

**THE UNCERTAIN BEST INTERESTS OF PREMATURE NEONATES:
AN EXPLORATION OF MEDICAL ETHICS**

By

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In Partial Fulfillment of the Requirements
for the Degree of**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of
Manitoba in partial fulfillment of the requirement of the degree
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TABLE OF CONTENTS

DEDICATION	ii
I INTRODUCTION	
Preface	1
Methodological Considerations	9
Thesis Outline	12
II BEST INTERESTS AS THE CURRENT STANDARD FOR MEDICO-LEGAL PRACTICE	
Locating Sanctity of Life and Quality of Life Mandates in Medico-legal Decision-making in Canada	17
Defining Futility: The Challenge	21
Inconsistencies in Values Informing Approaches to Decision-making	28
Euthanasia: The Complex Relationship between Substantive and Procedural Questions	32
III THE SOCIO-HISTORICAL CONTEXT OF THE PHYSICIAN-NEONATE RELATIONSHIP	
The Neonate as Patient	49
The Physician as Healer and Moral Authority	61
Medical Ethics for the 21st Century: Learning from Experience	78

IV	THE ETHICAL SIGNIFICANCE OF PROGNOSTIC UNCERTAINTY	
	Predictive Thinking, the Physician’s Hippocratic Legacy	83
	The Current Reality of the Physician-Patient Relationship in the NICU	88
	Significance of the Boundaries of Medical Practice and the Plurality of Medical Knowledge	93
	Medical Certainty Mistaken for Truth	100
V	EXPLORING OUR COLLECTIVE STORY THROUGH THE MANDATES OF SANCTITY OF LIFE AND QUALITY OF LIFE	
	The Significance of the Medical Context	106
	Sanctity of Life and Quality of Life in the Medical Decision-making Context	109
	Towards Co-existence: A “Science- Spirit” Consensus	125
	Concluding Remarks	133
	WORKS CITED	136

DEDICATION

For Allison

CHAPTER ONE

INTRODUCTION

I cannot but have reverence for all that is called life.
I cannot avoid compassion for all that is called life.
That is the beginning and foundation of morality.
Albert Schweitzer

Preface

In the last decade, the complexity of decision-making concerning initiation, limitation and withdrawal of medical treatment for the extremely premature neonate has grown, in part because of the emergence of new obstetrical and neonatal technologies, in part because of more aggressive clinical management. While these developments have significantly improved the survival of certain neonates these developments have at the same time, heightened concerns about the limits of viability. This has led certain critics to observe that the current capability of Neonatal Intensive Care Units (NICUs) to promote survivability in this population has resulted in a situation in which “health providers, newborns, and their families are often held hostage to biomedical technology” (Muraskas et al 160). Despite the past widespread public attention given to life and death decisions concerning infants with conditions such as Down's syndrome or spina bifida in bioethics literature, these cases are no longer typical. Rather, as has been noted in the recent literature, most of these life and death decisions today concern extremely low birth weight infants born at the limits of viability (Anspach 8; Campbell 1995, 86).

Previous investigations have certainly addressed the complex issues that characterize medical futility in the NICU¹, but there has been limited discussion of medical futility specifically in relation to the treatment of this particular population of neonates. These babies are known in the medical literature as the extremely low birth weight (ELBW)² or extremely premature neonate. In recent years, this medical literature has begun to raise concerns about how futility is to be defined for this infant population in the clinical setting and thus the concept of medical futility and its application in clinical practice has been the subject of considerable controversy and debate³.

Some critics have asserted however, that these so-called definitions of medical futility are conceptually ambiguous. While acknowledging the broad distinctions that have been made in the literature regarding quantitative and qualitative forms of medical futility and the proposed statistical indicators for determining futility, they argue that precise application of these models to clinical practice is problematic because of the sometimes-unpredictable nature of an infant's response to therapy, variability in physicians' management styles, and the ethos of different neonatal intensive care units (Schneiderman and Jecker 1994; Schneiderman et al, 1990). This is further confirmed by recent sociological studies of neonatal intensive care, which reveal the contextualized and complex nature of decision-making concerning life support. Renée Anspach's work in this area, for example, has led to better appreciation of the fact that such dilemmas can be viewed as evolving within, and constrained by, the biomedical culture of the Neonatal Intensive Care Unit (NICU).⁴

Canadian medical researchers Barbara E. Bay and Michael M. Burgess have voiced concern about the quickly developing medical technological advances and their significance as contributors to treatment dilemmas in the Neonatal Intensive Care Units. They raise concerns that because of our new-found methods to create and sustain life, there are now before us unfamiliar ethical dilemmas. This has led to the current situation where practitioners are increasingly finding themselves in the position of implementing - or withdrawing - treatments for which the ethical protocol has barely been addressed, let alone resolved (139).

While it is necessary to appreciate the difficulties of such responsibility for the individual practitioner in uncertain and changing circumstances, the ramifications of the presence of under-riding gaps in ethical guidelines should be of concern as well. Bay and Burgess observe that because such a situation exists, it is relevant and necessary to discern physicians' attitudes towards the treatment of certain newborns and the impact these attitudes have on end of life decision-making. Certain international approaches to practice are compared in this study, and gaps and differences in practice are identified. Interestingly, gaps and differences are also being identified amongst the participating Canadian practitioners as well. Many physicians, for example, were not aware of the legal ramifications and rights and liabilities of decision-making under Canadian law. Further, concern was raised regarding the specialties of neonatology and pediatrics and their different decision-making approaches based on differing priorities. Canadian physicians in this study also voiced a need for better delineation of practice guidelines regarding what treatments constitute extraordinary and ordinary care (146-7).

C. Anthony Ryan and colleagues agree that Canadian practitioners are indeed concerned about their capability to bear the responsibility of end of life decisions in neonatal intensive care in the face of changing technology, and their review of the literature has revealed widespread inconsistencies in practices (534). They forward factors such as medical uncertainty, fear of being accused of medical neglect, societal and cultural influences, and family values, as possible explanations for these differing practices (535). They also advocate further research in order to evaluate and interpret and clarify the decision-making processes that lead to the initiation of treatment and subsequent limitation or withdrawal of support in pediatric patients (538).

Thus, in the context of Canadian practice, physicians are approaching these decision-making situations with differing value systems or worldviews. They are also making these decisions with differing levels of knowledge concerning practice-liability defined by the law and they have acknowledged the need for improved education of the medical community in making these ethical decisions. They are also advocating an individualized approach to decision-making, which means what might mean futility for one, may mean full intervention for the next.

Certainly, the issue of selective non-treatment of newborns, whether due to handicap, defect or extreme prematurity has been, and continues to be one of the more complex issues in biomedical ethics. Fifteen years ago this complexity was well demonstrated and analyzed by Robert Weir in his 1984 text, *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine*. In the preface of his text Weir notes that:

[P]art of the complexity of the issue lies in the dilemmatic alternatives available to decision makers in such cases: to prolong an anomalous neonate's life often means the unavoidable continuation of severe handicaps that few adults would choose for a child to endure, but in some instances the only way of avoiding such a handicapped life is to withhold treatment in the hope that the defective child will soon die. (Weir 1984, vii)

As neonatal medicine continues its struggle with the questions of technological intervention, these “dilemmatic alternatives” referred to by Weir, and reiterated by the Canadian research previously cited, begs the question of exactly what ethical frameworks inform individual physicians and hospital policy guidelines here in Canada. Indeed, these Canadian studies affirm that the decision to withhold or withdraw treatment and the criteria guiding the application of these decisions continue to be important to issues of fair treatment and ethical analysis.

It is also important to acknowledge that despite the medical decisions being made, there is a lack of societal consensus on the value of initiating aggressive life-sustaining treatments of ELBW infants. It seems unclear whether neonatology is a dramatic success or a misguided effort. Three decades of advancements in the medical, surgical, nursing, and respiratory therapy care of ELBW infants have impressively brought a brand new meaning of viability but have barely nudged morbidity statistics. J. Martin Peabody, writing on this subject, has warned that medicine's intervention with smaller and smaller neonates has led to a situation where “the line between ordinary and extraordinary care is blurred, and the distinction between standard of care and experimental care has all but disappeared” (473-89). Indeed, it appears likely that as technology continues to progress, the envelope of viability could very well be pushed back further and further.

The capabilities of advanced technology enable physicians to sustain infants born at the edge of viability while the quality of life they face seems in critical question. These capabilities, as some have suggested, to do harm have increased exponentially over the past few years and the dilemma before us is choosing the best stance to take, “so as to serve patients and their families in an ethically sound manner” (Hefferman and Heilig 174).

My thesis research explores the current medico-legal standard of best interests in the uncertain prognostic situations created by the birth of an extremely low birth weight neonate. My point of departure on this issue is greatly influenced by ethicist Margaret Somerville's recent observations in *The Ethical Canary: Science, Society and the Human Spirit* concerning the difficulties in attaining moral consensus in the medical management of birth and death in our secular society. I note, in particular, her observation that:

In the past, we wove the metaphysical fabric in whom we wrapped the events of birth and death mainly using the resources that we found in religion. [. . .] But by the mid 1970's, we began to transfer our “collective faith” from religion to the extraordinary new science that was emerging. [. . .] One of the substitute forums for religion that has emerged in secular societies in the last fifty years is medicine and health care. [. . .] Our decisions about health care, especially when those decisions concern new scientific and technological developments, are never just about health care. They have a much wider impact on society as a whole. (Somerville 2000, 3-4)

Our search for ethics seems to be also related to a change in the basis of trust in society. It has been suggested that we can no longer assume the presence of trust in our society and its institutions (Dubose 17). As Somerville warns, we must take steps to ensure that it is present (292). My thesis research explores the moral authority traditionally attributed to the physician in Western culture for determining best interests.

Due to the recent changes to our society, as described in Somerville's statement above, it is a necessary step towards a clearer understanding of the difficult substantive and procedural questions surrounding end of life decision-making for ELBW neonates. As Somerville posits, we are indeed in the midst of a search for a new world-view as a basis for a new societal-cultural paradigm. She advocates a view that should be able to encompass both science and the human spirit. She acknowledges that for some, such a view can be expressed through religion, but it can also, in her view, be held independently of being religious, at least in a traditional sense (19-21).

The best interest standard has been forwarded as a compromise between the competing forces of sanctity of life (SLP) and quality of life (QOL) (Weir 1992, 314). This research endeavors to explore these elusive mandates in the medical decision-making context, in an effort to locate, describe and clarify their central theological-ethical concerns about the meaning of human life and the nature and limits of caring for it. I hope to demonstrate the possibilities for co-existence of these mandates in order to foster moral censuses on this issue.

In the last few decades however, religious presence in bioethics discourse has been waning. The coming century promises enormous advances in medicine, which will have staggering bioethical implications. John R. Williams, current Director of Ethics for the *Canadian Medical Association*, suggests that religious scholars and authorities can profit from the discussion of method in contemporary bioethics. The practice of interdisciplinarity, he proposes, is "a feature which can, and perhaps must, be adopted in the analysis of any ethical issue" (27). Somerville asserts that the weakness with this

method is the positioning of ethics as an “add-on” after the “real” work, [in this case, of science], is completed. She therefore advocates an approach that recognizes the major impact that a choice of methodology can have on the decisions we make, especially concerning ethics. The practice of transdisciplinarity, she proposes, “will compel us to find a common vocabulary between the disciplines based on a belief that the learning or methodologies of any one discipline are too confining to enable us to deal with the complexity of many most important and urgent societal issues” (286). My thesis research is, therefore, an effort to move beyond generality and vagueness to increased specificity and clarity regarding the ethics of end of life decision making in the ELBW neonate by bringing medicine, sociology, law, religion and philosophy together on the key moral and procedural questions. I hope to demonstrate that postmodern medicine must realize that such decisions cannot be made in a vacuum; I also hope to elucidate the challenge that bioethics poses to religious and non-religious individuals and institutions to re-examine some of their basic assumptions and teachings. This thesis is therefore relevant to, and important for, the future involvement of the discipline of religious studies and its role in successfully crossing what Somerville refers to as the ‘boundaries of religion, ethnic and national origin, and culture [in order to] capture profound shared realities of the human spirit that can give meaning to our lives” (286).

Methodological Considerations

The practice of transdisciplinarity, is still in the process of development, but has an aim of embedding various streams of knowledge in one another. It seeks thereby to re-create integrated knowledge. It is advocated that this will compel us to find a common vocabulary between the disciplines that will adequately capture the metaphysical reality that is essential to our human well being, both as individuals and as a society regardless of whether we are religious (Somerville 285-6). It can be observed that our Western democracies are characterized by being pluralistic, secular and multicultural. These same features also mean that these societies lack a shared story, or as Somerville calls it, "the collection of fundamental values, principles, attitudes, beliefs, myths and commitments that we need to buy into in order to function as a society, and that we use to give meaning to our communal and individual lives"(2).

This research seeks to move towards the development of this shared story, or societal-cultural paradigm, that is required to hold us together. The ethical issues concerning the ELBW neonate are relevant in that they exemplify the point that Somerville has made that, "[o]ur shared story has always focused on the major life events of birth and death. Indeed, the general level of respect for human life that permeates a given society is largely determined in these contexts"(2). It is the contention of my thesis research that the dilemmas presented by the ELBW neonate are an opportunity for us to encounter birth and death in its most powerful form.

This research will seek to explore the relevance of a sociological, philosophical, religious and legal understanding of moral and medical choices. From a sociological

perspective, for example, Renée Anspach, forwards the concern that “we still know far more about how people think life and death decision *should* be made than how they actually *are* made”(9). Participants, she notes, bring their personal values, beliefs and principles to the life and death decisions surrounding neonates. At the same time, however, they must also debate with colleagues, answer to superiors, and interpret the law. Therefore, in the NICU, decisions are not just individual undertakings but involve interactions between individuals. Decisions, Anspach concludes, are shaped by the social context in which they are made, and she proposed that the organization of the intensive care nursery as a work environment, structures the perspectives of those who work within it and this organization is further shaped by institutional forces outside of it (20-24).

As physicians face dilemmas for which their medical training provides limited training or guidelines, they often look to experts for guidance. Bioethicists are one group of experts who have assumed an influential role in developing policies for making life and death decisions. Whether physician, philosopher or theologian, the function is to examine the ethical principles on which decisions in medicine or the biological sciences are or should be premised. Such bioethical analysis of newborn intensive care has been written from the standpoint of normative ethics, or that branch of moral philosophy that concerns the values and principles that characterize right and wrong conduct. With varying approaches, ethicists have developed and continue to develop guidelines for moral conduct; that is, they attempt to arrive at rules, procedures and methodologies of reasoning that determine whether actions are right or wrong. This bioethical analysis of

newborn intensive care, addresses the ethical principles on which decisions to treat or not to treat seriously ill newborn infants are or should be based. It is important to observe, however, that bioethicists, whether physician, philosopher or religious scholar, remain deeply divided over the questions of what should be decided, which babies should be treated, and who should have the authority to make life and death decisions.

A point to be emphasized in this thesis research is that in choosing our values, attitudes and beliefs, we are choosing not only for ourselves as individuals, but also for our world. Bearing in mind Margaret Somerville's observation that secular Western societies are "based on intense individualism-possibly individualism to the exclusion of any real sense of community"(5), this research will be descriptive in nature, endeavoring to explore this perceived loss of moral consensus in society. I will expect to demonstrate that moral individualism as it operates in neonatal intensive care decision-making, may well be a reflection of a loss of community consensus. This practice of moral relativism (also known as situational ethics) may well be preventing us from determining what really is wrong morally, regardless of proposed good that may come from certain decisions.

This research will acknowledge the need to take into account social issues in doing ethics, and to examine the role the law plays in creating consensus on values and as an avenue for challenging them. It also proposes to examine the roles past and present philosophy and religion play in our values talk. Somerville suggests that values talk has been transferred to the media as "ethics talk." This ethics talk she says, is frequently interwoven with "law talk" concerning the same issues. She concludes that we have

become legalistic societies, and this change is connected with a loss of consensus on values, probably intense individualism and the impact of the media. Law provides a bottom line, working consensus on values, even if in substance we still disagree (10-11).

This thesis will endeavor to demonstrate that the best interests standard is an example of the role that Medicine and the legal process have played in forming our societal values. Indeed, end of life decisions for neonates in the past would have been largely the subject of moral or religious discourse, but are now explored in our courts and legislatures, in particular through concepts of individual human rights, civil rights, and constitutional rights. I will examine this situation in an effort to clarify and describe why we are searching for ethics, especially in relation to technological capabilities. I hope to confirm that the possibilities for moral consensus will be greater through an emphasis not only on respecting the rights of individuals who make up this society, important as this is, but also on our responsibilities to the common good in order to protect society and foster our sense of community.

Thesis Outline

Certainly, the debates surrounding the moral problems of medical management regarding neonates are not new ones. The task of Chapter II of this thesis will be to demonstrate the complexity and the influences, past and present, surrounding the issue of initiation, limitation and withdrawal of treatment in neonates. I endeavor to situate the topic of end of life decisions in extremely low birth weight neonates, as it will be studied in this paper. This begins with a discussion of the difficulties concerning the application

of the best interests standard as the approach guiding decisions in the clinical setting and as enforced by the Canadian judiciary. As well, I acknowledge the associated difficulties encountered in attempts at defining futility at the bedside, and the resulting inconsistencies in approaches to decision making. I also explore the issue of trust in the context of physician relationship with the incompetent neonatal patient, the legal guardian(s) and society. This is done in order to explore the assumption of values consensus with the physicians involved in decision-making and non-initiation and withdrawal of treatments in this population of patients.

In Chapter III, I endeavor to delineate the sociological and historical developments concerning birth and death of the neonate in Western culture. I examine the history of the neonate as a patient, alongside the changing role of the physician in Western culture. This necessarily explores the changes to the method of medical decision-making used by physicians up until the mid 1960's, guided for the most part, by Hippocratic ethics, which helped to situate the physician not just as healer, but as moral authority as well. I discuss the emergence of bioethics and the resulting changes to the way of doing ethics that this period catalyzed, and the involvement of medicine, philosophy, law and religion in these early debates concerning the ethical implications of the availability and use of new technologies in neonatal care.

The ethical significance of prognostic uncertainty for physicians, and its impact on how physicians make their decisions with regard to non-initiation and withdrawal of treatment is explored in chapter IV. The influence of the Hippocratic teaching concerning the tradition of predictive thinking and the current culture in medicine that

appears to foster aggressive treatment of ELBW neonates in prognostically uncertain situations are explored. I emphasize the importance of appreciating the social reality at the bedside with these neonates, and the associated difficulties physicians are having acknowledging their boundaries of medical certainty and the plurality of what constitutes medical knowledge. The purpose of this is to explore and clarify the meanings that can be found in medicine's response to this constant element in practice while caring for this population of neonates. As Robert M. Veatch points out, a critical transition has taken place between what he distinguishes as modern medicine and postmodern medicine. Modern medicine functioned under a prevailing paradigm of medicine as objective. Postmodern medicine revolves around the realization that decisions cannot be made in a vacuum. Veatch applies humanist non-foundational thought to ethical decisions in the medical arena and claims that personal judgments are inherent in all decisions (1991, 11).

This takes me into a discussion of the mistaking of medical certainty as truth, within the context of what Margaret Somerville refers to as the "pure science view" and its polar opposite the "pure mystery view" which has historically, in her opinion, resulted in two-dimensional or linear tensions between science and spirit (20). I will propose that these positions Somerville has identified are similar to the quality of life (QOL) and sanctity of life (SLP) views often appealed to in ethical deliberation in the medical context. One view operates from a faith in science (and that which science reveals, which brings it very close to religion, or a substitute for one, or an ideology); and the other view operates from a faith in revealed doctrine (revelation).

In Chapter V, I explore the possibilities of an understanding of these mandates in the manner Somerville advocates in her “science-spirit view”, where she locates a third dimension, one that allows space for the recognition that unavoidable uncertainty is not incompatible with regarding some things as inherently wrong. By exploring our collective stories through these mandates I hope to aid in the work towards achieving moral consensus on end of life decision-making for ELBW neonates by confirming Somerville's conviction that “human life consists of more than its biological component, wondrous as this is. It also involves a sense of mystery-made up of at least the mystery of the unknown or the mystery of the nameless, or both-of which we have a sense through our intuitions [. . .] and accepts that we should respect this mystery” (19-20).

NOTES

¹ As Robert D. Truong, Allan S. Brett and Joel Frader recently observe, the term futility is one of the newest additions to the lexicon of bioethics. They note that a clear understanding of futility has proved to be elusive, however. It is their concern that in reality, the notion of futility hides many deep and serious ambiguities that threaten its legitimacy as a rationale for limiting treatment (1560-4)). It is their suggestion that the rapid advance of the language of futility into the jargon of bioethics should be followed by an equally rapid retreat. I will take this definition up as a problem in Chapter I. Other examples of literature addressing the complex issues that characterize medical futility are J. Lantos, “Providing and Forgoing Resuscitative Therapy for Babies of very Low Birth Weight.” *Journal of Clinical Ethics*, 3(1992): 283-311. L. Nelson and R. Nelson, “Ethics and the Prevention of Futile, Harmful or Burdensome Treatment to Children.” *Critical Care Medicine*, 20, (1992): 427-33. R.J. Weir, “The Need for Consistency in the NICU”. *Journal of Clinical Ethics* 3, (1992): 11-14.

² In any effort to define the term “extremely low birth weight” (ELBW), neonate, it is significant at the outset of this research to point out that there is inconsistency in definition. Another term in the medical literature, “very low birth weight infant” (VLBW) helps to illustrate the difficulty. The VLBW infant is strictly defined as having a birth weight of less than 1500 gm, but because of an evolving situation, there is no clear

definition of the ELBW group. Jacobi and colleagues for example, have observed that the upper limit in some reports is 750 gm, complying with the World Health Organization (WHO). The WHO defines fetuses weighing less than 500 gm as nonviable, however, since even infants born at less than 500 grams may occasionally survive, this criterion is potentially invalid, since some reports include all infants born beyond 20 weeks gestation, without consideration to the birth weight at all (155-6). This is for the epidemiologists to determine, obviously, but for the purposes of my research this does demonstrate that we have been propelled into a frustrating situation by a complex evolutionary process, and not by objective decisions. Indeed, we were encouraged by the previous progress and successes of neonatal care in the VLBW group that have been since inappropriately extrapolated to ELBW infants. Because of the changes in definitions and expectation, and in some places because of legal obligations, the neonatology team is now called to treat babies with decreasing birth weights. At extremely low gestational ages and birth weights, no criteria observable at birth clearly distinguishes the live born fetus that is capable of long-term survival from one without such capability. One can only define a zone of uncertain viability below which long term survival is presently impossible and above which, given appropriate intensive care, survival is reasonably possible, although not assured. It is, of course, possible that this range will shift still further downward with time, a plateau will surely be reached unless new and different technology is developed, however.

³ For examples of such debates see L.J. Schneiderman and N.S. Jecker, *Wrong Medicine: Doctors, Patients, and Futile Treatment.* (Baltimore: Johns Hopkins, 1995). A.S. Tuong and Brett J. Frader "The Problem with Futility", *New England Journal of Medicine* 326, (1992): 1560-4. L.J. Schneiderman and K. Faber-Langendoen and, N.S. Jecker, "Beyond Futility to an Ethic of Care." *American Journal of Medicine*, 96, (1994) : 110-4. T. Tomlinson and H. Brody, . "Futility and the Ethics of Resuscitation." *JAMA*, 264, (1990): 1276-80.

