” (Nuffield Council, 122) Though they should be considered in other contexts, let us dismiss for now the very significant costs to families and private charities that future treatment and education of the imperiled newborn entails. Let us only consider costs borne by the community—since this is what we are after with regard to Medicaid in this section. If a baby is born in the NICU and funded by Medicaid, it is more-than-likely that the follow-up physician and hospital visits, in home nursing care, etc. will be paid for by Medicaid as well. Special education, if necessary, is also paid for by the community. All of these future costs to the community must be taken into consideration if one is going to do a true proportional analysis of how Medicaid monies are spent in the NICU.

A study published in JAMA found that being extremely low birth weight (>1000 g) means that one is extremely likely to have considerable long-term health and educational needs. Indeed, “ELBW children have extremely high rates of chronic conditions compared with NBW children. These conditions include asthma, cerebral palsy, and visual disability, as well as poorer cognitive ability, academic achievement, motor skills, and social adaptive functioning.” (Hack, 323) Predictably, ELBW babies had a significantly greater needed for ‘services above routine’ than children who were NBW. These included, “visiting a physician regularly for a chronic condition, nursing

care/medical procedures, occupational or physical therapy, special school arrangements, or an individualized education program…Many children saw multiple specialists.” (Hack 323).

It is notoriously difficult to estimate the costs of these treatments and services over time, but the Nuffield Council cited an EPICure study which looked at spending (in pounds) over 12 months at age 6 and compared the cost of ELBW children versus a control group born at full term. Here are the results in British pounds (Nuffield Council, 85):

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Cost for ELBW</th>
<th>Cost for Full Term Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Inpatient</td>
<td>605</td>
<td>116</td>
</tr>
<tr>
<td>Hospital Outpatient</td>
<td>255</td>
<td>53</td>
</tr>
<tr>
<td>Community Health</td>
<td>422</td>
<td>104</td>
</tr>
<tr>
<td>Drug Cost</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Education</td>
<td>7620</td>
<td>3470</td>
</tr>
<tr>
<td>Additional Family Expenses</td>
<td>573</td>
<td>120</td>
</tr>
<tr>
<td>Indirect Costs</td>
<td>56</td>
<td>17</td>
</tr>
</tbody>
</table>

The above numbers are dramatic enough, but they are even more striking when considered in total over the entire life of the patient. Consider the case of ‘Baby Sidney’ who was the subject of the important *HCA v. Miller* case in Houston, Texas in 1998. Sidney’s parents, under advice from their physician, decided that they would not resuscitate her after she was born and there was an official order made to not have a neonatalogist present at the time of her birth. However, hospital officials told Sidney’s father, Mark Miller, that hospital policy required that Sidney be resuscitated without consent. Sidney was born, resuscitated, and left so physically and neurologically
devastated that she has never been able to walk, talk or feed herself.\textsuperscript{263} The relevance of this case for the dissertation is not so much about the decision to give aggressive treatment, but about what happened after the jury found the hospital guilty and forced it to pay the Miller family compensatory damages for Sidney’s medical expenses. This is what the jury found:

a. Reasonable expenses of necessary care for SIDNEY MILLER in the past: $900,000
b. Reasonable expenses of necessary medical which, in reasonable probability, SIDNEY MILLER will incur in the future: $28,500,000

The hospital’s own expert witness even testified to the expense of the procedures the jury used to calculate damages: pediatrician visits, neurosurgeon/neurologist visits, routine medical care, cat scans, EEGs, emergency room visits, blood work, shunt surgery, shunt revisions, medications, physician/occupational/speech therapy, and others. (Report, 37)

The jury awarded the money to Millers with the expectation that they would have to pay for the future medical expenses, but if Sidney had been on Medicaid her parents would have been unable to afford her care and the entire expense would have been borne by the community. When deciding about proportionate use of Medicaid resources in treating imperiled newborns, then, one cannot simply look at NICU costs in the abstract (though these numbers are dramatic in and of themselves), one must instead look at costs to Medicaid and the community over the lifetime of the patient. Far from there being ‘no ethically supportable claims’ for giving comfort care to imperiled newborns based on resources, in light of our tragic healthcare and Medicaid crisis, it seems clear that a

\textsuperscript{263} Report of the Court of Appeals for the Fourteen Count of Appeals District in Texas in HCA, INC. v. Sidney Ainsley Miller, 4-10.
choice to treat a single NICU patient which will result in the spending millions and millions of dollars over her lifetime is a disproportionate use of resources.

