

**ETHICAL CONSIDERATIONS OF NEWBORN EUTHANASIA: A QUALITY OF LIFE
APPROACH**

by

Tomas Bednar

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Center for Bioethics and Health Law

This thesis was presented

by

Tomas Bednar

It was defended on

November 24th, 2010

and approved by

Alan Meisel, JD, Professor of Law and Psychiatry, University of Pittsburgh

Valerie B. Satkoske, MSW, PhD, Affiliate Faculty, Center for Bioethics and Health Law,

University of Pittsburgh

Thesis Director: Lisa S. Parker, PhD, Associate Professor, Center for Bioethics and Health

Law, University of Pittsburgh

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Tomas Bednar, M.A.

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This thesis develops the proper role of quality of life assessments in situations of newborn euthanasia. Initially spurred by the Groningen Protocol of the Netherlands, which was a protocol outlining the criteria for non-voluntary newborn euthanasia of seriously ill or impaired newborns, this paper considers the practice of newborn euthanasia within the context of the current decision making frameworks already in place in this country. Specifically, this paper relies on informed consent and the best interest model as well as the generally accepted respect for parental authority in medical decision making. In light of these current standards of practice, this paper argues that in order for newborn euthanasia to be ethically permissible, it must be split into two primary decision making processes. The first is the decision to provide euthanasia as a medical option, which rests solely with physicians. The second is the decision to actually euthanize the child, which rests with the parents or guardian of the child. Both of these decisions are dependent upon assessments of the newborn's current and future quality of life. The decision to provide newborn euthanasia must be based on a set of components of quality of life that are sufficiently universal so as to allow them to be applied to any newborn and to maintain a reasonable degree of uniformity of assessments between physicians in the same case and in like cases. This thesis identifies five components of a minimally decent quality of life that physicians should use to determine whether to offer newborn euthanasia as a medical option. Once this decision has been made, parents take on the responsibility of considering whether the child's

current and future quality of life justify newborn euthanasia. This decision is understood in the context of the broad deference that the medical community gives to parents in their treatment decisions made for their children. The physicians' decision to provide euthanasia as an option is meant to inform the parent's decision but is in no way meant to obligate compliance.

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“If we begin with certainties, we shall end in doubts; but if we begin with doubts, and are patient in them, we shall end in certainties”

- Francis Bacon

1.0 INTRODUCTION

In 2005 Eduard Verhagen and Pieter Sauer of the University Medical Center at Groningen in The Netherlands published an article in the New England Journal of Medicine wherein they outlined their 2002 protocol for non-voluntary newborn euthanasia (Verhagen 2005). According to Verhagen and Sauer, the goal of newborn euthanasia is to forgo “unbearable” amounts of suffering in newborns both in their present and future states. The protocol’s intended purpose was to create a framework of guidelines that would aid physicians in deciding on and carrying out acts of newborn euthanasia as well as serve to protect them from subsequent prosecution. The protocol was a result of the 2002 legalization of adult euthanasia in The Netherlands (<http://www.minvws.nl/en/themes/euthanasia/default.asp>). This legalization followed a thirty year period during which the practice of adult euthanasia had become socially and medically accepted (Thomasma 1998, 7-16). Even before the 2002 legalization, tentative guidelines for adult euthanasia that physicians could follow in order to avoid prosecution were already in place. However, the previous guidelines and requirements, as well as the ones that were passed into law in 2002, do not consider newborn euthanasia to be, by definition, proper euthanasia. The Dutch definition of the term euthanasia will be discussed in greater detail at the beginning of the next chapter.

The purpose of this thesis is to establish when it is ethically permissible for physicians to consider offering to parents active non-voluntary newborn euthanasia as a medical option in

cases of severely ill and impaired newborns.¹ More specifically, I aim to consider what should be included in guidelines that are created for the express purpose of helping doctors to determine when newborn euthanasia is an ethically permissible option. The reason for the defense of newborn euthanasia of seriously ill and impaired newborns as an ethically permissible act and for the creation of these guidelines stems from the argument that never-competent and incompetent patients have as much of a right to control their medical treatment as fully competent patients do (Meisel 1993). Furthermore, it is based upon the assumption that euthanasia is an ethically permissible medical option that should be available (and is available in some countries) to fully competent individuals who voluntarily seek to use it as a method of relieving their incurable pain and, more importantly, as a method of forgoing a continued subjectively unacceptable quality of life (QOL). From this it follows that never-competent patients (in this case seriously ill and impaired newborns) have as much of a right to forgo such a subjectively low QOL as competent patients do. However, in the case of seriously ill newborns, that subjective assessment is clearly not provided by the newborn, but is instead provided by the parents of that newborn.