⁴ See Renée R. Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery.* (1995)

CHAPTER II

BEST INTERESTS AS THE CURRENT STANDARD FOR MEDICO-LEGAL PRACTICE

Locating Sanctity of Life and Quality of Life Mandates in Medico-legal Decision-making in Canada

The practice standard of do no harm, or the principle of nonmaleficence, as it is called in ethics, appeals to many because it draws our attention to the well being of the infant (Beauchamp and Childress 120-2). It requires one to refrain from inflicting harm on another individual. This principle has been advocated in an effort to work towards the development of an infant-centered standard that justifies nontreatment only when it is in the infant's best interest. ¹ Understood in this way, to apply the best interest standard, is to weigh the benefits and burdens from the standpoint of the infant, while excluding from consideration the interests of the family and members of society. Such a standard aims to combine the objective medical data in a case with the more subjective assessments of patient suffering and prognosis, in order to arrive at a determination of whether the medical interventions being used or being considered will, on balance, be beneficial or harmful to a patient (Weir 1992, 314; Campbell 1995, 3; Sneiderman et al 500). English and Canadian cases indicate that the legal system will intervene when a parental refusal of health care significantly compromises the child's best interests. The best interests

standard as it relates to incompetent adult patients likewise fixes the physician's legal duty to the minor patient (Sneiderman 497).²

The medical profession has endorsed the best interest standard perhaps because it allows physicians to play a central role in determining the infant's best interest.³ The best interest standard also has its critics however. Some feel that the standard is hopelessly vague and difficult to apply in practice. Others argue that trying to imagine the best interests of those unable to speak for themselves as a misguided project. Still others criticize this standard for excluding what they see as the legitimate interests of family members and society.⁴

This approach is also the current standard of care upheld by the legal system in Canada. Thus, the law will intervene when a case can be made that parental refusal of health care or a physician's treatment or nontreatment significantly compromises the child's best interests. Parents have a right to decide on medical treatment for their child. This right to decide is derived from their obligation to provide the medical treatment that their children need to protect their lives and health. This right rests on the presumption that parents will protect their children's welfare and act in their best interests.⁵ For a variety of reasons, including religious beliefs, however, parents can refuse treatment for their children, even if medical professionals and others regard the treatment as essential to protect the children's health or life. In circumstances where serious harm could result from following a parent's decision that is contrary to the child's best interests (from an objective point of view), such that the result poses serious risk of harm to the child, the presumption that the parents are acting in the child's best interests is rebutted. This

means, essentially, that the parents can lose the right to decide for the child. In such a situation, when a court overrides parents' decisions concerning their children, they are fulfilling a responsibility that, in the legal context, rests on all of us, as a society, to protect children who are in danger and unable to protect themselves.⁶ For the physician as well, the act depends upon whether that physician's conduct benefits the patient. The evidence must satisfy the substituted judgment or best interest standard (Sneiderman 486).

These can be difficult situations due not only to the presence of a legal guardian, but due also to the uncertain prognostic situation, which often exists in the case of the ELBW neonate. Empirically-or statistically-based variables for so-called, physician made, clinical objective determination of best interests are therefore, often not available for the early gestation, low birth weight neonate, and this results in a situation where inherent in a best interest assessment is the application of a quality of life standard (Sneiderman et al 500; Campbell 1995 83). According to Canadian law, this is morally and legally permissible so long as its focus is patient-centered (Sneiderman 500).

According to current trends in Canadian case decisions however, this quality of life approach has not in fact enjoyed judicial approval through use of the best interests standard with regard to ELBW neonates. Rather, as Tara Rayne Shewchuck suggests, courts have apparently favored a course that treats all infants as deserving of treatment. She proposes that in many respects, best interests, in conjunction with a belief in the sanctity of life (SLP), has begun to motivate judicial thinking in treatment cases. As Shewchuck asserts, "judicial decisions about an infant's best interests most often fall on

the side of preserving life, which many judges believe is beneficial to the child” (335). She points to the decision in *McTavish*,⁷ which in her view heralded a new standard for ordinary treatment protocols. In ordering treatment for this almost certainly terminally ill, ELBW neonate, Shewchuk argues, “the judiciary stepped towards imposing a higher duty upon both parents and medical professionals. In the process, the standard of care is raised and the definition of futility is restricted; we then undermine the very real considerations of the child's best interests” (344).

Thus, there are differences in interpretation, and perhaps differences in the values of the individuals administering the best interests principle. Working towards an understanding and fair application of this legal and medical standard may therefore be better served by attempting to delineate the multiple and overlapping bases upon which treatment decisions are made with the infant's best interest in mind (Shewchuck 335). Such an exploration might raise attention to the assertion that “the core issue has to do with the various meanings of what is beneficial” (Weir 1992, 314) and help us to work towards greater clarity on what really are uncertain best interests of these neonates. This is important for better understanding of how we make ethical decisions in the current social climate.

In Canada, the combination of a faithful reliance upon technology and an adherence to individual rights has had curious results. Ironically, as science pushes at the bounds of the meaning of medical futility, the sanctity of life position may well be gaining strength. The judiciary has begun to rely upon it more frequently. Somerville proposes in her work that our scientific discoveries or technological progress are actually

acting to increase our awareness of “mystery” (15). We should be sensitive to this development, since it may help us to learn new ways of approaching ethics. In this action and reaction process between the evolving scientific standards and their interpretation in the courts, the true meaning of the child's welfare appears at risk of being lost. Instead of assessing whether the proposed treatment is in the best interests of the individual infant, as the standard requires, the decision makers appear to have become mired in a philosophical- scientific quandary. Indeed what we interpret this quandary to mean is important for how we manage ethics and technology in the future. This may help us to prevent an unfortunate consequence of too faithful a reliance on technology, which may result in losing sight, and consensus on what certain neonates’ best interests really are. This will also prevent us from leaving the neonatal patient and their families made vulnerable to what Robert Weir calls the “adult number crunchers connected with NICUs in the competitive marketplace of high-technology medicine”(1992, 314).

Defining Futility: The Challenge

One way in which physicians justify their decisions to withhold or withdraw treatment is by labeling it futile (Somerville, 15). Thus, closely tied to the difficult issue of what constitutes best interests, is the problem of determining when medical treatment is futile for this population of neonates. Joy Hinson Penticuff in her 1998 article, *Defining Futility in Neonatal Intensive Care* writes that there is “no settled consensus-in fact there is not even the most rudimentary agreement-about what circumstances justify abating aggressive NICU therapies” (344).

She comments that although there has been wide recognition that neonatal intensive care in extreme prematurity generates inherently the dilemma of weighing benefit against harm, there has been almost no substantive discussion about what constitutes benefit, what constitutes harm, and how the weighing of these might lead to a medically and ethically justifiable decision to stop life-sustaining treatment. Until theorists, clinicians and families begin to define futility, she has warned, that there is no recognizable limit to the application of NICU technologies other than death or discharge. Without a preliminary definition of futility, there will also be “no foundation on which families and clinicians can build trust and agreement about treatment goals and can recognize when aggressive therapies merely prolong suffering” (344-45). The difficulties associated with determining the physician’s obligations to provide care or treatment is that each item of treatment must be addressed individually. Therefore just because one treatment is medically futile, does not mean that all treatments are. And while there might be no obligation to offer the patient certain life-prolonging treatment, there is an obligation to offer those treatments needed for palliative purposes. And even if no treatments are medically indicated for the patient, care is always required (Somerville 158). There is no ethical difference between withholding or withdrawing care and treatment. The ethical acceptability of doing either depends on the same justifications. Interestingly, research has shown that about two thirds of physicians find it much more difficult to withdraw than to withhold treatment. Many factors could be at play here, ethical and emotional (Somerville, 157-8).

One of the reasons a preliminary definition of futility is lacking is because of the variety of approaches that have been, and are currently, utilized. Some past research has attempted to demonstrate and categorize the differing worldwide approaches to identifying futility. In the 1980's Nancy Rhoden, in her discussion of decision making in neonatal intensive care, identified certain strategies that different practitioners utilize when prognostic indicators are uncertain: she called these the "statistical prognostic strategy," the "wait until certainty strategy" and the "individualized prognostic strategy." In terms of cultural differences, she reviewed international practices, where she observed that Swedish physicians, for example, typically withhold treatment when the statistical data suggest a grim prognosis ("statistical approach"); British physicians are more likely to initiate treatment and withdraw in the face of a deteriorating clinical situation ("individualized approach"); and the trend in the United States has been to initiate treatment and continue until it is virtually certain that the infant will die ("waiting for near certainty") (34-42). Other approaches to decision making have been delineated in the literature. Muraskas and colleagues identify concerns about what they call the "patchwork strategy" which they describe as the approach of individual medical problems treated and managed separately, almost without consideration of long-term sequelae. This strategy they claim, lures intensivists and families on to the "treatment train" (169). Nelson also describes this approach, warning that "once on the train it is hard to get off "(36-43). Jecker and Pagon also identify several strategies when faced with uncertain conditions and outcomes based on "probabilities"(1986, 48-69).

Various notions of futility are inherent in all these treatment approaches. The literature defines strict futility or medical futility as a situation wherein a treatment will fail to reverse a physiological disturbance that will lead to a child's proximate death (Nelson and Nelson 1992). Such a definition of futility describes a condition wherein medical diagnosis determines that death is imminent, or that the treatment or care has no useful physiological effect. There is a strong consensus that such medically futile treatments, as defined here, need not be offered to patients, may be withdrawn and need not be provided in response to patients' or families' requests (Somerville 158). Thus, consistent with the ethical motto "do no harm," the *Ethics Task Force of the Society of Critical Care Medicine* states that health care professionals "are not obligated to provide treatment that they consider either 'futile' or 'burdensome'" (563-71).

Certain physicians use a more general conceptualization of futility, which imports a notion of quality of life (Shewchuck 339). These physicians have characterized treatment as futile for a variety of reasons. Examples are that, in their view, the suffering inflicted by the treatment does not merit the benefits it promises, the risk of the treatment outweighs its benefits, the cost of the treatment does not merit sustaining the quality of life the patient is experiencing, and sometimes because for a variety of reasons that involves the physicians' own ethical value judgments, he or she believes it is unethical to provide certain treatment and cloaks this judgment with the concept of the treatment being futile. Such a concept of futility, therefore, often includes complex value judgments, about quality of life factors. It allows treatment or care to be judged futile if the quality of life of the person who would be kept alive is below a certain standard.

However, the judgment as to what constitutes a life not worth living depends on deep personal values, attitudes and beliefs (Shewchuck 339).

Most ethicists and medical lawyers agree that this general concept of futile treatment or care is dangerous because it can be used to cover up a wide variety of value judgments, some of which are acceptable, and some which are not. The point is, that each needs careful, individual analysis and justification. Another way to capture the distinction between medical futility and a more general concept of futility is to differentiate between medical decisions, which are properly in the province of physicians, (strict or medical futility) and decision-making in a medical context, (personal value judgments) which is not (Somerville 160). This same distinction is captured in the contrasting terms quantitative, which is objective, and qualitative, which is subjective, and more open to different value systems in interpretation. Unfortunately, the clinical situation of the ELBW neonate is not always clear-cut. At the time of delivery, it is often not known prognostically how the neonate will fare. For the physician and the resuscitation team, strict or medically futile situations are difficult to determine for this population of neonates.

Peter Jakobi and colleagues make the observation that the discussion of the issue of determination of futility is further complicated by the fact that accurate epidemiological data of ELBW infants is lacking due to several factors, including variations in definition, legal registration, and management policies world wide (155). These writers also affirm that the situation exists in which different physicians might have different ideas on the viability prospects of infants at or before birth. This

prejudice, they suggest, may influence management, outcome, and even the place of delivery; thus, it becomes a self-fulfilling situation. They note that mortality rates of the ELBW infants from various institutions may be misleading, in that they actually conceal more than they reveal due to the various and inconsistent definitions and reporting techniques, unclear management policies, and statistical variables that are incomplete or biased (156).

C. Anthony Ryan and his colleagues endeavored to present an example of a Canadian approach to end of life decision-making for neonates in 1993, at the University of Alberta Hospital. They explained that, in the absence of medical certainty, decisions in both the NICU and the PICU were made by an “individualized approach.” According to these researchers, “the individualized approach entails a constant reassessment of prognosis and, with the involvement and consent of the family, allows the foregoing of treatment in situations in which there is a high likelihood (but not necessarily a near certainty) of severe disability or death” (537).

It is difficult to ascertain whether approaches for determination of futility in Canadian medical practice are consistent without direct involvement and comparison of the individual units, and such research is not yet locatable in the literature. The previously cited example in the literature of Canadian NICU practice, as experienced at the University of Alberta Hospital by Ryan and colleagues was described as an “individualized approach.” Statistically speaking, they reported that the majority of deaths in their NICU occurred either as a result of withdrawal of treatment (69%) or after failed CPR (13%) or a no-CPR decision (17%). A death from withdrawal of therapy was

most common. They noted that although the patients from whom treatment was withdrawn or for whom it was limited were high in proportion to the number of deaths, the “overall mortality rates in both units were low and comparable to those in other major centers”(156). They did not identify where these major centers were located, or discuss their methods of recording this epidemiological data.

The practice guidelines at this hospital are succinctly outlined in the article. These were to be present at the delivery of all infants born at more than 22 completed weeks of gestation. Infants weighing less than 500 grams were not resuscitated except in questionable cases (if infant is vigorous or thought to be growth retarded), in which case they resuscitate and stabilize the infant. In the NICU, a full evaluation of the infant's condition and prognosis, in addition to careful dialogue with the parents, may then result in either continuation or withdrawal of therapy. Significantly, the researchers in this article state that due to the “increasingly common practice of resuscitation of ever smaller and more immature infants a commitment to withdraw treatment in clearly adverse circumstances is necessitated” (537). This implies a negatively viewed trend, which these researchers felt a need to address. Their recommendation was that short periods (1-2 days) of aggressive conventional therapy, including tracheal intubation, ventilation, insertion of arterial catheters, and surfactant administration, are acceptable when the “temporary discomfort of the infant is balanced against the potential benefit of life with a significant chance of a normal outcome” (537).

They address some of the unfortunate outcomes (such as chronic lung disease) of these decisions to resuscitate. In addition to chronic respiratory failure, these infants had

other problems, including post-hemorrhagic hydrocephalus, cerebral atrophy, and seizures from repeated hypoxic episodes. These researchers admit that these cases were the most difficult ones for the health care team and parents alike, because of the infants' prolonged stays in the NICU and the strong bonds that developed with these infants and their families.

At the University of Alberta Hospital, the parents were said to be involved in all decisions, and the researchers noted that none of the decisions were made on the basis of allocation of resources or parental financial constraints. They also noted that if a difference in opinion persisted between the family and the health care team regarding a plan to treat or not treat, after extensive discussion, they would present the case before the hospital bioethics committee. (537). Determination of futility in the medical context however, remains elusive for this population of neonates. For physicians, the futility debate frequently reduces to what effects count as benefits and who decides which benefits are worth pursuing (Taylor and Lantos 1995, 3).

Inconsistencies in Values Informing Approaches to Decision-making

Explication of the over-arching worldviews or values informing the medical and legal decisions in these ELBW neonates' best interests is difficult. There are no consistent definitions or guidelines identifying futility in this population of neonates due to prognostic uncertainty, and a difficulty ascertaining what constitutes benefit for these neonates. It is not known with certainty whether there is consistency in approaches within Canada between institutions or among individual physicians. Previous literature

demonstrates that differences have occurred, and continue to occur, culturally and geographically. In Canada, a significant proportion of physicians staffing NICUs received their specialty training and/or held professional standing in a country other than Canada. These individual physicians' decision-making stances therefore, may be influenced by the particular approaches to decision-making that encompass the values, beliefs and principles particular to their cultural background. Further, it may not be unreasonable to expect to find differences between institutions and their policies in Canada.

Further, a number of our tertiary centers in Canada are religiously affiliated. Those centers with differing overarching philosophical values or religious tenets guiding care may well have differences in approaches to decision-making. This is significant since the literature has indeed suggested that values and their correlate beliefs are held not only by individuals, but also by professions, institutions, and whole societies. Lynn Payer⁸ for one, has demonstrated the way in which variations in preferred treatments between the United States, England, West Germany and France are determined more by national cultural values, than by any scientific rationale. Those institutions affiliated to the Roman Catholic Church, for example, may be expected to adopt different policies with respect to abortion and certain non-treatment decisions than, say, Protestant, Jewish or secular hospitals. It is also relevant to note that major medical centers may be driven by different value systems (predominantly concerned with research and teaching) than community hospitals (principally concerned with good clinical practice). Values and their correlate beliefs are thus both universal and particular phenomena. They are

universal inasmuch as all human beings necessarily live with and by beliefs and the values to which they give rise.⁹

In terms of a values statement for medical practice in Canada, the Canadian Medical Association Guidelines¹⁰ can be said to be an influential guide. They recommend that the management of the woman and her fetus or infant be based on many “underlying considerations, including the best interests of the mother and her infant and the views of fully informed parents” (547). These guidelines do not describe what these underlying considerations are, however. Certainly it can be said that both maternal and fetal interests are usually served by active support of both lives, but as the literature has shown, the medical community is struggling with the question of whether there may be instances in which avoiding support of the borderline viable infant may be a mutual benefit to the parents and the infant. These decisions have many ethical, medico-legal, religious, economic and social implications and many in the medical profession remain of the opinion that these decisions should remain the responsibility of the physician. This opinion is demonstrated in a statement written by Peter Jacobi and colleagues in a recent article dealing with when certain ELBW neonates should be allowed to die. It is their opinion that “[b]alancing all these considerations in the best interest of our patients is the art of our high-tech profession”(158).

I have brought attention to this notion of medicine as an art, and also as a high-tech profession, to point out that in the making of such decisions we should be careful to separate the “art” from the “science” when necessary. Somerville makes an astute observation on this issue, when she advises that we must be conscious of how our

responses are affected by our feelings “that children ought not to die and that we ought to be able to prevent such deaths, especially with our modern miracle medicine; our ‘do something’ reaction--that doing something is better than doing nothing; and our focus on the science of medicine, [the cure] sometimes to the detriment or even exclusion of the art [the caring] of medicine” (198).

The dilemmas we face in making these decisions are what cardiologist Dr. Maurice McGregor, writing in The New England Journal of Medicine, labels “the costs of our success.” Somerville points to three kinds of costs: the emotional and psychological costs of denying treatment or sometimes, of providing it; the symbolic costs (at the societal level, these decisions will be important factors in establishing the values on which we will base our society); and the monetary costs. This is not all physician- driven however, since part of the problem is society’s hesitation to take responsibility. For example, until very recently, we have avoided overt decision-making, certainly at the societal level, about the allocation of healthcare resources at the individual patient level. We have relinquished responsibility for such decisions by allowing these decisions to be taken by individual physicians-and sometimes nurses-on an ad hoc basis and often in a diffuse and latent manner. As Somerville observes, these professionals have a very important role to play in such decision-making, but she raises the question of whether such decisions should be entirely in their hands (157).

We must necessarily acknowledge that physicians are the end-stage allocators of almost 80 % of health care resources and, therefore exercise considerable power in this regard. Ethically and legally, however, since the treating physician has a primary

obligation of personal care to the individual patient, other obligations such as saving healthcare resources must be secondary. Such an approach, it seems, is appropriate to maintaining our trust in physicians, whom we must be able to trust when we are sick, when we are most in need, weak and vulnerable (Somerville 165). However, if physicians, institutions and Canadian society cannot be certain of consistent criteria for approaches to decision-making, and if the neonatal patient's best interest is to remain the responsibility of the physician, we must consider the impact this has on the requirement to trust physicians to make these decisions for ELBW neonates, as an accepted part of the practice of the science and the art of medicine.

Euthanasia: The Complex Relationship between the Substantive and Procedural Questions

According to pediatrician A.G.M. Campbell, "it seems a better policy to trust that parents and doctor(s) acting together will usually make decisions that are in the best interests of infants, with the courts available to deal with apparent abuses of trust or areas of irreconcilable conflict" (1995, 89). It has been observed that how physicians balance their conflicting duties to an infant and to its parents in this regard is the central issue in the controversy over decision-making in the neonatal intensive care unit (Strong 1984, 10-16). Situations requiring the decision to institute, limit or withdraw therapies in ELBW neonates are ones in which physicians have the power, in terms of professional skill and available technological procedures, to prevent death from occurring for an indeterminate period of time but they have been afforded the responsibility and authority

to choose not to do so. In the past, this has relied upon societal acceptance of the medical profession's traditional claim to public trust.

It has been proposed that, with the perception of cultural pluralism and the loss of an assumed moral consensus, participants in the medical relationship are becoming uneasily aware of what Edwin DuBose terms "the constituted nature of trust" (3). It appears that rather than engendering trust, the success of technological medicine in the last generation has often raised people's anxieties about their ability to make choices for themselves. Dubose, in his work, points to the problem of increased medical reporting that has raised public expectations of success in medical matters, yet has also exposed the dilemmas caused by medical progress. It seems, as he has indeed suggested, that our expectations of medicine have been accompanied by a sense of the gap between professional and public knowledge, exacerbating anxieties about our vulnerability in clinical encounters (Dubose 3). The claim to possession of formal knowledge and skill may not be enough from the public's perception, in our current social climate, to enable physicians to act in the best interests of their patients.

Recently, the Supreme Court of Canada has been recognizing the power imbalance between physicians and their patients and has sought to deal with and rebalance this by finding that the physician has fiduciary obligations to the patient (Somerville 165). The basis for this rebalance action has been in response to end of life cases involving adults, but by extension it should still mean that that the physician must act in the utmost good faith and without conflict of interest to protect the patient's interests and to honor the trust placed in the physician by the patient's parents or proxies.

This sentiment has been appreciated in medical literature commentary as well. Jellinek and colleagues in their 1992 article, "Facing Tragic Decisions with Parents in the Neonatal Intensive Care Unit: Clinical Perspectives", while emphasizing the point that such decisions are "among the complex, tragic, and stressful decisions faced by parents and physicians," (119) at the same time, affirm that "a decision to withdraw life supports or limit resuscitation in a newborn tests that basic sense of trust between the parent and physician" (120). Trust, of course, is essential to our social relationships and certainly to the clinical encounter that lies at the heart of medical care. Trust appears most precarious, and most necessary, at those times when our vulnerability, our sense of dislocation, is the greatest. In recent years, there have been philosophical challenges to the medical profession's traditional claims to trustworthiness. Ethicist Robert Veatch, for example, argues that it is conceptually impossible, according to contemporary philosophy of science to present "value free facts" to the client. He also suggests that there are good reasons why professionals "ought not to be able to know what their client's best interests are" (1991, 160-61).

Edwin DuBose and Robert Veatch both challenge the traditional notion that professionals can be trusted to act on a univocal set of virtues inherent in the profession, or that there is a single definitive conceptualization of how the profession ought to be practiced. Certainly, we cannot demand that medical advice (or ethics at all) be divorced from personal experience (nor can we afford to naively believe that it is even possible). Personal experience is invaluable in ethical evaluations. Perhaps this is a key transformation in thinking about ethics in our postmodern, post-religious age. The

greater challenge in ethics today, it would seem, is engaging in a search for the widest possible intersubjective agreement.