Though Meadow and Lantos overstep in claiming that NICU treatments are more cost-effective than other kinds of intensive care, a weaker claim that other kinds of medical care could be critiqued by the Social Quality of Life Model does in fact have merit. Though the specific factors to be considered in how to proportionately allocate resources would be different, there is no reason why one would have to in principle limit this reasoning to neonatal treatment. However, though it goes beyond the scope of this dissertation to suggest what this might look like, it another direction for future study and work.

**Discrimination Against the Disabled: Redux**

But recall that in Chapter Two the dissertation attempted to argue that the central argument being offered was not discrimination against the disabled. If taking these kinds of long-term costs into consideration is the key move in showing why we should limit neonatal care rather than other kinds of care, then it difficult to see how the dissertation could avoid the discrimination charge. Such long-term costs are directly related to the disabilities of Sidney and others like her. This seems to be exactly what one has in mind when one thinks about discrimination on the basis of disability.

But recall again the response to this charge given in Chapter Two. There is nothing *necessarily* discriminatory about the Social Quality of Life Model as applied to imperiled newborns—despite it being the case that disabled newborns will generally not fare as well as those without disabilities. One could factor long-term costs of *any* kind
which would be taken into consideration—they do not necessarily need to be directly related to a disability. Again, consider the imperiled newborn with severe heart disease that will require constant surgeries and expensive medicine over the course of his life but will otherwise have no problems and lead a flourishing life. Such a person is not disabled, but might be denied treatment under the social quality of life model as applied to imperiled newborns.

But perhaps a thought experiment would help to make this point more clear. Suppose a ferocious fire has broken out on the first floor of an understaffed rural hospital and one security guard has been given the task of clearing the second floor of patients given that the fire department is quite far away. Suppose also that the floor has two wings: one wing has patients with recovering from heart disease and the second wing has paraplegic patients currently in rehab. The security guard, in such a tragic situation where people are likely to die either way given the advanced stage of the fire, decides to go the wing of those recovering with heart disease since they are fine to walk on their own out of the hospital. In warning them of the danger and seeing them safely out of the hospital he will save more lives than if he went the second wing where he would have to carry or wheel each individual patient out of the hospital and save far fewer lives. Suppose that in doing so the security guard is unable to save the second-wing patients because by the time he is finished seeing the first-wing patients out the fire makes getting to the second wing impossible.

Could one justly complain that he engaged in wrongful discrimination against the disabled in this situation? Of course not. The fact that they were disabled was not the reason that he choose to not save them first—rather, it was the fact that it would take
more resources (time) that he could have responsibility used in such a tragic situation. Indeed, if the second wing had had post-cosmetic-surgery patients who were drugged such that he would also have had to wheel or carry them out of the hospital he would have made exactly the same kind of tragic calculation. In both hypothetical cases, discrimination on the basis of disability as such plays no role at all in his reasoning—only just distribution of his resources. The same is true of the Social Quality of Life Model with regard to imperiled newborns: discrimination as such never directly enters into consideration, but rather only indirectly as it (along with other factors) contributes to disproportionate use of resources.