¹ The decision making discussed in this thesis is limited to the “neonatal period” of a newborn’s life, which is commonly understood to be the first twenty eight days following birth. However, this does not mean that decisions dependent upon the current and future quality of life of a newborn are limited to this neonatal period. The majority of the arguments that follow could be applied to cases where the child has continued to age but still faces a severely limited quality of life. In fact, many of the factors that must be considered during this decision making process rely on determining the effects that illness or disability will have on the newborn well beyond the twenty eight day period. In cases where the newborn has continued to develop, different ethical issues may arise in the decision making process that are raised at the end of this thesis. By limiting my scope to the neonatal period it is my aim to examine the first (and probably shortest) chronological period when non-voluntary euthanasia becomes a viable medical option for severely ill and disabled patients.

Furthermore, just as fully competent patients do not have unfettered access to physician-provided euthanasia, there must be some objective set of limitations that prevents parents from euthanizing their newborns at will. That set of limitations are the guidelines that thesis develops, which are based upon a more objective perspective of the term quality of life and its application to euthanasia of seriously ill and impaired newborns.

It should be clear from the discussion above that the decision for doctors to provide newborn euthanasia as an option and the decision to actually euthanize a newborn are two distinct decision making processes. Despite reflecting many of the same considerations, each has its own unique factors and different decisional agents. This is discussed in greater detail in the fourth chapter. I will argue that the decision to provide newborn euthanasia as a medical option must be preceded by an analysis of the newborn's current and future QOL with respect to a list of attributes and capacities that make for a minimally decent QOL. This list is not intended to have a necessarily prescriptive effect on the parents or legal guardians who must ultimately choose whether to actually euthanize, as these decision makers may have countervailing reasons not to end the newborn's life. Instead, this list is meant to help doctors determine when it is ethically permissible to offer euthanasia as an option and subsequently when it would be permissible for the surrogate decision maker to choose euthanasia as a treatment option to be carried out by the physicians. My reason for arguing for the *permissibility* of newborn euthanasia under specific circumstances, as opposed to a moral obligation to pursue euthanasia, is to maintain the important distinction between the decision making processes of physicians deciding to provide newborn euthanasia as a medical option and parents or guardians deciding to actually euthanize. If doctors frame their recommendation for newborn euthanasia as a morally obligatory act, they ignore outright any countervailing reasons that parents or guardians may have against

the procedure. Such a prescriptive recommendation would be an infringement on the right that parents have as the final decision makers in the process to decide whether their newborn should be euthanized. Instead, doctors serve their primary role by using their medical expertise in evaluating the conditions material to a decision to offer newborn euthanasia as a medical option. After this decision to offer euthanasia is made, it is best for them to take up a supportive role of the parents who are left with the final decision to actually euthanize.

By creating a list of attributes and capacities required for a minimally decent QOL, I already assume that it makes sense to speak about QOL in terms of attributes and capacities. There are those who argue that QOL can be measured without reference to such individual traits (Koch 2004). Furthermore, there are those who argue that despite my assumed perspective on QOL, it is impossible to accurately judge the QOL of another individual (Albrecht et al. 1999). Many of these arguments raise valid concerns, which should not be ignored in the creation of guidelines for physicians regarding newborn euthanasia. For example, there are often wide discrepancies between QOL assessments of the lives of disabled adults made by non-disabled health care workers and those made by the disabled individuals themselves (Albrecht and Devlieger 1999). In many cases those individuals who do not have a disability believe that the QOL of those with a disability is quite low, when in fact the individuals with the disability believe that their QOL is sufficiently high. These conflicting opinions regarding a disabled individual's QOL highlight the subjective nature of QOL assessments. Since the guidelines for physicians regarding newborn euthanasia must necessarily rely on QOL assessments, they must take into consideration the subjective nature of QOL. This thesis will address concerns regarding QOL in general as well as various approaches to it from theoretical and practical perspectives.