Because the physician-patient relationship is one that inevitably involves structures of trust, loyalty and power, due to a disparity between a vulnerable needy person and one whose help is sought, it makes sense that trust is threatened between patients and physicians at this point in our history. The question of best interests of ELBW neonates includes an acknowledgement that death for certain ones may be deemed to be in their best interests. Closely associated with nontreatment and withdrawal of therapies, is the issue of euthanasia. The extraordinary scientific advances of recent years have contributed to the emergence of the euthanasia debate. As such, it threatens the sense of trust between the physician and patient. As Somerville observes, “[w]hen science and religion are viewed as antithetical, as they have been in recent times, science is likely to contribute to the loss of the sense that we, as human beings, are sacred in any way” (129). Further, trust is threatened in the practice of medicine through the factual reality of the possibility of the abuse of euthanasia. It is important to consider the effect that legalizing it would have on important values and symbolism that make up “the intangible fabric of our societies, and on some of our most important societal institutions, especially medicine and law” (Somerville 119).

As Somerville has proposed, “it is a very important element of the art of medicine to sense and respect the mystery of life and death, to hold this mystery on trust, and to hand it on to future generations, especially future generations of physicians” (148). Death, the final event in each human life, even for neonates born before their expected

time, therefore, provides some of our most profound ethical challenges. Until recently, with the exception of the Third Reich, the laws of all countries have prohibited euthanasia. The Netherlands however, since the early 1970's, have legally tolerated euthanasia, provided it complies with certain conditions (Kollée et al 234-41). In 1984, the Dutch Supreme Court ruled voluntary euthanasia was acceptable, provided doctors followed strict guidelines. But, under Dutch criminal law, physicians could still face prosecution. In the fall of 2000, however, the Dutch parliament voted to formally legalize the practice making the Netherlands the first nation in the world to do so (Johnson). Over the past decade in many Western democracies, there has been a rise in calls to legalize euthanasia; some of these calls have come from the profession of medicine itself (Billings and Block 21-30).

The euthanasia debate is a momentous one, because it involves issues ranging from the nature and meaning of human life and the most basic principles on which our societies are and should be based. Euthanasia is a deliberate act that causes death and is undertaken by a person with the primary intention of ending life of another person to relieve that person's suffering. In the competent adult treatment situation, refusals of treatment, including of life-support treatment and artificial hydration and nutrition and the provision of necessary pain relief treatment and treatment for other symptoms of serious physical distress, do not constitute euthanasia, even if these actions shorten life. As Somerville explains, "[i]n respecting refusals of treatment, the primary intention is to respect the person's right to inviolability---the right not to be touched, including by treatment, without one's consent. In giving pain-relief treatment, the primary intention is

to relieve pain, not to inflict death. In euthanasia, the primary intention is to inflict death in order to relieve pain and suffering. It is this primary intention that makes euthanasia unacceptable to those who oppose it” (Somerville 119). In the case of the ELBW neonate, these acts are not so clear-cut, since the neonate is unable to make his or her wishes known.

Two particular questions fuel the bioethical debates concerning neonates over the last 30 years, and they are still unresolved. One is the substantive moral question of whether it is ever the right decision to allow certain neonates to die, and the other is the procedural question of who is to make these decisions. Insight into the current medical and legal climate can be gained through consideration of current medico-legal commentary on the incompetent adult patient. As Sneiderman points out, in Canada, there is scant legal authority for the pro-position that life-prolonging (non-beneficial) treatment can be withdrawn or withheld from mentally incompetent adult patients. This principle has been confirmed by a considerable number of American state supreme courts, however, beginning with the 1976 landmark decision in the case of Karen Ann Quinlan.

In any event, neither civil nor criminal law has imposed a duty upon the physician to furnish treatment that offers no reasonable hope of benefit to the mentally incompetent adult patient. The law's silence is interpreted by the medical profession as the law's acquiescence in the practice of halting the life-prolonging treatment. In Canada, it is only in cases involving minors that the issue of abating treatment for incompetents has arisen (Sneiderman 467), and this is perhaps due to the added presence of legal guardians. The

LRCC (Law Reform Commission of Canada) has decried the failure of Canadian law to declare on the record, recognizing the medical practice of discontinuing life support measures for incompetent patients, and has offered its view on these two key substantive and procedural questions. As Sneiderman explains, the LRCC indicates its firm opposition to the “judicialization” of the decision-making process. Its opinion is that court involvement is necessary only when there is irresolvable conflict within the patient's family or between family and physician. Sneiderman quotes the following excerpt:

One would not wish to judicialize and hence to make adversarial a decision-making process which should be based more on consensus than confrontation. A judicial decision is necessary when there is some conflict. It may be superfluous when it is used merely to formalize a decision which has already been made and which no one has challenged and which involves no real dispute, controversy, or conflict. (Sneiderman 1995, 469)

He goes on to point out that the Commission, in fact, suggests that the incompetent patient's physician should be the central figure in the decision making process; that the physician should consult with the family but that the ultimate responsibility must rest on the physician's shoulders. They endorse the substituted judgment and best interests tests as the proper standards to guide the decision-maker. The Commission's 1982 working paper was followed up the next year with a report also entitled *Euthanasia, Aiding Suicide and Cessation of Treatment*, a report there simply echoed the policy recommendations contained the earlier document (Sneiderman 469). In this report, the LRCC recommended an amendment to the Criminal Code to clarify that physicians are not legally bound to continue to administer or undertake medical

treatment, when such treatment has become therapeutically useless and is not in the best interests of the person for whom it is intended.

As Sneiderman explains, the reason for its proposed amendment is found in the language of two sections of the Criminal Code:

On the one hand, there is section 215: 'Everyone is under a legal duty . . . to provide necessaries of life to a person under his charge if that person is unable by reason of . . . illness . . . to provide himself with necessaries of life.' On the other hand, there is section 217: 'Every one who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.'(Sneiderman 1995, 472)

In theory, then a Crown prosecutor could seek an indictment for manslaughter against a physician whose moribund patient died because life-prolonging therapy was withheld (e.g. omitting to resuscitate or to administer antibiotics) or withdrawn (e.g. disconnecting the ventilator). But, as Sneiderman points out, there is an air of non-reality to our hypothetical prosecution because no criminal charge has ever been filed in Canada against a physician for terminating an incompetent patient's life-support measures.

There is, of course, the rider that the best interests of their patients guide the physician who must act in accordance with accepted medical practice. In its 1982 working paper (and again in the 1983 report), the LRCC urged Parliament to state the law explicitly by Criminal Code amendment in order to lift the "veil of uncertainty" occasioned by its continued silence. Although that has yet to happen, Canadian physicians and hospitals have indicated their willingness to live with the law's "off the record" endorsement of the medical practice of abating life-support measures that do not serve the best interests of the patient (Sneiderman 473-4). As I discuss at the beginning

of this thesis, determinations of non-beneficial treatment or futile care, beg the question of how one is to define a procedure as futile when it is keeping the patient alive

The physician's authority as ultimate decision-maker cannot reasonably be interpreted to permit the withdrawing of treatment, without also permitting the withholding of treatment. Interestingly, there is still a mystique that views situations requiring non-resuscitation orders or no-code decisions, as somehow skirting the thin edge of the law. Hence the traditions of not recording do-not resuscitate orders on patients' charts, or recording them in pencil for later erasure. This concern is not without foundation. In 1974 the Canadian Medical Association passed a resolution stating that it is medically and ethically appropriate for a physician to write a no-code order when death is imminent and inevitable. In 1982, the Canadian Medical Protective Association endorsed the CMA's position. In 1984 the CMA and the Canadian Nurses Association, and the Canadian Hospital Association issued a Joint Statement on *Withholding Resuscitation for the Terminally Ill*. The joint document acknowledged that resuscitation is appropriately withheld in certain cases; and that when that contingency happens, a no resuscitation order shall be duly recorded on the patient's record (Sneiderman 484-5).

It is also important to clarify and discuss where this question of allowing to die fits within the context of the current euthanasia terminology. Non-initiation or withdrawal of life prolonging treatment in the incompetent patient has been traditionally conceptualized according to the typology of "passive, nonvoluntary euthanasia." However, terminology has changed over time, and in common parlance, the focus of the debate over the legalization of euthanasia has come to dwell upon mercy killing as

requested by mentally competent patients or the assisted suicide of such a patient. Therefore, instead of the term “passive euthanasia,” the termination of life prolonging treatment of the mentally incompetent patient has become known as “termination of life prolonging treatment,” and thus falls outside the parameters of the current euthanasia debate (Sneiderman 363).

These afore-mentioned debates may have impacted the attitudes of physicians and society towards regarding decisions to allow certain ELBW neonates to die, even though the major debate focus has shifted to the competent adult's right to choose death. The common definition of euthanasia is, itself, a source of confusion as well. The term euthanasia comes from *eu* (good) and *thanatos* (death) and this very broad definition of euthanasia can itself give rise to serious confusion. As is true of most ethical issues, our choice of language is significant. For example, the term “passive euthanasia” has often been used by people who are pro-euthanasia, to describe withholding or withdrawing of treatment because the patient, or in the case of neonates, the family, refuses treatment, and death results. They then argue that if these decisions (that they characterize as passive euthanasia) are morally and legally acceptable-as most people agree that they are, provided certain conditions are fulfilled-then euthanasia is acceptable as it should make no ethical or legal difference whether it is carried out through passive or active means. To the contrary, those who are anti-euthanasia base their case on the proposition that there are long-established, well understood profound and important differences between allowing a person to die and making that person die, that is, putting that person to death. Consistent with their position, they oppose the use of the term “passive euthanasia” to

describe justified withholding or withdrawals of treatment that will result in death (Somerville 132-3).

Thus, at the present time in Canada, the physician acts lawfully in the situation of the termination of life prolonging treatment while direct killing, say from lethal injection, the active form of euthanasia, is defined as murder (363 Sneiderman). Legal immunity for active euthanasia is given to doctors elsewhere in the world, however. In the Netherlands for example, this practice has progressively expanded from terminally ill, competent adults in serious pain and suffering to non-terminally ill competent adults in serious pain and suffering to non-terminally ill, handicapped, very young children (Somerville 147). Significantly, legal immunity is given to physicians in Canada with regard to the administration of necessary pain-relief treatment.¹¹ If given to relieve pain, in certain patients it might also shorten life. However, if it is implemented through what is called the Roman Catholic Doctrine of “double effect” it is not viewed criminally as murder. This is providing that the physician primarily *intends* to relieve the patient's pain, not to kill the patient, and provided a reasonable physician would agree that the treatment given was necessary to relieve the pain (that is, that it is objectively justified), the physician would not be legally liable for giving this treatment even if the patient's life is shortened as a result (Somerville 140).

The law, in effect, has endorsed another of the Roman Catholic positions on the termination of life-prolonging treatment, a position grounded in the distinction between ordinary and extraordinary treatment. This means that if the treatment provides a net benefit, it is considered ordinary treatment and is morally obligatory. If it fails to benefit

the patient, it is deemed extraordinary treatment and is not morally obligatory. Thus ordinary treatment must always be furnished, whereas extraordinary treatment may be legitimately withheld or withdrawn. Of course, this very notion of nonbeneficial treatment is value-laden. Thus, what determines under which heading a treatment falls is not the specific nature of the treatment, but rather the treatment's effect upon the patient and extraordinary treatment when it confers no benefit or its burden outweighs its benefit (Sneiderman 369).

Canadian physicians routinely disconnect respirators, issue and follow do-not-resuscitate orders, and remove or clamp feeding tubes. However, aside from the scant case law dealing with parental decision-making for young children, Canadian law has not spelled out that such practices are permissible for the patient whose prognosis is dismal and for whom life-maintaining treatment offers no reasonable hope of benefit. Still, Canadian physicians assume that they act within the law when they hasten death by terminating life-prolonging treatment for patients unable to make that decision for themselves (Sneiderman 467).

Another way of viewing this situation is through the lens of our response to death. Death, for the ELBW neonate, is largely a medical event that takes place in the hospital in isolation, from the community. In the Neonatal Intensive Care Unit, death can become sterilized, institutionalized, and potential is there for it to become depersonalized and dehumanized. Death, of these babies, for the most part, does not occur in a community surrounded by tradition, ritual and ceremony, giving death a human scale and face (Somerville 125). As Somerville observes, we are frightened of death, not only as

individuals but also as societies. We use law in response to fear, often instead of moral and religious exploration. She advances the suggestion that increased calls for the legalization of euthanasia are a way in which, as a society, we are seeking to symbolically tame and civilize death and reduce our fear of it. She notes that many of our societies' features that have contributed to the search for ethics are also highly relevant to the emergence of the euthanasia debate. Our societies are highly materialistic and consumeristic, with a loss of any sense of the sacred, even just, as Somerville notes, "the secular sacred" (126-7). It is possible, she proposes that the loss of a sense of mystery that death represents and, therefore loss of hope, and of a certain kind of faith and of trust, is at the source of the difficulties in reaching moral consensus on end of life issues (125).

Physician and ethicist Edmund Pellegrino, has voiced a concern that medical ethics, as it is currently practiced, (now considered to be specialty area within medicine called bioethics) is increasingly becoming a branch of moral philosophy and as such, becoming more and more responsive to shifts in philosophical opinion and fashion. Today's ethical management of patients, like medicine itself, is informed by a fusion of both theory and practice, although the theories may seem remote and abstract at times, they nevertheless function to guide reasoning. (1158). Explicating these theories will be a necessary part of my research.

Newborn medicine is so close to the core of living, and involves society so deeply that no change in care seems to go unchallenged. Perhaps, for this very reason, controversy has not been a stranger. It is that which lies hidden in the choices that

physicians and society as a whole make or don't make about how the vulnerable are treated, that is especially relevant for this research. This exploration of medical ethics and its philosophical influences will therefore begin with a historical overview, delineating some of the key developments and social influences on the medical management of neonates in Western culture. The goal is to situate the physician- neonate (and legal guardian) relationship in the context of current Canadian societal practices and beliefs. It is also my intent to separate the different discourses of societal influence, bioethical debates (involving medicine, law, philosophy and religion) and medical ethics, since part of the complexity of this subject is due to their overlapping relationships. My aim will be the establishment of a broader perspective concerning the roots and influences of medical ethics.

NOTES

¹ Examples include, physician, Norman Fost's "Ethical Issues in the Treatment of Critically Ill Newborns." In *Pediatric Annals*, 10, (1981): 17. As well as the *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* in its report "Deciding to Forego life Sustaining Treatment". (1983).

² As Sneiderman and colleagues explain, the marker that the law directs the physician to follow in treatment decisions for children and neonates is the best interests of the patient. If the patient's legal guardians (usually the parents) withhold consent to beneficial treatment, then the physician is duty bound to seek judicial authority to override their refusal if he or she is unable to persuade them otherwise. In every province, there is child welfare legislation that permits the apprehension of " a child in need of protection" which is defined to include the provision of necessary medical treatment. As generally happens, the child is returned to parental custody upon completion of the treatment (496). A number of case precedents in Canadian law exist to uphold the best interests standard for children and neonates. Sneiderman, Irvine and Osborne cite five Canadian cases as examples: These are, (Re Dawson) Supt. of family and Child Services v. R.D., Pub Trustee for B.C. v. Supt. Of Family Service, [1983] 3 W.W.R.618 (1983). Re Goyette,

[1983] C.S. 429. (Re Jacquet); Couture-Jacquet v. Montreal Children's Hospital, [1986] (R.J.Q. 1221, 28 D.L.R. (4th) 22, 3 Q.A.C. 209 (sub. Nom. Montreal Children's Hospital vs. J.) (C.A.). and (Re Cara B); New Brunswick (Minister of Health and Community Services) v. B.(R.)(1990). (Re K'aïla Paulette); Minister of Social Services vs. F.P. and L.P., [1990] 4 W.W.R. 748. (Re Sheena B); B.(R.) v. Children's Aid Society of Metropolitan Toronto (1995), 122 D.L.R. (4th) 1 (S.C.C.). These cases all represent decisions where the Court recognized the best interests standard as its guiding principle. In Goyette, Cara B and Dawson all decided in favor of treatment following petitions initiated by the physician or hospital. In Jacquet and Paulette, the family's decision was found to be in the child's best interests. Sheena B is distinguishable from the others in that the parents were not objecting to the treatment regimen as a futile attempt to ward off the ravages of a disease process. Only that blood products not be used, as the parents were Jehovah Witnesses. (495). The Dawson Court cited a 1981 English case, *Re B. (a Minor)*, [1981] 1 W.L.R. 1421 (C.A.) as a precedent for its ruling. In that case, the English Court of Appeal considered the plight of a 10-day-old infant with Down's syndrome, whose parents had withheld consent to surgery to repair her duodenal atresia. The Court ordered the surgery because it concluded that it was in the child's best interests to live (495). It is interesting to note that some ten years prior to this English case decision, such a case occurred at John Hopkins Hospital in Baltimore, Maryland. The physicians and hospital in this circumstance acquiesced to the parent's demands and their baby was allowed to die. This change in approach will be explored in more detail in this research within in the context of the raised consciousness that was emerging in the mid-1970's with regard to the medical practice and legal implications of terminating life prolonging treatment for neonatal patients.

³ Engelhardt (1973) who was one of the first to use the principle of nonmalificence, allows for nontreatment decisions based on the interests of others, but those who use this principle later, exclude the interests of others from consideration. See Norman Foster *Pediatrics* 67, 1981: 321, and Robert Weir's, *Selective Nontreatment of Handicapped Newborns: Moral dilemmas in Neonatal Medicine*. (1984). For an interdisciplinary endorsement of the best interest standard, see "The Committee on the Legal and Ethical Aspects of Health Care for Children"(1983), as established by the *American Society of Law and Medicine*. See also Strain for an endorsement by the American Academy of Pediatrics *New England Journal of Medicine* 309, (1983): 443-44.

⁴ For the criticism concerning its vagueness by Bartholome and a reply by Brody, see Brody and Bartholome (1988). For other criticisms of the best interests standard, see Arras (1984;1985). For the position that the interests of society should be considered, see Jones (1984). For the position that the family has legitimate interests and the neonatologist has obligations toward the family, see Strong (1984).

⁵ Tara Rayne Shewchuck explains how parents' rights to decide for their children have evolved since the time of the Industrial Revolution, when social reforms began to

recognize children's rights. Britain's' Poor Amendment Act of 1868, which imposed a duty upon parents to provide their children with food, clothing, lodging and medical aid, reflect the changes that were made by this movement. Gradually, parents' property like interest in their children evolved into an obligation to provide care. Throughout this series of incremental changes, a parents' decision-making capacity fundamentally remained intact its foundation nonetheless was altered so that the focus became more child centered (334)

⁶ As Tara Rayne Shewchuck explains, if a parent abridges his or her minor's interests, the state, under its *parens patriae* jurisdiction, may intervene to protect the child from harm. In both Canadian and American law, the common law and several statutory instruments, including child protection acts and several criminal law provisions, establish the duty of parents to make decisions regarding their child's medical care. In origin, the best interests test is relatively recent as children historically were treated as the property of their fathers. Around the time of the Industrial Revolution, social reforms began to recognize children's rights. Gradually, therefore, parents' property-like interest in their children evolved into an obligation to provide care. In both Canada and the United States the scope of the *parens patriae* power is quite broad and includes an inherent jurisdiction to make children wards of the court when warranted. Canadian courts have interpreted it as the state's jurisdiction to act on behalf of 'those who cannot care for themselves'. Courts must often balance this child-centered objective with the rights of parents to raise their children according to their own values. This has lead to disagreements regarding appropriate medical therapy between parents and physicians. As a mechanism of last resort the judiciary serves as a mechanism to resolve the contentious matter. Thus we must delineate the bases upon which we formulate treatment decision. As Shewchuck points out, philosophy, science and even defensive medicine play important roles in the process of determining what is in an infant's best interests (334-5).

⁷ *Re McTavish and the Director, Child welfare Act (1886) 32 DLR (4th) (Alta QB)*. This infant was born at approximately 26 weeks gestation weighed only 400 grams. The expert testimony established that apparently no neonate of that weight, which was nearly 350 g below the normal weight for an infant of that gestation, had survived. Nonetheless the provincial courts judge held that the Charter dictated that the right to life must take precedence over any competing right of the parent' to decide against it. He therefore ordered the continuation of treatment since this neonate still had a potential for life. It is significant to point out that the parents of this child were Jehovah's witnesses, and they opposed blood transfusions based not only on religious grounds but medical grounds as well. The infant was extremely premature and very small for its early gestation, and there was evidence that some doctors would take a more conservative approach and not give such an infant blood transfusions since her chances for survival were not great (Shewchuck 396-7).

⁸ See her work *Medicine and Culture* Penguin books, (London 1989).

⁹ See M.E. Marty and K.L. Vaaux, *Health/Medicine and the Faith Traditions: An Inquiry into Religion and Medicine*. (Philadelphia: Free Press, 1982)

¹⁰ See the *Canadian Medical Association Journal* 151 (1994): 547-551. "Management of the Woman with Threatened Birth of an Infant of Extremely Low Gestational Age."

¹¹ *Of Life and Death, the Report of the Special Senate Committee*, was released on June 6, 1995. The Committee was established in 1994, to examine and report on the legal, social and ethical issues relating to euthanasia and assisted suicide. The report contains the following recommendations regarding pain control and withholding and withdrawal of life-sustaining treatment: That the Criminal Code be amended to clarify the practice of providing treatment, for the purpose of alleviating suffering, that may shorten life and that criminal code be and amended and necessary legislation be enacted in order to explicitly recognize and to clarify the circumstances in which the withholding and withdrawal of life sustaining treatment is legally acceptable. That the division of Health Canada, responsible for health protection and promotion, in cooperation with the provinces, territories and national associations of health care professionals, develop guidelines and standards for the provision of treatment for the purpose of alleviating suffering where that treatment may shorten life, and guidelines to govern the withholding and withdrawal of life-sustaining treatment. That professional guidelines be amended so that they are consistent with these recommendations, the amended criminal Code, and the national guidelines. That the federal government, in cooperation with the provinces and territories, undertake a study in order to determine the frequency and conditions under which total sedation is practiced and the determine the frequency with which and conditions under which life-sustaining treatment is withheld or withdrawn under the recommended legislation and guidelines. They also recommended that education and training with respect to pain control be expanded and improved for all health care professionals. This committee recommends that nonvoluntary euthanasia remain a criminal offence but that the Criminal Code be amended to provide for a less severe penalty in cases where there is the essential element of compassion or mercy. (Canadian Bioethics Report, (July 1995): 1-4.

CHAPTER III
**THE SOCIO-HISTORICAL CONTEXT OF THE PHYSICIAN-NEONATE
RELATIONSHIP**

The Neonate as Patient

Neonates, at birth, have not always been afforded recognition as individuals with the corresponding rights as protected under the Canadian Charter today. This section will explore some of the important changes that have occurred on this matter at the level of society and of the individual. This will provide background to the socio-historical context of the physician-neonate relationship as it is practiced today, providing insight into the societal forces that impacted how the neonate has been, and is currently being, viewed and valued.

In Western history, newborn abandonment has been an accepted practice linked to many circumstances such as malformation, legitimacy, sex, and economic necessity (Garrison 1963, 1-173). An example of early medical influences directing the treatment of neonates would be that of Greek physician, Soranus of Ephesus, who practiced in Rome during the 2nd century. He outlined the assessment to take place and the characteristics of an infant “worth rearing” in his manual for instruction to midwives (Desmond 309).