**Proportionate Use of Medicaid Resources in the NICU: A Suggestive Proposal**

In deciding whether or not to treat an imperiled newborn on Medicaid in the NICU in light of the Social Quality of Life Model and Catholic Social Teaching one must rely heavily on one’s ability to predict outcomes: about survivability, about future disease and health, and about costs to treat such disease. If we cannot with relative-accuracy predict whether or not a baby will survive, what kind of life the baby will have if she survives, and how much it will cost to treat and care for the baby both in the NICU and over her life, then we are left with too little information to make a judgment as final and as dramatic withholding or withdrawing treatment from am imperiled newborn. The Nuffield Council is just one of many players in this debate who lament our current inability to make such predictions:

Neonatal critical care decisions are particularly difficult because of the lack of information from long-term follow up on which to base predictions of future health outcomes. It is crucial that accurate and up-to-date evidence from research is available to doctors and parents about the risk to and likely outcomes for babies.
in whom a birth abnormality or genetic disorder has been recognized antenatally or in the newborn period, as for extremely premature babies...Our view is that data linkage with longer-term events in later stages of a child’s life, through adolescence to adulthood, captured through NHS health records and educational records, will provide crucial information on outcomes. (Nuffield Council, 166)

Meadow and Lantos predict that, “Accurate and timely prediction of persistent residual morbidity for NICU survivors looms as the next ethical frontier.” (Meadow and Lantos, 1229) Until that frontier is explored in more detail, however, it is not prudent to make hard and fast recommendations about how to limit treatment of certain imperiled newborns with respect to Medicaid beyond what already has been said in this chapter. However, it is certainly prudent and important to make some broad suggestions about a practical model for limiting treatment, what factors should be taken into consideration in such a model, and what relative weight to give such factors. In addition, the model will help give researchers a sense of what kinds of studies are necessary to get the information needed.

A May 5, 2008 article in the Boston Globe reported that a task force of physicians from the Centers for Disease Control and Prevention, the Department of Homeland Security, and the Department of Health and Human Services came up with a ‘grimly specific’ list of persons who they believe should not be treated in a pandemic where medical resources are limited: people older than 85, those with severe trauma, severely burned patients older than 60, those with severe mental impairment, those with severe chronic disease, and others. They recommended that hospitals put together a triage team to prepare for such a situation.264 Though one may certainly object to some of the reasoning used to arrive at this list, the task force should be commended for attempting to

264 Tanner, Lindsey. ‘Who Should MDs Let Die in a Pandemic?’ Boston Globe (May 5th 2008)
prepare for the difficult decisions that must be made in a future triage situation. However, we have seen above that we are already in a triage situation at this very moment with Medicaid and an even stronger urgency should exist to think about Medicaid with the grim realism of the pandemic task force. Both to remind us of the gravity of this urgency, and for ease of determining how to treat or not treat certain imperiled newborns, such newborns at the time for their birth (and subsequently as evaluations/circumstances change and emerge) should be put into one of four medical triage categories:

RED. ‘Must Treat.’ Data show that the baby should be given aggressive medical treatment. Unless diagnosed previously with a terminal disease, all babies for the first three days after birth will be in this category and given a chance to ‘declare themselves’ since most babies who die do so in the first three days.

YELLOW. ‘Unclear – Emergent.’ Data at this point make it unclear whether or not to treat the baby. However, the circumstances are such that a decision must be made quickly by the parent or guardian in consultation with clinicians. Here, perhaps, the Lantos-studied ‘clinical intuitions’ of neonatal physicians and nurses would be given significant weight.

GREEN. ‘Unclear – Non-Emergent.’ Data at this point make it unclear whether or not to treat the baby. However, the circumstances are such that a decision need not be made quickly and can incorporate more study, the convention of an ethics consult, longer and deeper conversations between family and clinicians, etc.

BLACK. ‘Must Not Treat.’ Data show that the baby should be given palliative care.

An algorithm would need to be created into which one could feed data to produce one of these four categories.\textsuperscript{265} Data would be of the following three kinds.