Physicians Soranus and Galen described the examination guidelines to use as evaluating physical perfection, and as such, there appeared to be two levels, at which

decisions about the child were made: the medical decision concerning his normality as defined by society, and the father's decision on whether he should accept the child into the family or have it abandoned or cast out of the house. Plato and Aristotle, as well as the Stoics, Epicurus, and presumably Plotinus, all accepted the morality of the exposure of infants, and presumably also abortion, on eugenic or sometimes purely on economic grounds. ¹ Aline Rouselle has written that there is evidence that the umbilical cord was left too short to clamp or tie in certain newborns deemed not worthy of rearing. The law, she notes, condemned infanticide in AD 374, "probably, under Christian influence" (Rouselle 51). The various guidelines, however, as provided by Soranus, for general assessment and care of the neonate, were handed down, translated, and printed in various formats and remained contributory to the standard of Western newborn care for the next 1500 years (Desmond 309).

The fall of Rome and the changing social climate saw changes in the way the newborn was viewed. As the dominant force in Western Europe, the Roman Catholic Church began to strongly influence daily life. An example of these social changes can be seen in the church's decree that only women were to attend other women in labor. Men were not allowed to be present at labor and birth, and as Merdina Desmond has noted, violation of this law was punishable by death (309). Another significant development was that the baby was deemed by Roman Catholicism to be born in sin, but possessing a soul. Therefore, if not baptized before death, the infant would remain forever a lost soul, dwelling in limbo between heaven and hell. Accordingly, 14th century midwives of good character were empowered to perform emergency baptism in the home. This regulation

by the church involved institution of instruction in particulars of the rite, requirement of an oath, and licensing of the midwives (Desmond 309). Infanticide became viewed as a heinous crime during this period, and became associated with the complex social issue of witchcraft accusations.²

In 1538, Henry VIII commanded the clerks of his parishes to keep a register of burials, marriages, and christenings, reporting weekly totals to the court (Desmond 309). This was in response to fears surrounding recurrent visitations of plague. In 1662, John Graunt, published an exhaustive study based on 30 years of output of these Bills of Mortality. He determined that infants represented one third of all deaths. The figures produced surprise, but no change, "as death of the young was an accepted act of God" (Desmond 310). During the 18th and 19th centuries, midwifery was transformed, and childbirth moved more decisively into the sphere of physician and surgeon. Treatment of babies was based on an incredible array of nonspecific remedies. It seemed as though an aura of fatalism surrounded the sick infant and physicians had little to offer. The majority of ills remained as concluded in 1545 by Thomas Phaïre, as "desolate of remedye"(17).

Industrialization during the 19th century and factory employment of women brought about artificial feeding, mercenary wet-nursing, and child abandonment. Foundling homes abounded, and infant deaths soared in cities (English 67-70). The fortunes of the newborn, however, improved toward the end of the 19th century as the Infant Welfare Movement began in Western Europe, spreading to the United States after 1900. Two forces seemed to propel this movement. First, the infant mortality rates of

the cities were showing peculiar resistance to change at a time when deaths of older children were decreasing rapidly. The second force was the falling birthrate experienced all over Europe, but earliest and most marked in France. France was in danger of depopulation and vulnerability as a nation since fewer births foretold small armies to defend the republic. This issue was thoroughly explored by French writers of the day because their feared neighbor Germany enjoyed a high birthrate, increasing population, and large armies. England, whose birthrate was falling, but to a lesser degree, speculated on how the Empire might be populated and defended should the fall continue (McCleary 53-67). The French government's initial programs for increasing births were a failure and emphasis was moved to determining how infants' deaths might be prevented. The challenge to prevent these deaths was vigorously pursued by two obstetricians, Tarnier and Budin. They worked to preserve all newborn lives, the "nurslings" (healthy term infants), the "congenital debiles" (sick small or feeble) and the "weaklings" (premature infants) (Lucas 8-19).

The practice of prenatal care as known today, did not exist in the 19th century, but came into being as a 20th century phenomenon. John Ballantyne, an Edinburgh obstetrician whose conceptions and writings gave us the language and blueprint for continuity of care, has been credited with having opened this pathway. He believed that disease presenting after birth, in the neonate, was understandable only within the context of antenatal and intranatal life (Ballantyne 339-418). In 1901, he published a plea for construction of a pro-maternity hospital wherein pregnant women might be admitted for care and treatment. (Ballantyne 1901, 813). Later in the same year, a sympathetic reader

financed a bed in Edinburgh's Royal Infirmary for ailing expectant mothers. It has been proposed that from this single bed, the tradition of physician supervision throughout pregnancy arose (Desmond 313). When the Infant Welfare Movement reached America at the beginning of the 20th century, it had achieved positive results as demonstrated by changes in infant mortality. These rates were based on mandatory recording of births and deaths, a practice begun in England in 1838 and enforced on the continent for many years. High rates were associated statistically with poverty, poor nutrition, artificial feeding, contaminated milk, and maternal employment (Graham 1045-50).

The significance of the neonate socially may be viewed through three guides for public health action that had emerged during this period. According to the first, the saving of infant life is best achieved by protection and education of mothers before and after pregnancy. The second suggests, that the infant mortality rate is the best available index of the overall health and welfare of a community. For the third, that infant mortality is of multiplex origin and multiple activities are necessary to lower it (Newsholme 176-187 Garrison 1929, 778-779). Two organizations, the Federal Children's Bureau and the American Association for the Study and Prevention of Infant Mortality, come into this setting. Their influence made birth registration finally possible. The American Society for Study and Prevention of Infant Mortality conceived and organized by medicine, was formed in 1909, and met yearly for a decade in order to explore issues related to infant health and welfare (Billings 97-129).

During the late 19th century, the question was raised as to whether advanced care for the newborn was good for society. This became an issue during this period because

Darwin's hypotheses were strongly influencing human thought. Darwin theorized that wastage of life after birth was in harmony with natural law, leading to natural selection and survival of the fittest. This view offered an alternative explanation for infant death with "all for the best" displacing "the will of God". It encouraged therapeutic passivity in physicians and amazing public acceptance of the status quo (Desmond 314). Desmond gives the example of the following statement as illustrating this period. It appeared in a pediatric cyclopedia in 1889 by R.A.F. Penrose:

Over the threshold of life is written the declaration of nature's righteous and inexorable law 'The fittest shall survive' and this law so just, so stern in its un pitying exactions, is *the* law which governs not only life's beginning, but life's progress and life's end. . . . It is evident therefore that we are not to mourn, nor even to regret every child that is born dying or dead; . . . often this apparently sad termination . . . is a matter for congratulation rather than grief, . . . we may comfort ourselves when the results are unfavorable with the reflection that man cannot contend successfully against the laws of nature. (Desmond 1991, 314)

The call for increased action on behalf of the weakling and debilitated infant urged by Budin and Ballantyne was pursued in the United States. Nurseries for the premature and sick infant appeared in hospitals, and articles on management were published in scientific journals (Desmond 314). Not all physicians, however, were convinced that rearing of compromised neonates was good for the nation. Fulton for example, wrote that in "prematurity, congenital debility, birth injuries and malformation, we see in operation the pitiful but necessary elimination of the unfit" (115). Despite opposition such as this, when Julius Hess opened a premature station in 1922, referrals were many and welcomed. Hess believed that "we must all answer the question of

whether these small premature infants are worth saving.” At length, he concluded that efforts expended were of inestimable value, since the majority was functioning as normal citizens, although he did note, “nature has been kind to many who did not survive the ordeals of their early days”(Hess 1953, 425-434). It is worthy of note that these same observations made by Hess reemerged in the late 1970's with regard to discussions concerning the survival of extremely low birth weight infants (Desmond 315).

During and following World War I, delivery and nursery care was provided by obstetricians and by general practitioners with limited prior training. Obstetricians, discouraged by the Children's Bureau maternal mortality statistics, moved labor and delivery into hospital settings, believing it to be less hazardous there. This made obstetrics a full-fledged surgical discipline. Concomitantly, organized pediatrics, after decades of ambivalence and discussion, came to agreement regarding its role in medicine. Pediatricians would be specialists for children in all phases of their lives. Not only consultants in diseases of children they would engage in preventive pediatrics, child hygiene and child advocacy (Wile 174-187). Pediatrics, as a specialty, gained control of newborn nurseries after World War II (Desmond 317).

In the 1930's, prematurity became the primary focus of attention, fueled by hospital statistics, which indicated that premature death was the major component of neonatal death, comprising over half the total (Clifford 155). This revelation gave prematurity new importance. The extent of prematurity was unknown, since neither weight nor gestational age was recorded on birth certificates. Accordingly, in 1935, the American Academy of Pediatrics proposed that live births weighing 2500 grams or less

regardless of gestational age, length or other criterion be designated as premature, an arbitrary standard proposed by Budin and Ylppo. At the same time, obstetricians opted to set the dividing line between abortion and stillbirth at 20 weeks. Infants born weighing under 1000 g or before 28 weeks gestation were in designated as previable (Desmond 317).

During this period, two additional events evoked considerable public awareness of prematurity; the citywide Chicago Plan for premature infants, and the birth of the Canadian Dionne quintuplets. Inspired by the unique contribution of the premature to infant mortality, Hess and Bundesen, the Health Commissioner of Chicago, inaugurated a bold citywide program to prevent premature deaths (Hess 1951, 891-893). The Dionne quintuplets were born in 1934 in northern Ontario and an enthralled public followed their progress closely. Backed by eminent Canadian pediatricians, Dr. Dafoe enunciated the prevailing “hands off” philosophy of premature care. Desmond cites the following excerpt:

. . . the eternal vigilance of well-trained nurses overshadows almost every other essential in the care of the premature infant . . . the things which are not done . . . are almost as important as the things which are done. The premature infant is frail, does not stand handling and must be left undisturbed most of the time. Unnecessary manipulation may be as damaging as neglect. (Desmond 318))

As the armed forces returned after World War II, the birthrate began to soar. This baby boom created vast needs for hospitals, physicians, and nurses because 90 % of births were now conducted in hospitals. Length of stay was shortened and breast-feeding gave way to terminal sterilization of cow's milk and commercially designed formulas.

Technology advanced in the nursery and the “hands off” period ended and the “therapeutic explosion” began.³

A new direction in delivery room care came when Virginia Apgar introduced an objective scoring system for assessing an infant’s condition after delivery. The score evaluated tone, color, heart rate, and character of respiration and reflex response. Since the total score decreased or increased in a predictable order with depression and recovery, it provided guidelines for resuscitation. The key development here was that the infant was no longer a by-product in the delivery room but a new patient with assigned examiner. The Apgar score gained rapid acceptance and when adopted in 1958 for use in the *Collaborative Perinatal Study*, it was recognized as a basic reference point for newborn research.⁴

During the 1960’s, neonatologists moved closer to the birth, emphasizing asphyxia, abnormal cardiopulmonary function, and prompt diagnosis of congenital infection. This period brought many technological advances. Given delivery room assessments and an increasing complexity of care, the development of recovery and intensive care nurseries was a logical trend. Intensive care nurseries, with their monitors and accompanying laboratories, sprang up throughout the USA and Canada. They were well received and supported by philanthropy, and local state and federal governments. Regionalization of newborn care followed, with teams providing emergency care prior to, and during, transport to intensive care. Nurseries were classified into three levels; Level III (intensive) Level II (intermediate) and Level I (low risk). When early mortality and morbidity statistics appeared, neonatologists found that “inborn” babies fared better than

“outborn” transported babies. Thereafter the emphasis shifted to in-utero transport with admission of high-risk mothers to regional perinatal centers (Lubchenco 670).

The late 1970's saw the resistant neonatal mortality rates of small premature infants greatly reduced with infant mortality reaching the lowest level in history. However, chronicity and handicap accompanied survival as the age of viability was moved back further into the second trimester. Today, rising cost of care, questions of neglect vs. over treatment, litigation and burnout beset perinatology. (Guillemin 1983, 89-97;Guillemin 1986, 229-246; Desmond 320). ⁵ Physicians and society, evolved through the changes and practices to this point in medical history, and faced what it meant to provide moral medicine to these vulnerable humans. In 1992, the British Stillborn Definition Act further reduced the viability marker to the gestation of 24 weeks and the weight to less than 500 grams (Campbell 1995, 87). According to current Canadian outcome data, fetuses with a gestational age of less than 22 weeks are not viable and those with an age of 22 weeks rarely viable. The 1994 Canadian Medical Association recommendation is that treatment of all infants with a gestation age of 22-26 weeks should be tailored to the infant and family and should involve fully informed parents (CMA 1994 151: 547-551).

As this exploration has shown, an infant's quality of life has always been an important consideration in society. In antiquity, for example, infants did not achieve full rights including the right to life, simply by the virtue of being born, but had to show capacity for development in infancy and to demonstrate potential value to their community before being fully accepted. Drastic action (allowing these neonates to die,

or more accurately killing if intention is primary), through means of exposure or hemorrhage, was taken against abnormal infants who did not have such potential. It is significant to note that in modern times, the intentional termination of abnormal, and even normal, pregnancies has become widespread. The neonate once born, however, even at the gestational age of a premature fetus, has rights afforded to an individual, and therefore the right not to be killed. Yet, the same fetus, at the same gestation in-utero, may be legally killed through pregnancy termination if deemed abnormal (or not worthy of rearing). Such selective behavior is not new. What is novel, over the few millennia of human existence, is the idea that the “succor of all viable babies is a desirable social goal” (Silverman 1981, 12-16).

Historical context on this issue is important because as Somerville says, in our intensely individualistic society we are experiencing a loss of respect for others, the environment and ourselves. “*Re-spect*, she has reminds us, comes from the Latin word meaning to look back on. If we cannot see ourselves in context, if we lose our ties with the past—if we fail to look back—progress becomes synonymous with amnesia. The philosopher Mark Kingwell calls this the great fiction of the ‘eternal now.’ We fail to remember at our ethical peril. Respect is the mechanism through which we remember, and it requires us to see ourselves in a larger context than just ourselves” (7). As philosopher Richard Rorty suggests, compassion begins and ends with the consideration of another person as “fully human.” Our human story in the West with regard to neonates perhaps is influenced by our decision historically not to see the neonate as fully human, very much like the fetus is now viewed (or not viewed). Perhaps this

demonstrates a gap between our sense experience and the reality that is purported to exist. Rorty, in his work emphasizes the social influence upon the individual and his beliefs. Truth, or what for Rorty has substituted for it, is an intersubjective agreement among the members of a community (21).

The tension between understandings of the inherent value of the neonate's life and decisions to allow death as an act of compassion is articulated in the medical and ethical literature. For example, intensive care pediatrician, A.G.M. Campbell acknowledges that the infant's life has inherent value and dignity regardless of potential, however he notes that in the face of some of the worst injustices of faulty development, it seems wrong to most parents that so-called 'pro-life' groups call such decisions discriminatory, and insist that every infant has an absolute 'right to life', whatever the quality (1995, 99). Moral theologian Richard McCormick contends that we must avoid unjust discrimination in the provision of health care and life supports, but not all discrimination (inequality of treatment) is unjust. Unjust discrimination is avoided if the decision-making centers on the benefit of the patient, even if that benefit is described largely in terms of quality of life criteria (1978, 30-6).

Indeed, within the spectrum of abnormality or damage, there will always be some neonates for whom no medical (or societal) consensus on the best course of action will emerge even after exhaustive debate. It is with these infants that the particularly difficult and controversial decisions arise, because so much depends on where a line is drawn and who draws it (Campbell 1995 101). The next section explores the debates concerning the question of when, but also who, should make the decisions. The discussion moves

through the lens of the historical tradition of medical ethics, the changes that have occurred with the emergence of bioethics and the pivotal clinical debates that have followed those changes.

The Physician as Healer and Moral Authority

Due to influences and changes on many levels in society, we have been witness to the therapeutic explosion of the last 30 years with regard to neonatal management. The recognition of the neonate as an individual patient possessing rights and protection has presented, and continues to present physicians, as well as society, with difficult moral questions regarding the best interests of the ELBW neonate. The roots of medical ethics date back more than 2000 years and are important in this research for understanding the context, historically, of how physicians came to be the primary possessors of ethical power and responsibility in making end of life decisions.

In the clinical context, the moral question of selective nontreatment has been discussed and debated in hospital nurseries and NICU's since the 1960's, as changes to the methods of doing ethics were taking place in the Western world. However, it must be acknowledged that medical ethics has evolved from the beginnings as taught by Hippocrates 2500 years ago, into what is practiced today. Certain critics, such as Edmund Pellegrino, have emphasized the significance of these changes having suggested that this ancient ethical framework as it is practiced today, is "under the severest strain in its long history"(1158).

The reasons for this strain are indeed complex, influenced by social, political, economic and juridical developments. It has also been proposed that these threats to the survival and continuity of medical ethics as a distinct component of Western civilization may well reveal the societal and cultural significance of the crisis in which it is found today. Nigel Cameron, for example, writing specifically on the Christian stake in bioethics, suggests that the “marriage of value and technique which gave birth first to Hippocratic paganism and, in due course, which matured into an enduring Christian-Hippocratic consensus, is not to be deemed a mere curiosity within that highly distinctive cultural tradition.” He suggests that the medical tradition represents the “interlocking of Christian and Hippocratic values [. . .] one of the plainest examples of biblical-Christian values in the public square of the Western tradition” (4-5). More broadly speaking, Margaret Somerville proposes that we must keep in mind “that decisions about health care are never just about health care”(254). In democratic Western societies, she suggests that “what we do and what we do not do in providing health care establishes important values and symbolism for society as a whole, particularly with respect to whether we espouse a fundamental value of caring for one another. Moreover, the ethical and legal tone of a society can best be judged by how it treats its weakest, neediest and most vulnerable members” (254).

The school of Hippocrates produced what are considered to be the first literary sources guiding Western medicine and morality (1998, 6). The 2500-year-old oath and deontological books of the Hippocratic corpus⁶ are philosophically a mosaic of moral precepts written at different times and influenced by most of the major schools of ancient

Greek philosophy. Edmund Pellegrino describes this metamorphosis of the Hippocratic ethic, and has pointed to the Oath as the most influential core of Hippocratic ethics. It contains, in his assessment, most of the genuinely ethical precepts, such as the obligations of beneficence, nonmaleficence and confidentiality, as well as prohibitions against abortion, euthanasia, surgery and sexual relationships with patients. It exhorts the physician to lead a pure life that is a life of virtue. (Pellegrino 1159).

The method of decision-making for these 2500 years consisted in judgments about whether a given conduct was in conformity with these precepts. In Pellegrino's analysis, little evidence of rules or principles of moral choice in the modern sense can be found in Aristotelian Socratic, or Platonic moral philosophy. Instead, these philosophers focused on "the overall aims of the moral life, such as defining the good and the just and the cultivation of the virtues. In this view, the virtuous physician was one habitually disposed to act in conformity with the virtues of courage, temperance, and justice, and in accord with the moral precepts of the Oath. The key virtue was *phronesis* or practical judgment, whereby the physician was able to discern the right and good thing to do in the face of a particular moral choice" (1159). Socrates, Plato and Aristotle used medicine, however, extensively as a pedagogic tool, particularly as a model of the ethical use of knowledge. In medicine, they found a source of analogies likening health of body (medicine) to health of soul (philosophy). Likewise, medicine's norms of health became a model for the norms of the moral life. Indeed, philosophers ancient and modern have always written on such fundamental ethical issues as abortion, euthanasia, suicide, death and infanticide, issues that would fit the rubric biomedical ethics, as the term is used

today. Yet, as Pellegrino asserts, the ethics of the physician-patient relationship, the fulcrum on which the decisions of the physician and the well being of the patient balance, was not systematically justified or derived in any formal way. Even physicians who were philosophers such as Alcmaeon and Empedocles in the ancient world, or John Locke and William James in the modern, said little about the ethics of the profession in which they were trained. Karl Jaspers did devote two informal essays to the physician-patient relationship (Jaspers 153-167) but wrote no genuine moral inquiry into medical ethics. With minor modifications to remove traces of its pagan origins, the Hippocratic ethic remained essentially unchanged in the writings of influential physicians such as Percival and Gregory in England and Hooker in America (Pellegrino 1159).

The Hippocratic ethic was modified as it came into contact with the great world religious traditions since medicine is a sphere of life and a part of our social institutions but as Temkin writes, "it [medicine] had sufficient autonomy that it's history can be said to be associated with, yet not determined by, general social, philosophical and religious movements" (255). Pellegrino maintains that the basic Hippocratic texts were intermingled with Stoic notions of duty and virtue, congruent elements of the Jewish and Christian teachings and scripture, and the noblesse oblige expected of a gentleman. This is the moral background against which most North American and British physicians made, and still make, their ethical choices. In particular, the express concern with not doing things to alter the natural course of a disease that would occasion harm to a patient, the direction of attention toward the sick person and away from all exploitive or self-serving behavior by the physician, and the insistence on confidentiality, which all

indicate that fundamental to the Oath is the conviction that patients are to be accorded respect by physicians treating them. (Pellegrino 1159)

The first book to bear the title *Medical Ethics* was written in 1803 by an English physician, Thomas Percival. It combined the traditional virtues of medical decorum with injunctions concerning the behavior of physicians and surgeons in England's charity hospitals, and insisted that the duties of office had been granted to doctors by society as public trusts. This social ethics finds its expression in the ethical codes produced by the American Medical Association from its inception in 1847 through the mid-twentieth century. The Code was largely based on Percival's *Medical Ethics* and adapted to American needs and tastes and went through a number of revisions. Similarly, the Canadian Medical Association founded in 1867, accepted the responsibility for delineating the standard of ethical behavior expected of Canadian physicians. This *Code of Ethics* of the Canadian Medical Association, as approved by the CMA board of directors, October 15, 1996 lays down the physician's responsibilities to the patient, with regard to initiating and dissolving a patient-physician relationship as well as communication, decision making, consent, confidentiality, clinical research and professional fees. It outlines the physician's responsibilities to society, the profession and to oneself. It states that:

The Code is an ethical document. Its sources are the traditional codes of medical ethics such as the Hippocratic oath, as well as developments in human rights and recent bioethical discussion. Legislation and court decisions may also influence medical ethics. Physicians should be aware of the legal and regulatory requirements for medical practice in their jurisdiction. However, the Code may set out different standards of behavior than does the law. The Code has been prepared by physicians for physicians. It is based on the fundamental ethical principles of medicine, especially compassion, beneficence, nonmaleficence,

respect for persons and justice. It interprets these principles with respect to the responsibilities of physicians to individual patients, family and significant others, colleagues, and health professionals, and society. (CMA Advocacy and Communications 1996).

This demonstrates that medical practice is a fusion of Hippocratic writings, legal decisions and bioethics. Bioethics is, itself, a relatively new discipline that may be viewed through the specific debates, which involved the overlapping of medicine, philosophy, law and religion that have occurred since the mid 1960's. The mosaic of Hippocratic constructs first came into question in the mid 1960's as part of the general upheaval in moral values that occurred in North America. They can be seen as the result of a series of societal changes. Examples include a better educated public, the spread of participatory democracy through movements in civil rights, feminism, and consumer activism; a decline in communally shared values; a heightened sense of ethnicity; and distrust of authority and institutions of all kinds. Concomitantly, it would seem that the character of medicine was being altered. Specialization, fragmentation, institutionalization and depersonalization of health care were all contributors. At the same time, it is important to note also that the number and complexity of medical ethical issues expanded as the power of medical technology presented new challenges to traditional values. The net result cast doubt on the traditional moral grounding of society in general and of medicine, in particular, and created a demand for alternative models of teaching and practicing medical ethics

As Orr observes, up to this point in our history, medical professionals had been adequately addressing the '*can we?*' questions, which were technical medical questions.

The term or discipline *bioethics* was coined in 1971 to answer the ethics questions, the 'should we?' questions that were now new to the practice of medicine. The tone of the newly emerging discipline can be expressed in the words of the proverb '*the ability to act does not justify the action*' (Orr 138-152). As Veatch notes, modern medicine was centered around the assumption that medical decisions (decisions concerning what action to take with a patient, what medicine to use, what procedures to allow) could be based on non-contingent, non-relative facts (1996, 11). The prevailing paradigm was that medicine was objective. The ethically exotic cases, exemplified by Karen Ann Quinlan, resulted in physicians no longer being seen as omniscient decision-makers, but were nevertheless, thought to hold more knowledge of medical ethics than anyone else

The questions being raised were questions of moral value and these were the perennial questions to which both philosophical and religious moral philosophers had customarily addressed themselves. Although it has been asserted that it was the theologians who were actually the first to ask these questions (Verhey 55), secular philosophers were quick to embrace the new frontier of medical ethics. In fact Toulmin has even proposed that this discussion may have actually "saved the life of philosophy" (736-50). What occurred, over time, as secular philosophers developed the discipline of medical ethics, however, was that theological voices became less involved. Theological voices were, nevertheless, significant in their contributions to the developmental period of bioethics.

In 1971, a film presented at the Joseph P. Kennedy Jr. Foundation International Symposium on Human Rights, Retardation and Research entitled *Choices on our*

Conscience, stimulated some of the earliest interest in bioethical analysis. The film was a composite of three cases that had occurred in the pediatric department of the Johns Hopkins Medical School. It concerned a neonate born with Down's syndrome (Trisomy 21) who also had a frequently associated defect, a blockage between the esophagus and stomach (duodenal atresia) that prevented the passage of food. The child's two young parents refused the surgical treatment that would save the life (the developmental potential however would still be dictated by Down's syndrome) of their baby. Although vehemently opposed to the decision, the physicians and hospital acquiesced. Food and water were withheld, and the infant lingered for 15 days before dying. This film thrust neonatal intensive care into the discourse of the early bioethics and stimulated some of the earliest bioethical analysis. In fact, moral theologian James Gustafson's commentary on the film was delivered at the symposium and published in *Perspectives in Biology and Medicine* in 1975. It was a careful dissection of the ethical problem and a notable contribution of early bioethics literature. Interestingly, this case was widely publicized but produced no significant reaction from the medico-legal community.

In 1976, however, here in Canada, a similar case caused a contrary response from St. Joseph's Hospital in London, Ontario. The parents of a three-day-old Down's syndrome infant with duodenal atresia refused consent for remedial surgery. The hospital notified the Children's Aid Society and that same evening, a judicial hearing was convened in the hospital boardroom. The Family Court judge found that treatment was in the infant's best interests and consequently authorized the surgery, which was performed the following day (Sneiderman 496). This (unreported) Ontario case perhaps

demonstrates the raised awareness that was emerging in the mid-1970's concerning the medical practice and legal implications of terminating life-prolonging treatment for neonatal patients. This awareness had been facilitated by a number of significant individuals. Sneiderman suggests that the 1971 John Hopkins incident provoked the first public "gaze" upon such neonatal cases, the actual debate however, was ignited by an article published in 1973, by Drs. Raymond S. Duff and A.G.M. Campbell (496).

These two pediatricians presented the problem in the context of the statistical world of the intensive care nursery. They reported that out of the 299 consecutive deaths in their nursery at the Yale-New Haven Hospital, 43 (14%) resulted from deliberate decisions to withdraw or withhold life-saving treatments ("Moral and Ethical Dilemmas" 890-894). Essentially what this article did was to reveal to the world what neonatologists understood only too well: many premature babies who need the technology of the intensive care nursery fail the therapeutic rigors of that technology and are allowed to die by being deliberately removed from the ventilators.⁷ The article caused a furor and many letters of protest were written to the New England Journal of Medicine.⁸

Moral theologian, Richard McCormick S.J. reflected on Duff and Campbell's analysis in his 1974 article "To Save or Let Die". He revisited the familiar Catholic distinction between ordinary and extraordinary care. For McCormick, the term extraordinary was large enough to justify the omission of life-sustaining treatments on the basis of expected diminished quality of life, defined in terms of the potential for human relationship. John Fletcher's publication, "Abortion, Euthanasia and Care of the Defective Newborn", and H. Tristram Engelhardt's "Ethical Issues in Aiding the Death of

Young Children” were both published in 1975. Fletcher defended passive, but not active, euthanasia for the seriously compromised newborn and Engelhardt contended that maintenance of life for such children should be seen as inflicting the injury of continued existence.

A 1975 article entitled “Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal” by Albert R. Jonsen and Michael Garland affirmed the moral legitimacy of foregoing life support, the primacy of parental decisions in doing so, and in exceptional cases, the ethical propriety of hastening an infant's death. In response to this article, Protestant moral theologian Paul Ramsey vigorously repudiated the ethical propriety of hastening an infant's death as it was presented in the article. Ramsey's objection bore on what he said was "the circularity between the ethical principles assumed and the resultant policy." Ramsey judged that their attempt to state a "moral policy" for neonatal intensive care was, in effect, sadly confused. He suggested that they failed to establish any primacy or priority for ethical principles, and that they buried what principles they affirmed under a broad agreement about how difficult medical cases should be practically managed (1979, 234-5).

Duff and Campbell's article thus played a role in the emergence of new rights issue in the 1970's, namely the right to treatment of neonatal patients. This consciousness they triggered led to a new ethic: that the neonate as patient has the same moral and legal right to treatment that serves her best interests as does any older patient (Sneiderman 497). This ethic was further demonstrated in 1976 when lawyer John Robertson carefully analyzed the legal issues raised by pediatric euthanasia in collaboration with

pediatrician Norman Fost in the article entitled “Passive Euthanasia of Defective Infants: Legal Considerations”. They reminded doctors and parents about the potential criminal liability for withholding care. They suggested that either criteria be drawn up to designate precisely those classes of infants who can be allowed to die or, preferably, a due process for decision-making be formulated.⁹

In 1982, in the United States, a baby very much like the John Hopkins baby was born. The parents learning that their baby, (known as the case of Baby Doe), was affected with Down’s syndrome and esophageal atresia, refused to give permission for surgery to correct the condition. One of the attending physicians disagreed with the parents and the hospital sought a court order for the surgery. The Indiana courts upheld the parent's decision. However, on April 15, 1985, three years after the death of Baby Doe, and after much political debate, the Department of Health and Human Services issued regulations and interpretive guidelines to implement a new federal law endorsed and signed by President Reagan. These regulations required that all medically indicated treatments be provided to infants unless “such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life threatening conditions, or otherwise be futile in terms of the survival of the infant” (Federal Register 14888). These regulations also required that all states carry out surveillance of neonatal intensive care units for violations of the rules or risk losing federal funding for their Child Protective Services. Certain states, such a California, preferred to give up their funding rather than implement the regulations. Others implemented them but with varying degrees of vigilance. Regardless of their legal enforcement, many critics have noted

that these “baby Doe rules” tended to prompt over-treatment rather than prevent under-treatment.¹⁰

Another significant outcome of these regulations were that the ethical issues associated with care of the small premature (ELBW) infant became fused with the notably different issues raised by infants born with congenital anomalies. The Baby Doe legislation did not fundamentally alter the law of the United states in relation to the treatment of abnormal infants, but the media publicity and political opportunism that followed this case and others left American pediatricians feeling vulnerable to legal harassment and possible penalty if reported under the child Abuse Amendments of 1984 (Campbell 1995, 89).

As Campbell, too, observes, there seems little doubt that legalization of this difficult area of medical practice created a feeling of compulsion towards more aggressive treatment for all infants whatever their condition, their future quality of life, or the views of their parents (92). This quality of life issue was also seen from a different perspective in the United States recently where a parent's request for the continuation of aggressive life prolonging therapy for a quadriplegic, blind, and deaf child was refused by the doctors and nurses because they believed it was futile, inhumane and against the child's best interests (Paris et al 1990). Although legal interventions and the introduction of ‘rules’ for medical decision-making have been more prominent in the United States, it was in the United Kingdom, in 1981 that a pediatrician was accused, tried, and eventually acquitted of attempted murder following the death of an infant with Down's syndrome (Campbell 1995, 93).

Here in Canada, as in the example earlier, (Ryan et al), an individualized approach has been advocated. The Bioethics Committee of the Canadian Pediatric Society issued its own advice on the treatment of critically ill newborns and older children in 1986. The guidelines stressed that all children have a justified claim to life and therefore to such treatment as is necessary either to improve or to prolong life, but go on to point out that the capacity to prolong life is now so advanced that there is a real danger that the prolongation of life will become the sole end, irrespective of the havoc it may wreak on other persons or desirable goals. The decision to use life-prolonging treatment must be guided by the best interests of the child. Listed exceptions to the general duty of providing life-sustaining treatment include situations when the patient's life will be filled with intolerable and intractable pain and suffering. It has been noted that, absent from this list, in spite of the preamble noted above, is any reference to conditions of permanent unconsciousness or inability to interact with others (Campbell 1995, 97).

Tinier and tinier infants born earlier and earlier in gestation now have greatly increased chances of survival (Hack and Fanaroff 1989; Alberman and Botting 1991). To a remarkable extent the timing and manner of an ELBW neonate's death is dependent on technology, and using this technology responsibly is one of the biggest challenges of modern medical practice. As A.G.M. Campbell asserts, there are times when technological innovation simply makes it unwise and sometimes cruel to uphold an infant's right to life as absolute; or insist that in all circumstances, the interests of the family are secondary or should be ignored (89). A particular difficulty with assessing

the quality of life for infants (and others who have never achieved decision-making capacity) is the necessity of having proxy decision makers, usually parents. One pediatrician/ethicist points out the obvious conflict of interest that exists when the child is seen as presenting a potential burden to the family, and argues that this should disqualify a parent as a suitable advocate (Fost 1981). Prominent American pediatrician A.G.M. Campbell continues to advocate, that a policy of trust is the best route, wherein parents and doctors act together to make decisions that are in the best interests of infants, with the courts available to deal with apparent abuses of trust or areas of irreconcilable conflict (89).

With the erosion of the Hippocratic synthesis, many physicians have indeed sought guidance in court decisions and in legislation. They have also turned to the philosophers (Pellegrino 1159). Moral philosophy offers a systematic and relatively objective way to approach ethical dilemmas. It appeals to academic clinicians who have come aware of the growing complexity of ethical dilemmas, and the challenge of how to teach medical ethics effectively in a morally pluralistic society. Thus, the freedom of philosophical ethics from faith commitments suits the moral and religious heterogeneity of medical school faculty and students. The philosophers bring to medical ethics a variety of well-established moral traditions. Ethics deals with values, and doing ethics requires us to identify our values. Among the diverse schools justifying the choice of the values on which we base ethical decisions are principle-based or deontological ethics, situational ethics, utilitarian ethics, consequentialist ethics, casuist or case-based ethics (an approach similar to the legal doctrine of precedent), narrative ethics, feminist ethics, hermeneutical

ethics (an approach based on interpretation of a context or text), and virtue ethics (Somerville, 289).

Medicine as a profession, has adopted the theory of *prima facie* principles as its dominant way of doing ethics. This approach was adapted to medical ethics by Beauchamp and Childress in their text, *Principles of Biomedical Ethics*. They recognize the difficulties of attaining agreement on the most fundamental questions of ethics, on the nature of the good, on the ultimate sources of morality, and on the epistemological status of moral knowledge. In order to bypass these problems, they turn to certain principles, which on face value, should always be respected unless some strong countervailing reason exists to justify overruling them. In this *prima facie* category they choose principles especially appropriate for medical ethics: nonmaleficence, beneficence, autonomy and justice. This tetrad of principles has the advantage of being compatible with deontological and consequentialist theories and even with some aspects of virtue theory. Significantly, these four principles avoid direct confrontation with the intractably divisive issues of abortion, euthanasia and a host of others issues on which agreement seems impossible (Pellegrino 1160).

The principles of beneficence and nonmaleficence, are synonymous with the Hippocratic tradition's obligations to act always in the best interests of the patient and to avoid doing harm. On the other hand, the two other principles, autonomy and justice are more current in their origins. The principle of autonomy appears to directly contradict the traditional authoritarian and paternalistic Hippocratic ethic that gave no place for patient participation in clinical decisions. Modern physicians have had the greatest

problems with this principle since it is often erroneously interpreted as being in opposition to beneficence (Beauchamp and McCullough 22-51). Only lately have physicians accepted the principle of autonomy, largely because it is central to informed consent. Autonomy is of course, consistent with the individualistic temper of North American life, which emphasizes privacy and self-determination. This is one of the powerful societal forces that set the metamorphosis of medical ethics in motion. It is relevant here to note Margaret Somerville's observation that intense individualism tends to favor euthanasia for many reasons. The development of intense individualism breeds a loss of community that has left us feeling alone and often abandoned when we face death and bereavement. A highly individualistic society that gives prominence to personal autonomy and self determination is likely to encourage the belief that euthanasia is acceptable for those who want it, or by extension for those physicians or parents who want it. She proposes therefore that there is a complex relationship between a lack of belonging, intense individualism, and calls for the legalization of euthanasia. Each augments the other and each might be a response or consequence of the others (121). This can also be linked to seeing our bodies and those of others as objects. If we see others and ourselves as having worth and dignity this can be avoided, but we are having difficulty with this perception because our sense of community is also lacking. Further, death is largely a medical event and takes place in the hospital in isolation. Somerville cautions that we must give death a more human scale and face (123).

Of the four principles, justice is the most remote from traditional medical ethics. As Pellegrino observes, despite its prominence in the philosophies of Plato and Aristotle,

justice received no specific attention in the Hippocratic ethic that centered on the welfare of individual patients and not of society. Justice entered medical ethics much later, usually in relationship to the physician's forensic duties. In recent years, justice has entered medical ethics more forcibly, as disparities in the distribution of health care have become more apparent. The possibility increases daily, therefore, that physicians may become agents primarily of fiscal or social purposes rather than of the patient. Certain works, such as Rawl's contractarian *Theory of Justice* and his lexical or hierarchical ordering of obligations and principles relative to distributive justice have been a major contributor to justice moving to the forefront of medical ethics.¹¹

The authors of the four-principle approach are, of course, well aware of the limitations of a system of *prima facie* obligations, namely the difficulties encountered in applying any set of abstract principles to particular cases and in reducing conflicts between *prima facie* principles or within a single principle without some lexical or hierarchical ordering of the principles. To accommodate those shortcomings, Beauchamp and Childress propose four requirements that must be met to justify infringement of a *prima facie* principle or obligation: 1) the moral objective sought must be realistic 2) no morally preferable alternative is available 3) the least infringement possible must be sought 4) the agent must act to minimize the effects of infringement. In this way, the authors hope to steer a course between the absolutism of principles and the relativism of situation ethics. Their guidelines are helpful, but do not eradicate the inherent limitations of any set of *prima facie* principles that is not lexically ordered.

It is important to consider the worldviews held by individuals involved in ethical deliberation. Worldviews address the nature of the individual, the individual's relationship to others, and the individual's relationship to a Supreme Being. Orr has, for example, in his discussion of ethical levels of thinking,¹² asserted that the idea of worldview seems missing from current ethical deliberation, and that situational ethics has left us in a situation of moral impasse on the question of the best interests of ELBW neonates (144).

Medical Ethics for the 21st Century: Learning from Experience

There has been significant criticism of principlism. Alasdair MacIntyre contends that philosophical ethics is itself of limited value. He calls for "moral wisdom," something for which "philosophy does not prepare us" (1980, 18-43). The limitations of the principlism method of ethical deliberation has been the subject of criticism in Brody, who labels the four principles "mid level principles," meaning that they needed rational justification and a firmer grounding in one of the great moral traditions.¹³ Clouser and Gert complain of the lack of a unifying moral theory that would tie the principles together and ground them conceptually. Were such a unifying theory available it would make the principles unnecessary (1990, 219-236). Leon Kass suggests that perhaps, theological perspectives might offer "special insights" (1990, 5-12). Gustafson argues that philosophy is an insufficient tool for confronting the broad agenda of biomedical ethics. Gustafson calls for the inclusion of prophetic, narrative and public policy elements in the

discourse. These, he feels are more suited to resolve key ethical issues in health care than are principles (1990, 125-142).

This growing support for alternatives to principle-based medical ethics may indicate that the changes that have already been so rapid and profound are not yet complete. In the next decade, physicians who have just accommodated their thinking to the four-principle approach will have to sort out the place of each of the proposed alternatives. They must decide whether principlism can, or should survive and in what form and to what degree alternative theories should complement or supplant it. What these criticisms seem to portray is that there is something lacking, and perhaps it is not just a decision about what we value, but more succinctly why we value certain choices. Thus the real question is how to go from universal principles to individual moral decisions and back again. There is need for a comprehensive philosophical underpinning for medical ethics that will clearly identify and articulate our shared values whether religious or secular in origins. Elaboration of a new underpinning for medical ethics, however, needs to be made in light of contemporary philosophy and ethics and the strong challenges writers in these fields have raised. Richard Rorty, for example, denies the possibility of arriving at any truths through philosophy and the relevance of any theory of reality (Madison 3-19). Rorty, although having rejected the idea that human understanding is some objective structure of the mind, encourages interpretation of the world through a variety of paradigms. If there is no objective philosophical standpoint, then the idea that philosophy should be seen as the “queen of sciences” clarifying what counts as knowledge, is unsustainable. For Rorty, the aim of philosophers should be to

help their readers, or society as a whole, break free from outworn vocabularies and attitudes, rather than to provide grounding for the intuitions and customs of the present. ¹⁴

The Hippocratic ethic was virtue based, the oath that was its action guide consisted of specific rules and principles. MacIntyre suggests that the metaphysical consensus that fostered virtue theory for physicians is something of the past. ¹⁵ It would appear that principlism in its present form, too, is also unlikely to survive unscathed through this next decade. One development that may provide the needed reality check is the emergence of clinical bioethics. A field yet to be fully defined, clinical bioethics focuses on the clinical realities of moral choices as they are confronted day by day in health and medical care (Pellegrino 1162). Surely, the character and values of the agent are crucial to medical ethics, since the health professional is the agent who must interpret and apply it at the bedside.

To this end, Somerville proposes three concepts as fundamental to doing ethics. These concepts are values, trust and risk. She acknowledges that shared values help us to trust others and we tolerate higher degrees of risk being imposed by the decisions of those people we trust than those we do not (289-91). Good ethics she says depends on good facts, and good law depends on good ethics. The concept of risk she proposes is often among the most important of the ethically relevant facts. In physical risk, for example, there is uncertainty, and the situation of the ELBW neonate exemplifies situations of great magnitude and prevalence of risk. To manage this perceived uncertainty, the medical profession seeks certainty in diagnosis. The medical profession's inability to live comfortably with uncertainty, Somerville proposes, is a variation on the

discomfort with mystery, which can cause us to adopt simplistic reductionist approaches to very complex realities (Somerville 13).

NOTES

¹ See J.M. Rist, *Human Value: A study in Ancient Philosophical Ethics* (Netherlands: Brill Leiden 1982).

² See Deborah Willis, *Malevolent Nature* and Anne Llewellyn Barstow, *Witchcraze*.

³ 17 As Merdina Desmond has pointed out, examples of this therapeutic explosion can be seen in the advent of antibiotics, as well as in a plethora of new therapies which were attempted; many were successful, and others brought iatrogenic disease or secondary effects. An example would be the appearance of retrolental fibroplasias in premature infants due to excessive oxygen therapy, leading William Silverman to urge that rigorous rules of evidence be applied to changes in management and treatment. During the 1950's concepts of maternal-infant relationships broadened as well. According to Desmond, three factors contributed. First, maternal deaths fell with availability of antibiotics and type specific blood. Second, neonatal deaths continued at a high rate with the majority occurring on days one or two, circumstances pointing to prenatal or natal causation. Third, pathologists were investigating causes of death in the stillborn and with deliveries less hazardous for mothers, obstetricians increasingly emphasized fetal condition and newborn survival (319).

⁴ See V. Apgar: "Proposal for a New Method of Evaluation of the Newborn Infant". *Curr Res Anesth Analg* 32 (1953): 260. V. Apgar, et al. "Evaluation of the Newborn Infant-Second Report" *JAMA* 168 (1958, 1988).

⁵ JH Guillemin, LL Holmstrom "Legal Cases Government Regulations and the Clinical Realities in Newborn Intensive Care" *Am J Perinatology*, 1, (1983): 89-97.

⁶ See "The Oath" "The Precepts" and "Law" in *Hippocrates, translated by W.H.L. Jones*. (Cambridge, Mass: Harvard University Press, 1972), 263-333. See "Decorum" and "The Physician". Translated by W.H.L. Jones, (Cambridge Mass: Harvard University Press, 1981) 279-313.

⁷ In this (1973) study there were 299 deaths studied and 86% of these deaths resulted from pathologic conditions in spite of the treatment given. Of these, 66% were the result

of respiratory problems or complications associated with extreme prematurity (birth weight under 1000 g.). (Duff and Campbell 891)

⁸ See "Letters to the Editor" in the *New England Journal of Medicine* 290 (1974): 518-520.

⁹ Robertson had previously performed a legal analysis in which appeared in the *Stanford Law Review* 27, (1975): 213.

¹⁰ Discussion of this situation can be found in N. Rhoden and J. Arras . "Withholding Treatment from Baby Doe: From Discrimination to Child Abuse" *Milband Memorial Fund Quarterly* 63, (1985): 18-51. T. H. Murray, A Caplan, *Which Babies Shall Live? Humanistic Dimensions of the Care of Imperiled Newborns*. (Humana Press 1985). L.M. Kopelman, TG Irons and AE Kopelman. "Neonatologists Judge the Baby Doe Regulations" *New England J of Medicine* 318, (1988): 677-683.

¹¹ See Rawls J. *A Theory of Justice* (1971), 301-303. Rawls has somewhat modified his position, giving greater recognition to the role of community. His 1985 essay, "Justice as Fairness," concedes that the basic values of the representative moral agent—now called the "citizen"—derive not from intuitions formed apart from social reality but from 'an overlapping consensus' that undergirds the modern state. Further, Rawls contextualizes his theory, acknowledging social and historical particulars (Rawls 1985, 224).

¹² Orr has categorized these levels of ethical thinking into I World View, II Methods of Moral Reasoning III Ethical principles IV Ethical Rules and V Ethical Decisions.

¹³ See H Brody, *Ethical Decisions in Medicine*. (1980)

¹⁴ See Roger James "Analytic Philosophy" <http://www.philosopher.org.uk/anal.htm>.

¹⁵ See Alasdair MacIntyre's *After Virtue*. (1988).

CHAPTER IV

THE ETHICAL SIGNIFICANCE OF PROGNOSTIC UNCERTAINTY

We often make ethical mistakes when we seek certainty—a sense of control in situations that are necessarily uncertain.