\textit{Survivability and Length of Life Predictors.} Many variables would be factored into this group of data. Birthweight seems to be a key tool, but since babies are getting

\textsuperscript{265} Perhaps, though it would include more factors, it would mirror the algorithm used in the Tyson study to come up with a ‘predictor’ (available for public online use) for imperiled newborn outcomes.
bigger gestational age would probably play a larger role and should be weighted in the algorithm such that no baby under a certain gestational age should be treated. However, because the empirical data show that black babies and female babies do better than their white and male counterparts, race and gender should be factored-in as well. Other things to consider: SNAP and APGAR scores, prenatal care and tests, maternal health and steroid use, and other data that clinicians would be better able to assess. The relative weight of each of these pieces of data is something that should be a focus for future study.

*Short and Long-Term Costs of Treatment.* Again, this data group would consider many variables. Of course, one would need the first data group to predict and estimate both short term NICU treatment costs and costs for follow-up treatment over the life of the patient. One would then need to study in more depth the relationship between a certain level of premature birth and/or congenital disease and short/long-term costs for Medicaid. Emphasis should be given to studying this with regard to particularly common and expensive diseases. Obviously, total costs should be weighted in the algorithm such that the more costs a treatment produces the less likely it will be considered proportionate with the common good. But perhaps the weighting should go farther. Building on Todd Whitmore’s insight that Catholic Social Teaching on the universal destination of goods implies a ‘maximum living wage’ (Whitmore, 45), perhaps we could talk about a ‘maximum medical benefit’ (relative to total health care resources available, of course) that is justly available to a person from the community over the course of their lifetime. What that number would be needs to be the subject of further study and reflection, but perhaps a baseline figure could be relative to the cost of adding those to Medicaid who
aren’t quite impoverished enough to make the cut—like those mentioned previously who were dropped from TennCare.

Relationality. Though it was shown previously that attempts to use the broad category of ‘quality of life’ when rationing care causes more problems than it solves, perhaps something like future capacity for ‘relationality’ could be profitably considered in the algorithm as well and capture much of what is narrowly important about quality of life considerations without heading down a fruitless path of trying to define and apply it more generally. Admittedly, defining relationality is also a qualitative judgment that does not translate easily into a quantity that would be necessary for incorporation into the algorithm, but perhaps very broad distinctions could be made which could be quantified. Perhaps a relationality rating of ‘zero’ would be weighted such that no treatment would be given, a rating of ‘partial’ or 0.5 would make treatment less likely, and a rating of ‘full’ or 1.0 would have no effect on the outcome at all.266

Much would need to happen in order to make something like the above possible. As mentioned previously, much research and study would need to take place regarding predicting outcomes and estimating costs, but then more study and thinking would have to take place about the values behind the relative weights of certain kinds of data—and then about how to create an algorithm which reflects the values and weights. Obviously, this is a challenging project that would involve persons with different kinds of expertise: physicians, researchers, economists, statisticians, philosophers, theologians, etc. However, the fruits of such a project would be great in that instead of rationing Medicaid

266 This suggests the implementation of a RALY (relationality-adjusted life-year) rather than a QALY.
care in haphazard and unjust way we are today, we would instead have a system in place that transparently and publicly attempted to find a morally defensible method of distributing medical resources in our society’s tragic situation of medical want.

**A Preferential Option for the Poor?**

Catholic Social Teaching “requires that that the poor, the marginalized and in all cases those whose living conditions interfere with their proper growth should be the focus of particular concern. To this end, the preferential option for the poor should be reaffirmed with all its force.” (Compendium, 86) This is a ‘special form of primacy in the exercise of Christian charity’ which embraces not only those who are considered traditionally poor (the hungry, needy, homeless, etc.) but also specifically “those without healthcare.” (Compendium, 86) If these reforms are directed primarily at Medicaid, and Medicaid is the health insurance for the poor, then how could this dissertation claim to be consistent with Catholic Social Teaching? This policy recommendation, far from a preferential option for the poor, sounds like precisely the opposite. If you are poor, then you will have your NICU care curtailed—but if you are wealthy enough to have your own insurance then we won’t regulate you at all. Furthermore, many of babies on Medicaid in the NICU, especially in urban areas, are black. Is this dissertation essentially arguing *de facto* that we should let poor, black babies die? If this is the case, it is hard to see how it could even be taken seriously as a piece of scholarship—much less have ‘Catholic Social Teaching’ in its title.

The above is a powerful argument and one to which there must be an adequate response if this dissertation claims to be consistent with Catholic Social Teaching. There
are at least three things to say in response to it. First, does it follow that resources should
not be distributed proportionally within a given group because that group has been
wrongfully discriminated against? Let us continue the analogy of the battlefield triage
situation. Suppose that there was a black Civil War regiment that had just finished
engaging the enemy in battle and a white triage medic, assigned to their regiment, comes
on the scene. Suppose also that the US government was complicit in wrongful
discrimination by only assigning one medic to the regiment when, in fact, they required
three. The medic, despite the larger injustice of discrimination against the regiment,
should not add to the injustice by refusing to proportionately distribute medical
resources—even if other white regiments are not forced to make the same tragic choices
he is. If he passes over the first patient he sees because the soldier would take too long to
stabilize relative to the other needs of the soldiers for which he is responsible, he is not
‘racist’ or ‘having a preferential option for white soldiers.’ He is making a decision
based on the factors and variables over which he has control and to which he has been
assigned. Similarly, this chapter’s argument about Medicaid does not presuppose control
of how health care resources are distributed more broadly, but only with regard to
public policy about how community resources are spent. It is true that it is a grave
injustice that only one triage medic was assigned to the black regiment—and it is true
that it is a grave injustice that we spend so little on Medicaid compared to the medical


267 Indeed, it is far more likely that Medicaid and the other reforms suggested would be
implemented before wholesale reform of the health care system came along. But, nevertheless, the
conclusion of the dissertation has suggestions about broader reforms to the US health care system that may
follow from its more central proposals.
need of the poor.\textsuperscript{268} However, neither are legitimate excuses for disproportionately distributing the resources that do exist.

Second, there is indeed some regulation—both direct and indirect—of private insurance proposed in this chapter already. Direct regulation comes in the form of making it illegal to treat, and for insurance companies to cover, a host of terminal neonatal ailments. In addition, private spending on NICU care is indirectly regulated by attacking the culture of treatment which produces overtreatment—and thus overspending—in the first place.

Finally, it is also a fact that private insurance companies often look to Medicaid for the ‘OK’ to make policy and reimbursement changes. If Medicaid makes a change, then private insurance companies generally follow suit. This happened with regard to physician billing, for instance, when Medicaid insisted that the attending physician actually be a part of a treatment in order for it to be billed (i.e. it was not just the work of a resident physician) all the private insurance companies immediately demanded the same thing. With regard to reimbursement rates, the connection is even more direct. Private insurance carriers often pay, particularly for treatment at out-of-network facilities, based on a percentage of something called the ‘CMS Rate.’ The Center for Medicare and Medicaid Services determines its reimbursement for all medical services and publishes them annually\textsuperscript{269} thus allowing for private insurance to use their rates as a baseline.

\footnotesize{\textsuperscript{268} Though it is the case that a disproportionate number of Medicaid babies are black, and limitation of Medicaid NICU resources would disproportionately affect blacks, it can hardly be said that the constructive proposal with regard to Medicaid is \textit{de facto} racist. This is because built into the algorithm, and based on studied medical outcomes, would be a significant (30-100%) advantage of blacks over whites.\textsuperscript{269} \textsuperscript{269} \url{http://www.cms.hhs.gov/home/medicaid.asp} (accessed June 23rd 2008)}
Some pay more and some pay less, but if Medicaid were to lower its reimbursement rate for a given procedure it would ultimately affect the private insurers as well. What this means is that if the suggested Medicaid regulations of this chapter were enacted, it is more-than-likely that the reforms would be picked up by private insurers as well—particularly if they were helped along with federal tax breaks for adopting the same system. After all, the short and long term costs of choosing to treat imperiled newborns covered by private insurance are also problematic for these companies—they drive up premiums for their members, hurt profits for their shareholders, etc. Indeed, once this change ‘cycles through’ it would mean that private insurance premiums would go down such that some of the poor who do not qualify for Medicaid could possibly afford private insurance. This would most certainly be a preferential option for the poor.