Margaret Somerville

Predictive Thinking; The Physician's Hippocratic Legacy

Predictive thinking has been part of medicine since the time of Hippocrates. This teaching can be found in the Hippocratic corpus called *Prognostic*, in which the writer connects the importance of careful prognosis with the determination of proper treatment¹. Today's doctors, of course, can choose among numerous treatment options well beyond those ever imagined by Hippocratic writers. These treatment options have led today's physicians to the complex situation of the selection of certain ELBW neonates for non-treatment and withdrawal of therapies.

As Shapiro pointed out some 20 years ago, medicine's approach, in the midst of technological development, has been to continue to strive to acquire accurate data in order to make more precise and clinically rigorous probabilistic predictions (1509). Today, this trend continues, and it would appear that the difficulties of this approach have become especially noticeable and problematic in neonatal medicine. The ELBW neonate has multiple system problems which are complex, difficult to diagnose, and virtually impossible to predict with any certitude as to an outcome. The literature documents that the overly quick use of prognostic labels by some physicians actually

results in situations where it might be determined prematurely, on the basis of the individual physician's value system, that certain newborns should be allowed to die. Physician Norman Fost, for one, voices this concern, adding that some of these pediatricians also have not done the requisite diagnostic work on which to base such prognostic claims (1981, 17).

It is, then, potentially problematic that, in moving from diagnosis to prognosis, some physicians do not adequately try to specify the prognosis for different neonatal patients having the same general diagnostic condition. Significant also is the fact that extremely premature neonates have not had opportunities for survival until recent years, and consequently, there are insufficient long-term studies of the effects of various treatment options on these children from which to extrapolate to current cases. As Jecker and Pagan note, because judgments of futility and inhumanity may be difficult to make in the perinatal setting, owing to diagnostic and prognostic uncertainty, the actual outcome for a particular patient will always depend upon circumstances of persons, places, times and cultures (1986, 51).

Thus, the ethical significance of careful prognosis in neonatal cases must be emphasized, especially in our current climate of the patient physician relationship.² If physicians overestimate the severity of the long-term consequences of a condition (in terms of the child's mental deficiency and/ physical handicaps), that prognosis may lead to a decision to allow an infant to die when in fact the child's best interests appears to call for continued life. If physicians underestimate the severity of the long-term consequences of an neonate's condition, that prognosis may result in prolonged, often

ineffective, treatment of a child whose best interests seem to call for death rather than continued suffering.

Hippocrates introduced the use of observation as a basis for the diagnosis. This drive toward rationalism and objectivity, it has been proposed, prepared the way for the rejection of the spoken word in medicine and laid the groundwork for the deterioration of the physician-patient relationship from one that is profoundly personal in tone to one that is increasingly impersonal (Stevenson and Young 7). It has been noted by Eric Cassell as well, that a result of this trend is that the more physicians have concentrated on disease, the less attention they were able to devote to illness and to the person who fell ill (230).

Fundamental to the Oath is the express concern that attention is given to the patient in order to avoid any exploitive or self-serving behavior by the physician. Physicians Duff and Campbell endeavor to articulate such an ideal relationship between doctor and patient in their article "Moral Communities and Tragic Choices". To do this they draw on the seminal work of Martin Buber,³ by describing this relationship as that of an 'I' to a 'thou', rather than that of an 'I' to an 'it'. In this view, they assert, each person is an individual, an 'I', who is embodied in a living organism. Also, each person is related biologically and socially to significant others, and there is a major other or 'thou' component within each person. 'I-thou' relationships between persons imply nurture, intimacy, and full reciprocity. Of significant note, in this framework, responsibility and power are shared, though not necessarily equally, because it is acknowledged that people differ in their capacities and interests (277).

As Young and Stevenson point out, although many of its textual details may be dated, other writers agree that the Hippocratic oath affirms something fundamental, that patients are to be respected as subjects, as 'thous' and never to be regarded as objectified 'its'. The form this respect has taken has changed with the passing centuries. It is thought that ancient physicians who followed the teaching of Hippocrates would have distanced themselves as a mark of respect. This art of healing was a silent one, which precluded the objectification of the patient; although treated at a distance, the patient remained a subject because of the physician's posture, which approached one of reverence. It has been suggested that the ancient separation between the Hippocratic physician and the patient also opened up a symbolic gap into which modern science inserted itself. With the introduction of laboratories and new technologies at the turn of this century the distance between physician and patient first widened and then closed again, as physicians laid not their hands but their medicines and machines on patient (Young and Stevenson 2- 3).

The irony of this is not fully appreciated without realizing that the Oath imbues the physician patient relationship with respect for nature and for the person who is in and of nature, and clearly admits, through the admonition to do no harm, a modern consideration that application of medicines and machines should be avoided if they do not serve the sick person. Further, touching patients indirectly, not with hands that palpate various organs but with medications and machines, can erode the patient's subjectivity in the encounter with the physician. This has led to, as David Rothman argues, physicians becoming strangers at the bedside. ⁴ It appears that in our current

times, as the giving and receiving of information and consent have become prerequisites to practice, the same philosophy that discouraged doing things to interfere with nature has strangely acquiesced across the centuries to more tampering with nature and invasion of the personal realm than was even imagined possible.

The emergence of the principle of respect for autonomy, which has occurred in North America with rapidity in the years following the Second World War, may have served to restore subjectivity to the interactions between many patients and their physicians. In the case of neonates, however, it seems that biotechnological advances have contributed to the objectification of these patients, a situation further complicating the difficulty encountered when the physician is unable to communicate verbally with the patient at the bedside. Although Duff and Campbell propose that the infant may be respected as an independent 'thou', there is, as Young and Stevenson observe, the potential for the infant to become regarded as an 'it'. Unless members of the treatment team make strenuous and conscious efforts to over-come tendencies of this type, they can impede the attainment of the goal of respectful treatment as inspired by the Oath (4).

While the abstention from all intentional wrongdoing and harm is a Hippocratic legacy, in neonatal medicine, both doing and not doing are categorically iatrogenic once the physician-patient relationship is established. Because harm is fundamentally contextual and perspective-dependent, agreement or mutual understanding can only confirm its occurrence. The situation of the newborn patient is challenging and anything but straightforward because communication and agreement with the infant are impossible. Obviously, harm cannot be confirmed through enquiry of the patient, but

the concern to do no harm in medicine reflects a moral sense and is primarily a moral obligation to another person, actual or imagined, by self-reflective sentient being engaged over time with that person, whether actual or imagined. Thus, the fetus or newborn is a legitimate beneficiary of the physician's Oath, by virtue of the physician's parents or proxy's emotional engagement. *Primum non nocere* therefore assumes such an informing and emotional engagement. It presupposes an 'I-thou' relationship between physician and patient through sentient intermediaries.

The Current Reality of the Physician-Patient Relationship in the NICU

Since illness in the fetus or neonate cannot be elucidated through questioning, it is only through observing and probing that it can be imagined. Physicians, through various observatory and evaluative procedures, try to fathom the illness of the fetus or newborn person, even if it cannot be ascertained through questioning, because there is both an objective and personal aspect of the human circumstance in which dysfunction is experienced. The body of the individual always grounds the physician's inquiry. In utero, the state of being a fetus or newborn is inextricably intertwined with that of the mother. Once born and separate from the body of its mother, the neonate's body, regardless of gestational age, is lived in and experienced by the one whose body it is. Although injury or death may easily be construed in technical terms, these are actually personal in nature; it is on that patient, that neonate, therefore, that the focus becomes directed.

This can be seen in clinical decision making with regard to withholding life-sustaining treatment, which usually begins in the delivery room when an ELBW infant is born. Such situations lead to the next more difficult dilemma, that of withdrawing therapy that is considered futile. As Thomasma and Braithwaite observe, these infants do not have a biography as yet, a history of choices made in which values are the precipitate. Therefore, they are only just acquiring an identity. At the heart of the moral sense, then, is a judgment of proportion between burdens and benefits. They suggest that the value of continued life itself is assumed, unless the family and physician jointly determine that damage is being done to the individual newborn, that life is being cruelly prolonged that has been assaulted by nature itself (1986, 715). Should the infant be judged to be dying, and a proper infant care review committee hearing be conducted, withholding and withdrawing care still entails many ethical pitfalls (Kopelman et al 677). As Helga Kuhse is correct to argue, withdrawal or withholding of feeding to bring about the death of a newborn is not necessarily in the baby's best interests. While it may be believed that death itself might be in the baby's interests, a method of slow and sometimes painful dying by dehydration and starvation cannot be said to be in the baby's best interests (1988, 90)

This decision-making often becomes repetitive in the newborn intensive care unit, as a critically ill infant's prognosis is reevaluated from minute to minute and hour-to-hour. The decision to withhold additional therapy may then be intertwined with or substituted for active withdrawal of life sustaining therapy. Added to this situation are maternal, paternal, and perhaps, other familial hopes often unrealistically raised.

Multiple members of the care-giving team become emotionally as well as medically involved. Often the medical decision-making burden falls upon the medical house officer, perhaps new to neonatology, new to decision making about life and death matters, and reluctant to take this ultimate responsibility. It has been observed in medical ethics literature, that we ill prepare our medical students for such instances, as young house officers are often justifiably dismayed by their role (Stahlman 163).

A 1998 study by Doron and colleagues, illustrates the bedside dilemma faced by physicians. In this study the researchers analyze delivery room resuscitation for extremely premature infants. Their objective is to identify whether it is physicians' or parents' preferences that primarily determine the amount of treatment provided at delivery. They study the factors associated with the provisions of resuscitation and conclude that physicians resuscitated extremely premature infants at delivery when they were very uncertain about an infant's prognosis or when the parents' desires about treatment were unknown. This study suggests that when parents' preferences are known, parents usually determined the amount of treatment provided at delivery. These findings confirm that the decision to resuscitate an extremely premature infant at delivery is complicated due to uncertainty about prognosis, and according to this particular study, physicians prefer not to make such decisions in isolation. The physicians' perception of the parents' preferences for treatment and the value system that upholds parental decision-making seems to be influential.

These researchers observe that the reasons for physicians' valuing of parental decision-making and of the attitudes that underlie physicians' and parents' willingness to

recognize and limit ineffective care should be emphasized in future research. This approach may be more fruitful they claim, than focusing on resuscitation at delivery in the quest to decrease over treatment of extremely premature infants (580). It is already well established, that extremely premature infants often die, or survive with severe handicaps, despite administration of invasive and costly medical care.⁵ Making decisions about treating extremely premature infants is a complex process, with components attributable to physicians and parents. Frequently, physicians blame parents,⁶ and parents blame physicians,⁷ for the over-treatment of these infants. The treatment of newborns is unique in that the physician must concentrate on the present welfare of a patient who has no past and whose future can only be conjectured. As Guillemin and Lytle observe, more than with cases of adults or even young children, the NICU physician treating neonates is “clinically in the dark” (122-3). It is apparent that decision-making in the NICU simultaneously reflects the urgency, significant uncertainty, and parental as well as physician dread of the outcome that faces the seriously ill infant.

Being “clinically in the dark” can lead to unfounded medical optimism as well, which may prevent health professionals from perceiving the problems of medical futility and medical inhumanity or actively managing these concerns. Medical researchers such as Nancy Jecker and her colleagues have pointed to the ethics of the medical profession, which encourages physicians to push technology to inappropriate levels. Among the values inherent in modern medical practice, they suggest, are faith in science, a commitment to conquering disease and forestalling death, and a desire to bend nature to

one's will (1991, 5). As a result, some researchers suggest that physicians may come to regard survival as evidence of professional skill and view a patient's death as evidence of professional incompetence (Pace 169).

In another related article, Jecker makes the point that in the medical setting, prestige and praise are seldom lavished on those who do nothing, stand by, wait, or accept death (1990, 2392). Rather, she has observed that health professionals are applauded for acting, intervening and forestalling death. Once set in motion, this active goal-directed virtue could easily acquire a momentum of its own. To balance and limit this tendency, it has been suggested in the literature that virtues such as cautiousness, patience, non-recklessness, and humility be honed, since in the absence of these balancing virtues, more goal directed values could assume excessive proportions. (Erde 2021). Nancy Jecker too, conveys concern about this aspect of physician practice when she observes that “[o]nly by continued reflection on cases that raise issues of futility, inhumanity and medical uncertainty can health professionals grow more aware of the values inherent in their medical practice and act to shape them” (1986, 67).

Over 40 years ago, sociologist, Renée Fox, in her research on physician behavior, acknowledged that all physicians are confronted with problems of uncertainty. Some of these problems result from incomplete or imperfect mastery of available medical knowledge and skills; others derive from limitations in current medical knowledge; and still others grow out of difficulties in distinguishing between personal ignorance or ineptitude and the limitations of medical science (1957, 207). Like her sample of physicians of the ‘Metabolic group’ working close to the growing edge of things,

neonatologists today often are faced with the challenge to practice on the outside of well-established medical knowledge.

The Significance of the Boundaries of Medical Practice and the Plurality of Medical Knowledge

It is important to consider the underlying reasons as to why physicians were found in Doron's study, to feel more comfortable in allowing certain ELBW neonates to die when parent value systems played a role. Certainly, the particular aspects of situations that warrant recognition in limiting ineffective care cannot be studied here. However, what can be explored is what prognostic uncertainty represents ethically, for the physician. As Somerville notes, "[w]e often make ethical mistakes when we seek certainty-a sense of control-in situations that are necessarily uncertain" (15). Prognostic uncertainty represents the point at which the horizon of known experience encounters the unknown. In the practice of medicine, no matter how knowledgeable or well-practiced the physician, no matter how many tests have been run, there is the moment of crossing that represents this boundary. This is significant since such boundaries or limits of provinces places us between meanings that are taken for granted, therefore exposing the risk or uncertainty that constitutes these moments of interaction. It has been suggested by Edwin DuBose in his work on medical ethics, that if we approach the issue of prognostic uncertainty in this manner, we may access meaning structures that elude us in everyday medical practice with neonates. These situations of uncertainty expose to us, he suggests, "hidden, yet present, meaning structures" (27).

He points to the unspoken and common understanding of the world as it is assumed in social transactions. This common understanding is shared until otherwise apparent. These idealizations build a mutual sense of reliance and normality into everyday interactions. Thus, personal disparities in knowledge are less threatening in these interactions since it is accepted that some individuals know things that others do not. People, DuBose observes, tend to take the world for granted by assuming that the real world exists independently of their knowledge of the world, and that these two are in direct correspondence. This assumption of reciprocity of perspectives and typicality allows people to rely on their perceptions of others in social reality (68). In the doctor-patient relationship, and in health care matters generally, these idealizations are complex. Doctors, health care workers, and patients do not share a complete interchangeability of standpoints, nor can they ignore the differences in their respective biographical situations. For example, S. Kay Toombs has argued that physicians understand illness differently than patients and therefore exhibit traits, which they feel are consistent with their horizon of meaning (219). As Zaner too, points out, this approach to medical "reality" stresses that moral issues must be presented solely within the context of their actual occurrence--moral analysis must begin at the bedside, with an appreciation and understanding of medical "experience" (27).

The physician's pre-understanding of medical work (including the doctors understanding of knowledge and fiduciary responsibility) governs his or her response to the patient or in the case of the neonate, the patient's family or proxy who also possesses a particular pre-understanding of the nature of the physician and medical work. The

physician, as member of a profession, encounters his or her work from within a "horizon of meaning"--what Heidegger referred to as a "fore-structure of understanding" (188). This horizon of reality is constituted by a tradition. Partly institutionalized and partly informed by an individual's biographical situation, it represents a certain way of understanding, determining, and acting in and on the world, as well as certain habits of mind and relevancies, all of which give meaning to the work of the physician and give him or her a sense of identity and authority in the world of everyday life.

Many physicians have been encouraged in their training, and have themselves, encouraged a faith or belief in the power, authority and promise of scientific medicine. The fact remains, however, that the medical profession is unable to eliminate or control human finitude and suffering. Physicians have often objected to outside interference in what they perceive to be the special prerogatives of their work, claiming that their professional codes already establish sufficient moral and ethical guidelines for their practice (DuBose 36). Many physicians look upon philosophical and theological analysis of their work as meddling and potentially debilitating to their care for their patients. It appears that the analysis requires that the focus be placed not on the specific organizational structure of the medical profession, but on the way in which its members interpret their own organizational world (DuBose 46).

The modern health care system is a complex network of practices growing out of different historical traditions, embodying different values and different methods. For the people involved in it, the system weaves together ways of knowing, acting and valuing that constitute health care. As members of this amalgamation called a system, physicians

operate within this interrelationship and contribute in their practice to it. It is necessary to address the number of modes of knowledge that operate in medicine. As Toulmin writes, “in medicine, more than any other discipline, our task is [. . .] not to define ‘medical knowledge’ restrictively but to recognize the plurality of different types of medical knowledge” (41).

It is evident that medical knowledge is dedicated to the values of restoring and maintaining health and relieving suffering. As this research has suggested, medicine cannot be reduced to a value-neutral science. Medical work involves the physician with the physical lives, beliefs, expectations, and values of people who occupy the multiple realities of the world of daily life. It is true that the physician knows more than a patient about medicine, but biomedical knowledge is not all there is to medicine. The boundaries between the technical and the ethical are, at least in part, social constructions. They are social constructions because technical judgments are inherently probabilistic. It is a social judgment what percentage of success justifies some medical action. Again, the physician's knowledge must encompass more than pure technical or biomedical scientific knowledge. The doctor must know his or her patient's wishes, feelings, and desires, and the way in which the physician's own values play a role in treatment decisions (Zussman 124, 151). Perhaps it is not coincidental then, that as the scientific biomedical model has led to an increase in expertise and technology, there has been a corresponding development of public concern with health care.

In sociological theory, morality, as a sense of value and meaningful existence, and ethics, as a means for evaluating behavior within morality, develop over time within the

reciprocal relationships of society's members. Ethical thinking helps shape and maintain the ties that bind individuals to each other and to the community. An individual or group's behavior and choices regarding appropriate behavior arise from the patterns of life deemed meaningful by a community. As long as these actions can be assigned meaning, and, therefore, can be made acceptable within the limits of such a reality, some sense of harmony is maintained. As Etzioni points out, many have suggested that this lies in what might be called "the human arch." The human arch is thus comprised partly of community and partly of individuals situated within the arch. In this view, it is not possible to conceive of community without individuals, or individuals outside the social realm (173). Both individuals and the community have a basic moral claim, and any position that omits one of these two intertwined foundations leads to positions even their respective advocates find hard to defend. Etzioni refers to the resulting sociological moral paradigm as an extension of Buber's I-Thou, namely, as the "I and We paradigm" (Etzioni 1988).

As the scientific model became prominent in the last century, it began to shape the social structures of meaning that today typify the medical profession. The orientation of objectivity over subjectivity, of acts over feelings, became a primary value in health care. As science shapes the natural attitude of the everyday world, we see that its boundaries have begun to overlap with other disciplines such as law, religion and philosophy. It is important to acknowledge then, that science cannot provide meaning, which cuts across multiple realities. The spirit of the secular age is marked by an emphasis on the world as shaped and structured by human reason and will. However, in

the midst of the gradual secularization of Western society, it is clear that the way in which we view the world and organize a meaningful existence depends upon the model of meaning and structure of reality to which we subscribe (in which we have faith). There are many models available in the world, each claiming to represent reality most adequately by defining experience in the most meaningful way. As DuBose observes, whether we examine a particular religious, scientific, political, psychological, or economic model or paradigm, each represents a “reality” according to its own terms and truth claims (Dubose 85).

While a model may be consistently meaningful in itself, thereby offering some means of identifying “norms” for behavior, it cannot extend its reality claims beyond its own parameters. Existing in a world made up of multiple provinces of meaning, a person may be able to ignore these competing claims for a time, but finally inasmuch as these provinces are finite, anomalies appear to challenge meanings as understood. The problem goes deeper than recognizing a plurality of models or paradigms. DuBose suggests that social existence involves the gift of life, of meaning, and of place in the world. A person born into an ongoing tradition is given an identity and a means for making sense of reality. It is crucial to appreciate that giving represents only one half of a person's relationship to the everyday world. The giving one returns to the world completes identity. It is through this exchange that people participate in “reality.” Therefore persons participate in reality by giving and receiving through combinations of relationships (Dubose 88).

Added to this situation, the art of medical decision-making often masks an enormous range of science. As Thomasma observes, physicians and patients face a crisis about what it means to be 'scientific' in medicine: should patients be tested to death in order to apply with greater certitude the knowledge we have gained from others, or should they receive healthy doses of compassion, care and personal attention (147)? No matter how solid the data, the interpretive filter will always be the physician's clinical judgment. As the physician addresses the problems of the newborn with the family, medical values appear most prominently. But families often possess a complex of values, only one of which is longevity. Further, there are few objective data in the final analysis of medically futile treatment. Thomasma recommends that, instead, adjustments between data and individuals must take into account the personal value history of the patients, their own need to preserve their identity, and the circumstances from which the data themselves were abstracted. Perhaps this is why physicians in Doron's study seemed more comfortable making decisions to end life when the values of the family are known. Thomasma affirms that these epistemological and ethical problems are compounded when one considers decision-making for newborns. Here the families of such neonates must trust the physician's judgment in ways that are not part of the normal doctor-patient relationship, since decisions are to be made about a very vulnerable individual who has not yet constructed a value history. This trust must occur in the midst of experimental designs and/or abstract data, that may or may not apply to the newborn, and that may not yet have demonstrated sufficiently that the physician should recommend one treatment over another on a purely objective basis (159). As Hilary Putnam notes, the knowledge

involved in modern medicine includes both abstract and probabilistic reasoning as well as practical and value-laden reasoning. He argues that the difference between the two has occupied every major thinker in the past two centuries:

The difference between these two ways of understanding events—the difference between controlling objects and relating to subjects, between ‘objectifying reason’ and human (or humane) understanding, if you like—has exercised thinkers in every generation in the last two hundred years. (Putnam 1986, preface)

Medical Certainty Mistaken for Truth

In the modern age, the scientific interpretation of knowledge becomes associated with truth, with certainty, and in this way it makes a claim to power. As biomedical knowledge with its investment in techno-medicine grows, the power differential between the physician and patient extends beyond limits acceptable to the public. The otherness represented by the power and authority of the medical professional threatens people, and sparks a desire to assert some control over physicians through distrust, litigation and legislative constraints. As DuBose observes, this reversal reveals the slave's struggle against the master to be a struggle for mastery. Also it shows the modern thirst for objective, certain, and clear knowledge. If we can know the facts, then we can know finally and fully; all disputes can be resolved, and chaos controlled (DuBose 95).

Illness (as the absence of health) may be more important than ordinarily admitted in the philosophy or theology of medicine. As DuBose suggests, the perception of mortality and the need for relationship is the void made present by illness (97). The growth of the scientific structure in medicine reflects a desire to minimize uncertainty

and to control the limits of medical work. This desire shapes the profession's sense of its identity, the value of its work, and consequently, the nature of its relations with the public. While this orientation has produced great advances in medical power and authority, it also structures relations among people in particular ways. The structure has created a distance between the vulnerable patient and the powerful physician. Trust as control has moral, social, medical and theological repercussions. It adds fuel to the feeling of moral impasse in matters of medical ethics. Socially, it reveals the presence of interest groups. Medically, it fosters the practice of defensive medicine. From a theological perspective, it also does damage to the community of interdependent people by fragmenting a commitment to mutual enhancement. In our post-religious culture it is telling that we are more concerned than ever about what the experience of human health and illness has to say about perceptions of faith.