Catholic Social Teaching’s critique of the attitudes and practices of treatment of imperiled newborns in the NICU found that they were not consistent with a proportionate distribution of resources directed toward the common good: a decent minimum of health care for all. While discussion about wholesale changes to our health care system are beyond the scope of this dissertation (though they will be gestured-at in the conclusion), the reforms suggested in this chapter at least move us toward that goal. Resources would be freed up to either (1) improve physician reimbursement rates or (2) expand the number of impoverished that can qualify for Medicaid—both of which would move many closer to having a decent minimum of health care. The latter would obviously do so by giving people health insurance who otherwise could not afford it (like, again, our TennCare examples), but the former would allow those on Medicaid get needed care by seeing physicians they normally could not because of the low reimbursement rates. This
problem is especially true with regard to obstetricians who, more and more, do not see Medicaid patients for prenatal care because of the very real fear they will lose money in the process. Improving Medicaid reimbursement rates in that area with targeted expansions, for example, would lower the incidence of ELBW births and start a cycle which would lessen the need NICU care in the first place—in effect, far from abandoning Medicaid babies, limiting NICU care in this way could actually improve overall care and outcomes for infants on Medicaid.
CONCLUSION

Do the sometimes staggering costs of neonatal intensive care mean that at some point the economics of care determine the meaning of best interests [of the infant]? We shy away from such considerations, and this is undoubtedly a healthy response. But how long we can sustain it I do not know.

Richard McCormick

This dissertation has attempted to systematically consider some important facts which, when considered jointly in the same health care context, have dramatic implications. The health care system of the United States leaves nearly 50 million of its people without health insurance of any kind and many millions more with insurance that does not meet their medical needs. This is due to a number of complex factors, but perhaps the most important one is that we distribute resources, not with regard to patient population need, but with regard to considerations like profitability of treatment, ability of patient to pay, political trends, sympathetic/unsympathetic nature of the patient, the ‘culture’ of certain areas of medicine, etc. Rationing of health care resources based on these criteria often results in disproportionate treatment—with certain patients getting huge shares of our medical resources and others getting smaller shares or even no share at all.

A paradigmatic example of this disproportionality, this dissertation has argued, is treatment of certain imperiled newborns in the neonatal intensive care unit. Especially when critiqued by the Social Quality of Life Model in light of Catholic Social Teaching,
the ‘culture of treatment’ in the NICU has been found to be in need of serious reform. This is not because imperiled newborns are less than full persons without a right to be considered on the same level as any other patient; but rather because what is in a newborn’s best interest cannot be isolated from the duty of all to live in right relationship with the rest of humanity in conformity with the common good. Part of what it means to live in right relationship is using only a proportionate amount of medical resources available to the community. And given the dramatic numbers offered in Chapter Four, it seems that some treatment of imperiled newborns is disproportionate with the common good. Such treatment, in light of our tragic health care situation, ought to be foregone.

Quite appropriately, this author and many others are very uncomfortable with such a conclusion. Such discomfort might tempt one to shy away from dealing with the reality of our tragic healthcare situation. However, as Duff and Campbell remind us, we cannot live outside the human condition—and this condition is riddled with tragedy. For if “we resist accepting tragedy as part of human experience, we fail too often to deal with tragedy, and thus we cannot discover and adopt the least tragic choice in situations where only tragic choices exist.”\textsuperscript{270} To simply let our health care resources be distributed the way they are currently—in a \textit{de facto} triage situation—is a greater injustice than the remedy proposed in this dissertation.