Certainly, neonatology is a recently specialized area of medicine in which medical advances continue to save the lives of many ailing infants. Like most areas of health care however, it is not a perfect science, and thus not all infants can be saved, no matter how advanced the technology or how well trained the physician. Some people, including some prominent scientists who do not want to have any explicit ethical restrictions placed on the pursuit of knowledge, argue that the "morality of the market place" will, and should be allowed to regulate their science (DuBose 16).

In an effort to move towards the development of a common language for doing ethics, Somerville proposes three competing possibilities for a new world view as a basis for a new societal cultural paradigm. These views seem to illustrate the 21st century's

faith commitment struggles. One of these views is what she calls the "pure science" view, which takes a position that science does, or will be able to explain everything, including such characteristics as altruism and morality that we think distinguish us from other animals and most clearly identify us as human. This view operates from a presumption of doubt, although an alternative view is that it operates from a presumption of faith in science, or a substitute one, or an ideology (Somerville, 20). It seeks meaning in human life only through science and similarly seeks to exercise control through science. What it means to be human and the meaning of human life are seen and explained only in terms of scientific constructs. Most importantly, the pure science view is intolerant of the belief that there is a mystery in human existence-which often results in the negation of a sense of wonder-and within its parameters there is no recognized space for spirit. The proponents of this view are comfortable with the use of reproductive technologies and with euthanasia, seeing most decisions concerning reproduction or one's own health as personal matters involving only individual values and preference (17-18).

In contrast, the second view she describes is the "pure mystery view," which operates from a basic presumption of faith in revealed doctrine (revelation). The pure mystery view often decries science or is expressly anti-scientific (20). This view adopts an intense sanctity of life stance, which can be compared to respect or reverence for life, and to respect or reverence for death. Many people who hold a pure mystery view believe that all medical treatment must be continued until no vestige of life remains. These same people could also have moral difficulties with providing necessary pain-relief

treatment that could or would shorten life. Often, this view is derived from fundamentalist religious beliefs. It seeks meaning, and likewise control, through religion. This view does encompass a sense of wonder, but the wonder is not elicited by the new science, which is seen as frightening, at best and possibly evil (18-19). Inevitably, decisions regarding when to forego treatment must be made. To this end, medicine, philosophy, law and society are deeply divided over questions of what should be decided, which babies should be treated, and who should have the authority to make life and death decisions

Principles of moral philosophy, whether they stem from secular or non-secular sources, play a significant role in our decision-making processes. Such principles are useful when choices are difficult and no clear precedents legal or otherwise, exist to guide the decision makers. In essence, underlying beliefs and value systems -- whether parents, physicians, judges or legislators- guide all human decisions to some degree. (Shewchuk 335) These two stances that Somerville describes can be understood within the context of two other prevalent dichotomies that exist under tension in our culture, namely, quality of life and sanctity of life views. The sanctity of life and quality of life views will be explored in the next chapter because they have played a significant role in framing the questions we have asked, and the answers we have given on end of life issues for neonates. This will lead to a discussion of the third stance that Somerville forwards, and advocates, namely the “science-spirit” view.

NOTES

¹ See "Prognostic" in Hippocrates, translated by W.H.S. Jones, (Cambridge Mass: Harvard University Press, 1959).

² Somerville has observed that because of science and its unprecedented discoveries and powers, it is now one of the areas where many of us are concerned to ensure trust and trustworthiness. Like medicine she says, science has traditionally been governed by "blind trust" largely because of the huge gulf in understanding between scientists and the general public. Scientists and physicians must earn the public's trust through the process of being responsible and accountable (291-3)

³ Martin Buber is an interesting choice by these intensive care pediatricians. As Whaling has noted, Buber was a "genuinely global figure." His global outlook arose mainly out of his Jewish background, but Christianity and Eastern religions also influenced him. Buber's main concern was with man, and his basic approach was philosophical. His methodology was that of philosophical anthropology. His primary interest was in man's relationships with other men, with nature, and with God. These relationships could take the form of an I-it relationship with others as objects, or an I-Thou relationship with others in the immediacy of encounter. Built into this approach was an emphasis upon the primacy of personal I-Thou relationships, which could not be objectified and therefore could not be studied as phenomena. For Buber, interpersonal or intrapersonal encounter could not be quantified but was nevertheless crucial (211-13).

⁴ See David J. Rothman. *Strangers at the Bedside: A History of how Law and Bioethics Transformed Medical Decision-making.* (New York: Basic Books, 1991).

⁵ See A.A. Farnoff, et al. "Very Low Birth Weight Outcomes of the National Institute of Child Health and Human Development Neonatal Research Network. May 1991 through December 1992". *Am J Obstet Gynecol* 173, (1995): 1423-1431. Allen, MC Donohue, PK Dusman AE. "The Limit of Viability-Neonatal Outcome of Infants Born at 22-25 Weeks Gestations". *New Engl J Med* 329 (1993): 1597-1601. Muraskas, JKW, Myers TF "Neonatal Viability in the 1990's held hostage by technology" *Pediatr Res* 39, (1999): 234. Jacobi, P., Weissman, A., Paldi E.. "The Extremely Low Birth Weight Infant: The Twenty First Century Dilemma". *Am J Perinatol* 10,(1993): 155-159. J.E. Tyson, et al., "Viability, Morbidity and Resource Use Among Newborns of 501-800g Birth Weight". *JAMA* 276 (1996): 1645-1651. M.W. Doron, "Delivery Room Resuscitation Decisions

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⁶ M. Kapp, "Futile Medical Treatments: A review of the Ethical Arguments and Legal Holdings". *Journal of Gen Medicine* 9 (1994): 170-7. Kolata, G. . "Parents of Tiny Infants find Care Choices are not theirs". New York Times Sept 30 CXLi: Section A., 1991. Rosenthal, E. "As More Tiny Infants Live, Choices and Burdens Grow". New York Times Sept 29 (CXLi:1)1991. M.R. Sanders et al., "Perceptions of the Limit of Viability: Neonatologists' Attitudes Toward Extremely Preterm Infants". *J Perinatol* 15, (1995): 494-502.

⁷ J.V. Pinkerton et al., "Parental Rights at the Birth of a Near Viable Infant: Conflicting Perspectives". *Am J. of Obstet and Gynecol* 177, (1997): 283-290. S. Chira "A New Medical Quandary at Heart of Trial". New York Times Aug 3 (National section) 1994. Silverman, WA "Over Treatment of Neonates? A Personal Perspective". *Pediatrics* 90, (1992): 971-976.

CHAPTER V

EXPLORING OUR COLLECTIVE STORY THROUGH THE MANDATES OF SANCTITY OF LIFE AND QUALITY OF LIFE

It is a question whether without restoring the category of the sacred, the category most thoroughly destroyed by the scientific enlightenment, we can have an ethics able to cope with the extreme powers which we possess today and constantly increase and are almost compelled to use.

--Hans Jonas

The Significance of the Medical Context

My focus in this chapter is on the ethical reasoning about end of life decisions through the advocating of sanctity of life and quality of life positions in the medical decision-making context. As James Tubbs has recently observed, argumentative positions advanced in the public forum concerning the issue of allowing certain neonates in the NICU to die are often oversimplified and sloganized (6). He also notes that health care is a realm of human activity that provides a context, and an area of application for moral visions and claims which are broader than their medical applications. Some moralists, object to the term bioethics for this very reason, that the term seems to suggest a new kind of moral reflection rather than simply locus of application for moral theories, norms virtues, etc. (Tubbs 2). Thus, an examination of sanctity of life and quality of life arguments in the medical context will be a lens through which to view certain central ethical and theological concerns about the meaning of a neonatal patient's physical life and the nature and limits of caring for it. These concerns reflect aspects of our collective

stories, they may lead to better understanding of what is necessary for the achievement of a shared language, and help us move closer to moral consensus on this issue.

As I have shown in previous chapters, in the practice of neonatal medicine in particular, physicians are continually confronted with uncertain prognoses. In certain situations the risked burdens of continued therapy were chosen because the infant's prognosis was "still so imponderable" (Sneiderman 499). The fact is, that it will be years in these types of cases involving ELBW neonates, before one can determine from the vantage point of hindsight whether their decision was in the infant's best interests. The law, however, does not demand that kind of wisdom.

As Courtney Campbell observes, if we consider what is driving moral debate concerning end of life decisions, we are likely to find what has historically been deemed a question of religious meaning right at the core, for it is difficult to discuss this issue without invoking the notion of "suffering" (6). Even prior to its significance for such controversial issues, the concept of suffering seems central for the most fundamental of concerns of bioethics. It is the experience of the inexplicably arbitrary and typically destructive, of what Weber referred to as the "ethical irrationality of the world." It is, as Campbell observes, this perception of illness and disease that lies behind the Latin root (*pati*) of our "patient," meaning "the one who suffers" (7).

The nature and purpose of life, and the place of health, medicine, suffering, and death within a vision of human nature and destiny, while integral to religious discourse, are common human questions of meaning that often seem peripheral in the quandary-centered concerns of bioethics. It is precisely because these are human questions, that

they require examination, “lest our assumptions about pluralism and ethics consequently compartmentalize our moral lives” (Campbell 8). The prophetic responsibility of bioethics necessarily entails probing beneath the visible manifestations of the crisis to identify the root causes of the problem and articulating an alternative vision of health care system based on ideals of justice in community that may only be approximated in practice. Somerville advances a “science-spirit” view, which she proposes might create a third dimension, a space for human spirit, one that also fosters our imagination and creativity. This view implies an openness to all ways of knowing, and significantly, a comfort with uncertainty, ambiguity and paradox, and the courage to admit that one does not know, thus the courage to change one’s mind. It is a complex, active, constantly changing interweaving of certainty and uncertainty with the certain open to becoming uncertain and vice versa. This is not, she says, equivalent to adopting a situational ethics approach. Thus, recognition of unavoidable uncertainty is not incompatible with regarding some things as inherently wrong (20-21). If we are to find support in the search for a “science-spirit paradigm” as advocated by Somerville, it means perhaps acknowledging that the contributions of religious traditions may enhance this responsibility. In several respects, this view can be significant in reminding us of the limitations of an ethic of principles.

Somerville's vision seeks a structure to hold both science and human spirit. She acknowledges that for some people, this view is expressed through religion, but it can be held independently of being religious, at least in a traditional sense, as is the case for most people. She advocates two important values for doing ethics in our world. These

are that we must always act to ensure profound respect for life, in particular, human life, and that we must protect and promote the human spirit (9). The remainder of this thesis will be dedicated to a preliminary exploration of the values inherent in two traditionally opposed mandates. Similar to Somerville's "pure science" and "pure mystery views," I hope to demonstrate points of agreement that can be located in quality of life and sanctity of life positions, much as points of agreement are located in Somerville's science-spirit view. These common features, I hope to show, are compatible with the overarching values of a profound respect for life, especially human life, and the protection and promotion of the collective human spirit.

Sanctity of Life and Quality of Life in the Medical Decision-making Context

As I have demonstrated, contemporary bioethics is marked by great complexity and, as a result, often by much confusion as well. Physicians, lawyers, philosophers and theologians differ in these deliberations over which values, principles or virtues are to receive priority in a given issue. Examples might be whether to choose divine providence over human choice, human autonomy over community solidarity, the natural acceptance of death over a commitment to life, respect for the givenness of human nature over the commitment to alleviate sickness and suffering. One cause of complexity and confusion is the failure to distinguish between differing discourses. As we have seen, they are often confused and collapsed into each other and the result is ambiguity of meaning and context.

Those who readily allow quality of life considerations a place in the medical and ethical decision-making process and others who repudiate such criteria on sanctity of life grounds have commonly found themselves in bitter and irresolvable opposition. The polarity of these two points of view can be particularly acute in the neonatal setting. Ethical consultant Ernlé Young makes the observation that the sanctity of life point of view is usually religiously inspired, and notes that the weight of theological opinion at least in the conservative Jewish, Roman Catholic and Protestant communities favors this posture (Young 464). Young quotes this uncompromising statement by Moshe Tendler, an orthodox Jew and Professor of Talmudic Law at Yeshiva University as evidence of this stance:

There are certain indispensable foundations for an ethical system and one of them is the sanctity of human life. This concept has a corollary; that is that human life is of infinite value. This in turn means that a piece of infinity is also infinity and a person who has but a few moments to live is no less of value than a person who has 70 years to live.

And likewise a person who is handicapped and cannot serve the needs of society is not less a man and no less entitled to the same price tag-a price tag inscribed with an infinite price. A handicapped individual is a perfect specimen when viewed in an ethical context. This value is an absolute value. It is not relative to life expectancy, to state of health, or to usefulness to society. (Young 1995, 464)

She also includes Ashley and O'Rourke's no less tenaciously held Roman Catholic point of view:

Physicians, nurses and health care workers should give public witness to their belief in the sanctity of life, the integrity of every person, and the value of human life at every stage of its existence by their compassion and care for their patients. (465)

Against this inter-faith consensus in favor of the sanctity of life position, Young cites some Reformed Jewish theologians who, in private conversation if not in their published writings, allow that quality of life considerations have a place in the decision-making process (465). Further, a larger number of Roman Catholic theologians are prepared to do the same, both verbally and in writing, an example being Richard McCormick's work in this area.¹ Many liberal protestant theologians are in their writings as outspokenly in favor of quality of life criteria having a legitimate role in decision-making, as their more conservative colleagues are opposed to this. According to Joseph Fletcher:

The traditional ethics based on the sanctity of life-which was the classical doctrine of medical idealism in its pre-scientific phases-must give way to a code of ethics of the quality of life. This comes about for humane reasons. It is a result of modern medicines successes, not failures. New occasions teach new duties; time makes ancient good uncouth, as Whittier said.

There are many pre-ethical or 'metaethical' issues that are often overlooked in ethical discussions. People of equally good reasoning powers and a high respect for the rules of inference still puzzle and even infuriate each other. This is because they fail to see that their moral judgments proceed from significantly different values, ideals, and starting points. (Fletcher 1973, 114)

As we have seen the prevailing climate in Canada is towards a standard of the neonate's best interests, quality of life being a licit criterion, yet sanctity of life is still receiving acknowledgement in the struggle as well. The achievement of the cultural paradigm that Somerville advocates will require that these two mandates co-exist. There has been past support for this very approach in the literature. Roman Catholic theologian, Richard McCormick has exemplified this:

Actually, the two approaches ought not to be set against each other [. . .]Quality of life assessments ought to be made within an over-all reverence for life, as an

extension of one's respect for the sanctity of life. However, there are times when preserving the life of one with no capacity for those aspects of life that we regard as *human* is a violation of the sanctity of life itself. Thus to separate the two approaches and call one *sanctity* of life, the other *quality* of life, is a false conceptual split that very easily suggests that the term 'sanctity of life' is being used in an exhortatory way. (McCormick 1981, 397)

Since individuals, institutions and societies are both rational and non-rational, exercising both faith (beliefs) and reason, morality can never be confined to the limits of reason. As I have already shown in this research, ethics at times must plunge, as Young puts it, "into the murky water beyond that boundary" (Young 462). Our postmodern, post religious culture has led to a situation where medicine, law and society as a whole, no longer have a comprehensive understanding of what to value and why. A necessary step towards coming to consensus is to attempt to understand the sources of our current impasse.

The sanctity of life principle (SLP) has been the one most fundamentally and continually appealed to in Western culture as the justification for moral rules, laws, human rights and social policies. Of important note, however, is that the SLP has often been advocated but much less often understood. It has been asserted that the principle is still our best available source and focus of moral consensus, but even one of the strongest proponents of its continuing validity, the theologian/philosopher Daniel Callahan admits, "the principle is vague in its wording, erratically affirmed in practice, and open to innumerable differences in interpretation" (1968, 185).

This lack of clarity is not new. Marvin Kohl suggested more than 20 years ago that the SLP needed to be dramatically reconstructed. He observed that those who

actually talk this way, using the same speech or orthographic patterns, do not mean the same thing when using the position that 'human life is sacred'. The sanctity of life principle (SLP), he says, has been open to, and has often been given, different interpretations. It has been chameleon-like, changing its colors according to the moral theory it has rested upon. Kohl suggests that it is almost as if a "family of related but differing principles were hidden under the rubric of the SLP in order to give the impression of moral consensus" (1974, 3). Surprisingly, relatively few studies in which the SLP is at issue to one degree or another seem to acknowledge the element of ambiguity in the principle or to indicate and justify how the authors understand that principle. To determine what the SLP means in the medical context and whether there is or can be any consensus and practical utility to the principle in neonatal intensive care, requires first, an attempt at a coherent understanding of the principle.

As philosopher John Keown has recently observed, the uncertainty of the meaning of this concept is due in part to the legal revolution of the Western world in the last thirty years. He makes the recommendation that the courts, by reinstating the law's consistent application of the SLP doctrine could restore moral and intellectual consistency, coherence and clarity to the law (255). He advocates what he calls, a proper understanding of the moral significance of individual autonomy, of autonomy as enabling us to make decisions that promote rather than frustrate human flourishing (255).

The sanctity of life principle clearly has religious origins. In Western thought, the development of the principle owes much to the Judaeo-Christian tradition.² It is also worthy to note that respect for life is also deeply rooted in Eastern thought (Keown,

2000). Judaism and Christianity, as well, have shaped Western Law to a large degree and thus, the centrality of the SLP principle in Law is largely religious in origin and orientation (Keyserlink 10). In the medical and legal context, we can best make choices about which values we choose to continue protecting in any new formulation of the SLP principle by recalling and articulating the religious and secular values and insights which shaped and continue to shape this principle.

As Edward Keyserlink observes, there are a number of frequently recurring themes, which can be found in a review of the theological roots of this principle. A general agreement between Protestant and Catholic analyses of the SLP principle suggests that the first theme has been that the human's dignity, worth and sanctity are from God, and not due to some quality or ability in man. Moral theologians and others, who have argued this theological point in our current times, have based their views, in large part on Karl Barth's theology of creation, redemption and an expression that Barth borrowed from Albert Schweitzer, a respect for life. For Barth, life is sacred and worthy of respect not because of something in life itself by itself, but because of what God has done, a God who is Himself, holy. Keyserlink quotes Barth³ to illustrate this point:

Life does not itself create this respect. The command of God creates respect for it. When man in faith in God's Word and promise realizes how God from eternity has maintained and loved him in his little life, and what he has done for him in time, in this knowledge of human life he is faced by a majestic, dignified and holy fact. In human life itself he meets something superior. He is thus summoned to respect because the living God has distinguished it in this way and taken it to Himself. (Keyserlink 1979, 11)

Paul Ramsey⁴ makes the same point, and contrasts the religious position to the secular or modern one when he writes:

. . . in the modern world view the sanctity of life can rest only on something inherent in man. . . . One grasps the religious outlook upon the sanctity of human life only if he sees that this life is asserted to be surrounded by sanctity that need not be in a man; that the most dignity a man ever possesses is a dignity that is alien to him . . . The value of a human life is ultimately grounded in the value God is placing on it. . . That sacredness is not composed by observable degrees of relative worth. A life's sanctity consists not in its worth to anybody. . . (Keyserlingk 11)

The second major theme of a theological explication of the SLP is that life is a gift in trust, it is on loan, and man does not have dominion over it. This is a theme, which reoccurs constantly in both Protestant and Catholic analyses. For example, Ramsey says, “every human being is a unique, unrepeatable opportunity to praise God. His life is entirely an ordination, a loan, and a stewardship” (13). While there is substantial agreement between Protestant and Catholic analyses, there are remaining questions about their use in ethical analysis of end of life issues. The first has to do with what theology proposes as one of the bases of the SLP, namely the lordship and absolute sovereignty of God over human life and death. Many in our secular society question why a sovereign God who cares for human life, which a sovereign deity must if the sovereign deity holds human life as sacred, does not prevent or cure illness. Since a sovereign deity does not in fact appear to do so, one can only conclude that if this deity really is sovereign this deity does not in fact care, or that this deity wants people to have at least some degree of control over human life, death and sickness. The problem raised here of course is the problem of evil, one with which theology has grappled with for centuries.

A large part of Judeo-Christian theology, opts for the second of the two possibilities indicated here, that God shares with his people some decision making power

in life and death matters. Not only theological treatises, but a considerable amount of Christian practice supports this conclusion—even in “Christian” states and times it was generally permitted to take another’s life in defense of one’s own, or to imprison and to execute those judged dangerous to society (Keyserlingk 12). As Keyserlingk notes, a second question, quite significant for use in the medical context, has to do with whether one can in fact reconcile the religious view that human beings get their worth and dignity entirely from God, with the secular modern view, which sees human sanctity and dignity as inherent in and, intrinsic to human beings. He has quoted Daniel Callahan to illustrate this point:

[I]n the theological problematic . . . it makes no sense to talk of man apart from his creator and redeemer; the ‘natural man’ does not exist, but only the created and redeemed man. . . . In part this helps to solve the problem of an ‘alien dignity’ which would denigrate man’s intrinsic worth, but at the same time, it requires that we accept the full theological framework; and that is just what many cannot do. (1968, 190)

Certainly, the religious explication of the SLP principle is appropriate and convincing only to those who accept the religious viewpoint, those who are believers. Since a large number of people are not, or never were religious, that basis alone for the SLP principle is hardly likely to be one around which a consensus can be identified or built. However, there are some significant conclusions from the theological roots of the SLP principle. First, human life may not be taken without adequate justification, and valuing human life is not the result of the worth a human being may attribute to it. It is therefore, fair to say that the SLP has been and continues to be, basic to our society, and its rejection would endanger human life.

Although the roots of SLP are clearly religious, even theologians have supported the view that as such, religion is not the only possible basis for such an important moral principle. For example theologian James Gustafson has said that:

For most persons involved in medical care and practice the contribution of theology is likely to be of minimal importance, for the moral principles and values can be justified without reference to God, and the attitudes that religious beliefs ground can be grounded in other ways . . . Functional equivalents of theology are present in the patterns of actions and the ethical thought of persons who find theology to be a meaningless intellectual enterprise (1975, 270).

As Keyserlingk explains, there have been attempts in the past to articulate and argue a functional equivalent of the SLP. He cites Edward Shils who attempts to forward an understanding, which is built on the “common experience of mankind.” Shils says that despite waning theological belief, many of the actual or prospective interventions of biomedicine give rise to a “deep abhorrence or revulsion.” He observes that the source of the revulsion or apprehension is deeper than the culture of Christianity and its doctrine of the soul. Indeed, he suggests that the Christian doctrine was enabled to maintain its long prosperity and to become effective because it was able to conform for so many centuries to a deeper protoreligious “natural metaphysic” (1968, 2-38).

This point is significant both for those who are and are not religious. It recognizes the experience of a deep respect for human life, as affirmed in religious teaching and by the existence of the Charter of Rights and Freedoms. The acceptance of the equality and value of lives of individuals could be at its source, ultimately just the nature of things; the way things are, or as Shils himself writes:

The chief feature of the protoreligious 'natural metaphysic' is the affirmation that life is sacred. It is believed to be sacred not because it is a manifestation of a transcendent creator from whom life comes: it is believed to be sacred because it is life. The idea of sacredness is generated by the primordial experience of being alive. Of experiencing the elemental sensation of vitality and the elemental fear of its extinction. Man stands in awe before his own vitality, the vitality of his lineage and of his species. The sense of awe is the attribution and therefore the acknowledgment of sanctity. All else man feels to be sacred derives its sanctity because it controls or embodies that sacred vitality of the individual, the lineage and the species. (Shils 1968, 12-13)

Shils does not include the "alien dignity" version of sanctity proposed by the theological perspective acknowledged previously. Shils and the secular perspective in general see dignity, worth and sanctity as inherent in humans, grounded in the way things are, not only given and maintained by God. Keyserlingk is correct to observe that Barth and Shils have both been able, each from their quite different perspectives, to speak about our standing in awe before human life (15). Barth wrote that, "Respect [for life] is man's astonishment, humility and awe at a fact in which he meets something superior- majesty, dignity, holiness, a mystery which compels him to withdraw and keep his distance, to handle it modestly, circumspectly and carefully" (1936, 339).

Some, like Danner Clouser, argue that sanctity could be seen as at least a 'derived' property of life given the prior acceptance of religious propositions such as creation. But, he claims that, apart from the religious context, "there is no universally accepted theory-if at all-that entails a property called 'sanctity' (Keyserlingk 16). He therefore concludes that sanctity of life "is more something we pledge ourselves to, a commitment, than it is an objective property that demands acknowledgement" (1973, 120-21). Human beings, of course, continue to show indifference to and destructiveness

towards the lives of their fellow humans throughout the world. Shils counters this evidence with his belief that, "It's [life's] sacredness is the most primordial of experiences, and the fact that many human beings act contrarily, or do not apprehend it, does not impugn the sacredness of life[. . .] The fact that many human beings often act irrationally does not deny the value of reason" (19). Certainly, as Shils notes, there does seem to be a widespread intuition that life is valuable and inviolable, despite the exceptions and the "gradations" of sanctity we all too readily grant in our dealings with others.

As Keyserlingk suggests, simply the experience of something, of course, is not in itself proof of its worth, or its value. Nor does the mere experience of something, even if it is common and universal, impose an evident moral duty or series of duties. Historically, he says, we have seen similar difficulties of proof and evaluation involved in the related moral view and argument based on Kant's thesis, that persons are ends in themselves, not means. There has been a tendency in the various versions of this view to assume too much in the assertion that persons or rational beings are ends in themselves or have absolute value, even if that is granted (16). As Kluge comments:

Only by confusion between a rational being on the one hand and its life on the other could we conclude from the fact that the former is an end in itself that the latter has absolute value as well--without any qualifying consideration. It is entirely compatible with the thesis of rational beings as ends in themselves that only a certain quality of life is deemed livable for them, and that in the eventuality of its non-realization, the life of that being ought to be terminated. (1975, 142)

There remain vast differences in the perspectives of theology and that of intuition and experience. No one has yet managed to satisfactorily reconcile the two approaches in

theory. The most important point of practical agreement, of practical consensus, is of course in the affirmation of the principle itself, at least in its generalization and orientation, as the fundamental one and the starting point for all biomedical decision-making. That, itself, is no small matter. As Richard J. Pendergast confirms in his letter in the *Annals of Internal Medicine*:

The concept is an expression of a basic intuition about human life that can be had by men who are not religious in the narrow sense of the term[. . .] the intuition that gives rise to the concept of the sanctity of life is somehow related, in an intrinsic positive way, to the mystery that overhangs all finite existence. Religious concepts and myths specify the nature of this mystery, but such specification is not necessary to recognize its existence and the fact that it must be taken into account somehow (at least in terms of reverence, caution and humility) when we deal with persons. (Pendergast 1973, 979)

As Margaret Somerville observes, the great religions have traditionally given us a compelling shared story, allowing us to pass on our most important values to future generations, enabling us to form and live in families and communities, and also functioned to stimulate and extend our human imagination. One way to view the search for ethics then is as the search for societal values in a secular democracy. In this type of society, we no longer automatically have access to a received set of values through a shared religion, and we can no longer impose values or assume there is consensus on them. We must, rather, find and agree on these values and a very important context in which we are seeking to do this is in relation to how we should and should not use the new science (4-5).

Perhaps, for ethics, medicine, or law to acknowledge and articulate the validity and importance of quality of life concerns, they need to imply no threat to a commitment

to the sanctity of life. Quality of life need not involve either making the sanctity of life a “relative” value or positing “exceptions” to the principle of the sanctity of life. The crucial condition for a happy and productive relationship between them is that they work out their real identity and be themselves. One issue that must be broached, and seems to create the most difficulty for SLP and QOL to coexist, is the position that has been held by some, that vitalism, (much like Somerville’s “pure mystery” view), is the only valid expression of the SLP. Vitalism is an approach which insists that where there is human life, even mere metabolism and vital processes, no matter what the neonate's condition, or the families wishes, it would be inconsistent with the SLP either to cease to preserve it or to interfere with it.

In this view then, wherever there is human life, any human life, whether comatose life, fetal life, deformed or suffering life, the sanctity of life principle is the final, conclusive reason against taking, ceasing to preserve, or for that matter, altering it. The principle is not one reason to weigh along with others; it is the only one that counts. Nor does the principle in this view admit of a need for any further qualifications or exceptions. It is applied to all issues in which human life is in danger and being taken, not preserved or altered.

Vitalism sees the SLP and QOL concerns as opposed and irreconcilable. Its proponents assume that if one allows QOL factors to enter into medical decision-making, even as one of several things weighed, one is partially or totally rejecting the SLP. As Keyserlingk points out, however, this assumption can even find its way into supposedly value neutral opinion surveys. He cites a survey of physicians, nurses and medical and

nursing students on attitudes toward euthanasia. Though the questions dealt with both active and passive euthanasia as well as a number of ambiguous attitudinal implications and conditions, the report of the survey describes the weighting of the questions this way, “weights were assigned to statements so that responses indicative of a favorable attitude toward euthanasia were assigned a low score, while attitudes favorable to the sanctity of life principle were assigned a high score.”⁵ Given the added ambiguity of the term when used in the medical practice, it is at least simplistic to suggest that the practice is always opposed to SLP. It is also assumed in this view that QOL thinking must necessarily involve value judgments about the worth, usefulness or meaningfulness of the lives under consideration and that these judgments necessarily imply a comparison of the relative worth, utility and meaning of different lives.

Vitalists are generally suspicious of the motives of those who wish to include QOL concerns in medical and research decision-making, no matter what conditions, safeguards or guidelines might be proposed at the same time. This idea that once some form of killing, letting die or altering of human life is legitimated in a particular instance, though it may be compassionate, sometimes morally justifiable, despite goodwill and best available safeguards, this leads to wrongs of ever increasing magnitudes. Historical precedence is often used to defend this position, namely the Nazi medical/experimental atrocities and the slippery slope argument. However, there is much uncertainty as to the original intentions of the Nazi program, and some maintain that racism was in fact the original intention and that indiscriminate euthanasia is likely to develop only in a Nazi like society (Khol 137). Somerville points out that we might learn valuable lessons from

asking whether there are any factors in our society, and its science and medicine, to which we should respond with concern and care because they are similar in some ways to facts that were present in German society, and its science and medicine at the time of the Nazis. Fascist ideology incorporated the notion of perfection, whether of people or the self-perfecting state. When mentally or physically disabled people are characterized as a “problem” and this “problem” is seen as an obstacle to fulfilling a political agenda, dealing with it through medicine or science, placing a medical or scientific cloak on it makes the ethical concerns less obvious. Science can be used to replace morality or ethics as a justification of certain actions through the act of placing technology between ourselves, and those who are harmed by its use. This can result in a situation where we see the technology, and not ourselves, as causing the harm (297-9).

Another formulation of the vitalist option is the argument that to take human life, to not preserve it or otherwise to intervene in the natural processes as long as life persists, even if only at the biological vitalist level, is a form of playing God. Vitalists have suggested that this prerogative of giving life belongs to God, and that prerogative may not be usurped. Conversely, the prerogative of taking life is God's alone. In his wisdom God has decided who should live and who should not; who should die and when. As Kluge explains, consequently, euthanasia as a preternatural hastening of the appointed time of death constitutes an unacceptable interference in the work of God (Kluge 137). Such “playing God” arguments are used by those who accept the validity of quality of life concerns, when criteria are too lax or when judging others of being too wide in their understanding of quality of life.

There is a final more global argument, which lies behind and fuels much of the vitalist interpretation's tenacity and appeal. The argument begins by identifying in our great preoccupation with limiting, ending and modifying human life a common, dominant and regrettable theme running through all the biomedical issues. The target of this argument is largely the preoccupation with the defective side of human life and the consequent compulsion to prevent it, end it or remake it. Abraham Kaplan expressed it more than thirty years ago as thus:

If we are not capable of modifying life, we have at any rate the problem of medical experimentation [. . .] And if all else fails, we come finally to the problem of euthanasia-how we can put an end to life which we have been powerless to prevent or improve upon [. . .]there is irony in that fact [. . .] that our deliberations on the sanctity of life take place against the background of a deep and widespread preoccupation with death that is characteristic of our culture. (Kaplan 1968, 154-155)

The vitalist approach, therefore, has claims that the SLP provides the answer in a final, absolute, manner to the questions about ending life. No other principle or qualification of the sanctity of life principle is required. Human life at any level must be preserved. QOL and SLP are opposed and mutually exclusive, but a number of arguments exists counter to this stance. The essential ingredient towards co-existence, or a "science-spirit" view which supports the idea that biological life is not always "sacrosanct" and that QOL concerns can express and protect a commitment to sanctity of life, can perhaps be found in established religion and medical piety. While some have sought to replace sanctity of life with a quality of life ethic, such as Joseph Fletcher (1973, 12) and others with the moral rule, don't kill (Clouser 1973, 119-25) still others

argue for substitutes such as the love principle or the rule of benevolence. However, Marvin Kohl, suggests a “reformulation,” not a discarding of the SLP (30).

The SLP although somewhat elusive and indeterminate, is not totally without substance and meaning, both in terms of what it means and does not mean. It does point to an absolute value of human life and worth; it insists that human life is always worthy of respect and protection; and it argues that life should always be supported without adequate justification to the contrary. Inasmuch as these assertions have always been under attack in open or subtle ways in medical legal and other debates, the SLP continues to require articulate and strenuous defense.

Towards Co-existence: A “Science-Spirit” Consensus

As this research has endeavored to demonstrate, the association of vitalism with the sanctity of life concept is erroneous and unsupported by a careful reading of both the religious and experiential/philosophical roots of the concept. It is true that the religious roots of the concept emphatically insist that human life ultimately comes from God, that God is ultimately the source of its worth and dignity, and that man does not have dominion over it. But these same religious roots and perspectives affirm that God has deputized to man some of this dominion, some of this control over life. The theological notion of life held in trust or on loan by us includes a degree of responsibility and decision making by us, even in matters of life and death. The biblical/theological understanding of the world, creation and life being entrusted to man means that he is

responsible, a decision maker, a transformer, a builder-all of this in response to God's command and with respect for the sanctity of life. Judeo-Christian morality and practice have long affirmed that there is no inherent contradiction between acknowledging God's dominion over life and death, and yet acknowledging that individuals or the state may, in self-defense take the lives of those judged to be unjust aggressor threats to the common good (Keyserlingk 31). The key point to be advanced here, is that there are Judeo-Christian historical precedents in contexts other than medical in which it was and is thought consistent with the sanctity of life to allow life to be taken and even to take life.

In doing ethics in the 21st century it is important to appreciate that responsibility for decision-making and action in the world is left to humans, and when they accept that responsibility they are neither playing God nor playing human, but being human. Since both theology and human experience in this preliminary exploration have suggested that God does not in fact directly intervene in the biological processes of life and death or make life and death decisions, humans would be abdicating responsibility to passively leave the care, protection and control of life to God. When it comes to the many social problems of medicine physicians have often retreated behind the cliché that they won't play God. However, throughout the nature of a physician's work, they do not wait for God to show the decision by making some outward manifestation before they undertake a Caesarean section, order a transfusion or perform a risk-fraught open-heart operation, or knowingly administer a lethal dose of narcotic with the intention of relieving pain.

If we are listening carefully, we may hear that there is a conviction of both moralists and physicians that there are still some limits, there is still some line beyond

which intervening with and controlling life should not be allowed to go. Although the SLP is somewhat vague and indeterminate, it is not meaningless. If it is the function of indeterminate ethical principles to judge and test determinate rules of conduct, then clearly the principles cannot achieve that goal unless there are in fact such rules. The SLP would remain for all practical purposes meaningless, and useless however, if it were not given concrete content by the rules that express it and support it. As Daniel Callahan reminds us:

Thus the 'sanctity of life' implies a spectrum of values ranging from the preservation of the species to the inviolability of human bodies, from man in the aggregate (present and future) to man as an individual (present and future). The discrete rule systems each serve an aspect of human life: species life; familial; lineage-life; person-life; and body, individuality-life. Each aspect of human life therefore has an appropriate rule system designed to protect and foster that aspect. (1968, 208)

Certainly, the SLP by itself cannot answer all the questions, but it does at least help to raise the right ones, and to establish and test parameters for the rules. And the particular moral rules in their turn give content to the principle that not only human life in general is to be protected and respected, but individual bodily life. The question remaining of course, and especially apposite in the case of the ELBW neonate, is what kind of human condition and what human qualities do we value and protect. The rules cannot be formulated or reformulated unless we recognize the legitimacy and urgency of quality concerns in the context of human life and death, and establish our quality choices first of all.

Technology presents us with a growing number of options regarding the kind, condition and quality of life now possible and to come. The options require choices, and

the choices are as much and as inescapably about quality as about only existence and quantity. Quality choices related to technology may have been less pressing and more avoidable in a simpler age, but now in more and more cases, not to choose is to choose. To avoid principled choices between competing technologies and social policies, choices made partly at least on the basis of the different qualities of living and dying they promote, is often in effect to choose the least desirable, the least moral-if not for this generation, then the next.

The use of the SLP as a tool to determine all moral decisions in advance without any consideration of further questions and individual circumstances, is therefore to distort the real role of that principle and to use it as a decision avoiding not a decision making tool. If this is so, however, the question becomes how useful and morally legitimate is the QOL concept in helping to shape moral rules, in determining justifying reasons for both preserving and ceasing to preserve human life, and in establishing the inherent features of human life.

This thesis research has maintained that concern for the neonatal patient's best interests should begin by rejecting the most frequently proposed meaning or connotation of quality of life in the medical health context, namely that it must inevitably and fundamentally involve more or less wholly subjective judgments about the relative individual or social worth, value, usefulness or equality of the lives of persons. This is further supported by the fact that the SLP inasmuch as insists that the respect and protection due to human life ought not be based on judgments of relative worth, value or

usefulness. Indeed, such versions are rightly seen as opposed to and judged wanting by the SLP.

Another important point to be made here, is one that Paul Ramsey has forwarded, that the causal influence may be technology, but that will not be a reason for bioethical deliberation about the when and who of end of life decision-making. Impelling reasons like costs of salvaging neonates, or technological capabilities are not the same as a good moral reason. In order to find a principle of selectivity that accords with the ethic of what he has advocated as “the equal and independent value of all human lives,” it is necessary to understand the meaning of moral policy as more than a justification of decisions actually being taken. Therefore it is important to realize that people must manage to be and act morally under the conditions of finitude. “That is nothing novel,” as Paul Ramsey says, “it is the human condition” (1979, 262)

Especially in the case of the ELBW neonate, it is not clear whether modern medicine can discern with any reasonable certainty exactly when an infant enters the stage of irreversible “dying” or distinguish clearly between life prolonging treatment and those which are merely prolonging the infant's dying process. In an attempt to deal with this uncertain situation, Richard McCormick cites “relational potential” as a measure of infant's interests in continued life (1981, 349). McCormick's, relational potential standard would measure not only the infant's capacity to respond to medical care but also his or her capacity (or potential capacity) for recognizing and maintaining meaningful relationships with those caring for him or her.

Unfortunately, medical prognoses concerning these potentialities cannot usually be made with as much confidence or specificity as can predictions of permanent unconsciousness or intractable pain. It must be appreciated that intractable pain is subject to prognostic error in these situations, too. Any predictions about a handicapped infant's future satisfaction or happiness are value laden. However, McCormick's point is valid that we should accept the responsibility (and inherent risks) of making treatment choices for our children in ways, which somehow reflect our understanding of what makes human life human. Certainly human interrelatedness or anticipation of it is usually a precondition of our ability to wrest any genuine comfort and any meaning from conditions of suffering due to pain or despair. Without relationality one cannot enjoy the absence of pain or interpret the positive significance of pleasurable impulses, or distinguish between satisfaction and simple endurance, and one cannot hope.

However, infants with no relational potential retain a significant interest in avoiding pain, and our treatment choices for them should focus upon keeping them as pain free as possible until they die. It is clear that diagnostic and prognostic discernments and predictions about the pain and discomfort associated with various conditions and treatments are matters of clinical judgment. However, judgments regarding whether one would want to be kept alive under various conditions of non-relationality, pain, or discomfort are not clinical discernments, but rather matters of personal valuation. Since infants cannot formulate or explain to us what their interests and values are, proxy decision making on their behalf should rest primarily in the hands of those most committed to discerning what the infant's best interests are and acting in

accordance with those interests. Usually it is the parents who best fit that description. But some argue that parents are not the most appropriate decision makers because they are not the most medically informed impartial and disinterested parties (Miles 48-50).

Of course, some parents may be unable to comprehend the medical data given them or unwilling to place their baby's best interests ahead of their own psychological or financial concerns. On the other hand, though, our traditional understanding of family includes the presumption that parents have shown an interest in their children's welfare by their willingness to bring them into the world, and that parents have a social responsibility to teach their children about the interests and values they should have. This is why our legal tradition has allowed parents so much discretion in decision making for their children in various aspects of life. As James Tubbs observes, families are, among other things, communities of shared religious and moral values, beliefs and expectations (186). As we have seen, the recent medical literature has supported the inclusion of parental values in the end of life decision-making process.

Thus, parental discretion should have a primary place in neonatal treatment decisions at least where there is some reasonable basis for questioning whether treatment is indeed in the infant's best interest. In cases of decisional conflict, then an interdisciplinary body, an institutional ethics committee should review the case. The role of this committee should not be to adjudicate but rather to facilitate exploration and analysis of available options and the ethical rationales. Parents therefore should not be treated as adversaries or outsiders but as persons who are assumed to care deeply for their children and who are in need of personal support and they share in their baby's suffering.

Hawerwas observes that to be a parent “is to perform an office for a community of seeing that a child finds his or her way to the moral best that community has to offer” (Tubbs187).

To include QOL consideration in life saving or life support decision making by no means must imply harm rather than improvement or benefit to the patient. If QOL is limited only to what is intended here, then quite the contrary is the case and must be the case if the concept is to have any justifiably normative value. Investigations, prognoses and conclusions arrived at concerning a patient's actual or potential level of function or degree of suffering, need not inevitably and exclusively lead to decision to cease or not initiate life supporting treatment. Given that the SLP imposes the burden of proof on those who would cease to support life, the consideration of QOL factors should more often lead to the opposite decision-to initiate or continue that treatment if there is any realistic hope of minimal human function and controllable pain and suffering. Even when QOL factors do contribute to a decision to cease or not initiate life saving or supporting treatment there remains the continuing obligation to seek to improve the newborn's care and comfort. The SLP surely calls for a least the same respect and consideration for dying life as for healthy life. If greater needs call for greater care and concern, then the dying deserves more, not less of it, than the healthy.⁶

CONCLUDING REMARKS

This research has endeavored to demonstrate the tension that exists between sanctity of life and quality of life under the rubric of best interests in the medical-legal context. It has shown that there are different understandings of both these stances amongst individuals and between the disciplines of medicine and law. I have worked to expose the danger in futility judgments and the inconsistency in practices at the individual, institutional and international levels, and what this represents for ethical deliberation. This is an area that requires more attention and study for clearer understanding.

I have also shown that there have been major changes in society, medicine and science in the last thirty years that have contributed to issues of decreased trust and fears concerning euthanasia in this population of neonates. I have clarified the inherent uncertainty in treatment and withdrawal of treatment decisions, and the difficulties associated with leaving physicians with full responsibility for such decisions which are often in fact, value laden. I have also shown that there is evidence in the literature that many physicians are indeed open to sharing responsibility and have advocated clearer guidelines and communication in this regard. The moral decision-making as shared seems to be a viable option to explore, and there seems to be ample grounding to support Margaret Somerville's advocating of a transdisciplinary approach, and support for her over-riding principles of a respect for life and maintenance of the human spirit. It appears however, that we must be open to discussion of what is represented by the various languages of our culture and working towards a common language for doing ethics.

The example in this research of such an approach has been the preliminary uncovering of the mandates of sanctity of life and quality of life. I have tried to show that both stances represent valuable insights and conformation of our desire to value human life and maintain human spirit and our interconnectedness. It is important that, rather than seeing our values as just being handed down to us and passively adopting them, we can view our values as coming out of our search and that, in turn, can result in our shared commitment to them. Such a view could mean that we will care more, as both individuals and a society, about upholding and protecting our values.

This research and discussion is indebted to Margaret Somerville's stance, and those before her, that in choosing our values, attitudes and beliefs, we are choosing not only for ourselves as individuals, but also for our world. This is commitment to respect all life, the human spirit and our world both present and future, through an adoption of a "science spirit" view, which recognizes there are many questions we must ask about any given issue, and there may be no one right answer. This view recognizes that there is more that we can do with our new science than what we *ought* to do, thus opening up the debate concerning what we should and should not do. This view requires the courage to live with uncertainty that making such distinctions involves. This approach would indeed lend itself to further exploration and perhaps an opportunity to gain greater clarity on what is in the "uncertain" best interests of extremely premature neonates, through an acceptance of this uncertainty, an overriding respect for human life and spirit, and a clearer understanding of the values of our collective community and of ourselves.

Certainly, death is one of the oldest focuses of human fear, curiosity and philosophical debate. As Somerville eloquently states:

It is the last great act of life. It must remain so, if we are to live fully human lives and pass on the capacity and opportunity for this to our descendants[. . .]We must not let our justified fear of death overwhelm our sense of the mystery of it and of life. If we do so, the loss and harm to each of us and to society will be beyond our present imagining. (151)

NOTES

¹ See Richard McCormick's "The Quality of Life, the Sanctity of Life", *Hastings Center Report* vol 8 no 1 1978: 34.

² See Harold J. Bergman, *The Interaction of Law and Religion*, (N.Y: Abingdon Press, 1974) 49-76. See also Julius Stone, *Human Law and Human Justice*, (California: Stanford U Press, 1968) 9-35.

³ Keyserlink cites Karl Barth, *Church Dogmatics*, Vol. 3, Part 4, (Edinburgh: T &T Clark, 1961), 339.

⁴Keyserlingk cites Paul Ramsey, "The Morality of Abortion" in John Rachels (ed), *Moral Problems: A Collection of Philosophical Essays*, (N.Y.: Harper and Row, 1971), 11-12.

⁵ Keyserlingk..cites C. Winget. . T. Frederic. R.C. Yeaworth. " Attitudes Towards Euthanasia", *J of Med Ethics*, 3, (1977): 20

⁶ For an excellent treatment of the obligation and significance of care, see Paul Ramsey, "On (Only) Caring for the Dying", ch 3 of *Patient as Person*, (New Haven: Yale University Press, 1970), 113-164.

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