But as was mentioned in Chapter Three, dealing with this tragic reality by foregoing treatment to imperiled newborns cannot be our only response to the problem. It is true that we will never fully eradicate disproportionate treatment in any healthcare

system, but we can take further steps even beyond what this dissertation argues. Not only
can the critique of the Social Quality of Life Model in light of Catholic Social Teaching
be leveled at areas of medicine outside of the NICU, but we need not accept our current
health care system’s general structure as it now exists. Perhaps the most obvious
example of ‘structural sin’ in our culture is a health care system which causes the poor
and the old—who are at high risk for disease already—to have dramatically worse health
care than the financially comfortable and young. There is no need to take for granted this
kind of two-tiered system and level a critique only of the lower tier. Though it obviously
goes beyond the scope of this dissertation to make an argument in this regard, it is
certainly worth mentioning some basic points about this in the conclusion and as a
direction for further work.

Given the dominant political culture in this country, it is highly unlikely that
system-wide change away from a two-tiered system will come in the foreseeable future.
However, let us look again at one result of the Oregon debate over rationing:

In Oregon, the rhetoric of rationing pulled into the open decisions that privately
occur every day and that deny services to uninsured or underinsured Americans.
OHP’s experience points to an unanticipated but possible political benefit of
rationing rhetoric: it reconfigured debate toward openly acknowledging, as a
society, what medical services Americans—even the politically eviscerated poor—should receive or go without. And it put politicians in the vulnerable
position of pulling the plug on particular medical services. Paradoxically, a
process ostensibly aimed at saying no might force voters and politicians—as it did
in Oregon—to recoil in horror and say yes.271

This is exactly the author’s hope for the long-term effect of the argument of this
dissertation. In the short term, the hope is to more proportionately allocate resources in

271 Jacobs, The Oregon Health Plan and the Political Paradox of Rationing: What Advocates and
Critics have Claimed and what Oregon did., 178.
the lower tier of the system, but the long term hope is that many ‘recoil in horror’ at the conclusion of this dissertation and say yes to system-wide reform of our healthcare system. Many citizens are aware of the plight of the uninsured and underinsured in the United States—and yet this is apparently not horrific enough to shift the political culture to say yes to dramatic and system-wide change. Perhaps foregoing life-saving treatment for babies in the NICU will be enough to give our culture the shock it needs to clear the conceptual space needed for this kind of systematic shift in thinking about health care.

But what would such a system-wide shift look like? Again, it goes beyond the scope of this dissertation to make an argument, but a broadly Roman Catholic understanding according to the National Conference of U.S. Catholic Bishops would require that the following criteria be met:

- **Universal Access.** Whether it preserves and enhances the sanctity and dignity of human life from conception until natural death.

- **Priority Concern for the Poor.** Whether it gives special priority to meeting the most pressing health care needs of the poor and underserved, ensuring that they receive quality health services.

- **Comprehensive Benefits.** Whether it provides comprehensive benefits sufficient to maintain and promote good health, to provide preventive care, to treat disease, injury, and disability appropriately and to care for persons who are chronically ill or dying.

- **Pluralism.** Whether it allows and encourages the involvement of public and private sectors, including the voluntary, religious, and non-profit sectors, in the delivery of care and services; and whether it ensures respect for religious and ethical values in the delivery of health care for consumers and for individuals and institutional providers.

- **Quality.** Whether it promotes the development of processes and standards that will help to achieve quality and equity in health services, in the training of

---

providers, and in the informed participation of consumers in decision-making on health care.

• **Cost Containment and Controls.** Whether it creates effective cost-containment measures that reduce waste, inefficiency, and unnecessary care; measures that control rising costs of competition, commercialism, and administration; and measures that provide incentives to individuals and providers for effective and economical use of limited resources.

• **Equitable Financing.** Whether it ensures society’s obligation to finance universal access to comprehensive health care in an equitable fashion, based on ability to pay; and whether proposed cost-sharing arrangements are designed to avoid creating barriers to effective care for the poor and vulnerable.

Though the Catholic Church admits that it is no expert in creation or practical application of economic or health care systems that would most likely meet these criteria, it goes without saying that achieving this kind of reform is a tall order—especially in light of the hyper-autonomous culture of the United States. The Catholic Health Association has therefore argued that, “While change is needed immediately, it is acknowledged that systemic change is most likely to be a gradual process, rather than occurring all at once.”

>273 A sequential strategy is needed to achieve the change required. But before our culture can start down this path with the urgency required to push through to the final goals, it is worth noting that the proper motivation and energy needs to be present in order to shift our American values in this area. Again, perhaps non-treatment of certain imperiled newborns would serve as just such a needed motivation and energy creator.

But what do we do in the meantime? Suppose we limit neonatal care in a way that is similar to how this dissertation suggests and we are going through the sequential

---

processes required for system-wide reform: what about the Medicaid babies in the meantime? Do we simply sit back and let them die? Not if we are convinced by the example of the early Christians. Recall from Chapter One that in the ancient Greco-Roman world:

by far the most common social reason for exposing a newborn was poverty. One more mouth to feed might all too easily mean taking food from family members who already suffered hunger. Indeed…it appears some families had genuine hope that their children would be saved—leaving the infant at a street corner, near a public building like a temple, or even at spots just outside a city of village that were specifically designed for exposure. Such hope was not always misplaced. Though scholars disagree as to the rates of survival, it appears that at least some of these infants became foster children and less fortunate ones were picked up to be used as slaves or prostitutes. At any rate, the fact that this kind of exposure was common may say less about the attitude of the parents or culture toward the moral status of such infants than it does about the social realities with regard to scarcity of resources—and the desperation that such scarcity would drive some families who clearly wanted to give their infant child a chance at life.

As mentioned in the introduction to the dissertation, early Christians saw it as their moral duty (even when subjected to ridicule by the surrounding culture) to save these infants who required a disproportionate amount of resources for their family to sustain. A similar situation would be the modern-day result if the central argument of this dissertation informs our public policy with regard to treatment of imperiled newborns. Infants whose treatment would be foregone today would be analogous to infants exposed in the ancient world by families who could no longer afford their care, but would hope for their adoption after being exposed. Instead of nuclear families being unable to provide for them given a tragic lack of resources, our wider ‘social family’ (considered, perhaps, as individual Medicaid programs) is unable to provide for them also because of a lack of resources—at least as our health care system is set up right now. Just as ancient Christians adopted these children at such a rate that it became an identifying mark of
scorn and ridicule for their community, today’s Christians would need to step up in a similar way. Hospitals—especially those with Roman Catholic affiliation—should set up programs such that their NICUs could take certain babies who were denied treatment via Medicaid (perhaps those who were refused treatment primarily because of its short and long-term expense) and fund their care. And anyone who is convinced by the example of the ancient Christians should then feel compelled to support such programs274 financially through charitable donation. And, if also convinced by Catholic Social Teaching, one should feel compelled to do so not simply by giving ‘from one’s surplus’ resources, but by sacrificing in a way similar to that of the early Christians: in a way which considers these infants as part of one’s family. For, in light of Christian solidarity, that is exactly what they are.

274 As well as other programs and charities that would support the child’s long term needs.
"Nearly 5 Babies Killed Weekly, FBI Data show." CNN.


Morse, Steven B., Samuel S. Wu, Changxing Ma, Mario Ariet, Michael Resnick, and Jeffrey Roth. "Racial and Gender Differences in the Viability of Extremely Low Birth Weight Infants: A Population-Based Study." (2006).


Panicola, Michael R. "Quality of Life and the Critically Ill Newborn: Life and Death Decision Making in the Neonatal Context." Ph.D., Saint Louis University, 2000.


Shearer, M. H. "The Economics of Intensive-Care for the Full-Term Newborn." 7, no. 4 (1980).


258