I will not address the question of whether euthanasia in general is an ethically permissible act. I will assume that under specific circumstances it can be. However, this thesis will consider the ethical permissibility of newborn euthanasia by considering when it is ethically permissible for physicians to provide euthanasia as medical option. I will spend the beginning of the next chapter looking at some terminological definitions of euthanasia and the distinctions between voluntary euthanasia and non-voluntary euthanasia, as only the latter can apply to newborns. I will argue that the inability of newborns to determine their own medical care is the main reason why QOL issues are fundamental in any discussion of newborn euthanasia.

2.0 BACKGROUND

Much of the debate regarding euthanasia involves the varying definitions of the term. In The Netherlands, the strict definition of euthanasia involves the “termination of life by a medical practitioner at the request of the patient” (Dutch Ministry of Health 2007). Thus by The Netherlands’s definition, involuntary and non-voluntary euthanasia are not, by definition, euthanasia; any act of medical killing that does not involve the explicit request of the patient is not technically considered to be euthanasia. Furthermore, it is important to note that the motivation of the medical practitioner is not mentioned (e.g. acting out of mercy or compassion). This definition can therefore be seen as emphasizing the patient’s active participation in the decision making process, which puts weight on the role of the patient’s autonomy and provides the patient the ability to control the circumstances of her own death.² In contrast to the Dutch

² While this is the strict definition of euthanasia in The Netherlands, the criteria for assessing whether the doctor has exercised due care toward a patient seeking euthanasia state that the patient must be experiencing “unbearable suffering” without any prospects of improvement (Dutch Ministry of Health 2008). Furthermore, the doctor and patient must come to the conclusion that there is “no other reasonable option” beyond the choice of euthanasia. These two requirements imply that if a physician were to act on a *non-terminal* patient’s request for euthanasia, there may be a legal basis for prosecution to occur. Since a non-terminal patient has the option of choosing terminal sedation, it is unclear that euthanasia is the only reasonable choice. However, the distinction between terminal sedation and active euthanasia is a contested issue that relies upon the questionable doctrine of

definition of euthanasia, the American Medical Association defines euthanasia as “the administration of a lethal agent by another person to a patient for the purpose of relieving the patient’s intolerable and incurable suffering” (AMA Code of Medical Ethics 1994, 93). First, it is important to note that the AMA does not consider any act of euthanasia, thus defined, to be ethically permissible.³ However, its definition does provide a nice contrast with the Dutch definition. Unlike the Dutch definition, the AMA’s definition includes the administrator’s motivations, implying that the driving motivation of euthanasia is not a respect for patient autonomy but is instead an act of mercy killing. Moreover, unlike the Dutch definition, the AMA’s definition does not discriminate between situations of medical killing where a patient has made an autonomous request and situations where he has not.

This thesis is interested in *active non-voluntary* newborn euthanasia. The distinction between active and passive euthanasia is at the very least complicated and perhaps ethically irrelevant. However, the intuitive difference between the two rests on the perceived difference between killing and letting die.⁴ Acts of active euthanasia such as the administration of a lethal drug are understood as acts of killing. Acts of passive euthanasia such as the withdrawal of life-sustaining treatment are understood as acts of letting die. In both situations the goal is the relief

double effect as well as the ethically problematic distinction between killing and letting die (Rachels 1986; Perret 1996).

³ The AMA cites three reasons why euthanasia is not permissible: (1) it is fundamentally incompatible with the physician’s role as a healer, (2) it would be difficult to control, and (3) it would pose serious societal risks.

⁴ For a more detailed treatment of the distinction between killing and letting die see Rachels 1986 and Perret 1996.

of suffering with the death of the patient accepted as a means to relieve suffering or discontinue or avoid a poor quality of life.

The goals motivating active non-voluntary euthanasia are fundamental to this thesis and will be made explicit later on. However, they can be briefly summarized as relief of the newborn's extreme degrees of pain as well as the forgoing of poor quality of life in the newborn's present and future states.

Involuntary euthanasia is the medical killing of an individual *despite* his wishes to the contrary. These wishes could be explicitly expressed by the patient himself, or inferred from the patient's other values and beliefs. Involuntary euthanasia is nearly always considered to be ethically impermissible. It goes directly against the goals of voluntary euthanasia, which is a respect for and consideration of a patient's desires to control the circumstances of his own death. Involuntary euthanasia has been nearly universally condemned as an ethically and legally impermissible act.

Voluntary euthanasia, which is the only type of euthanasia that Dutch law recognizes, requires the explicit request of the patient, and is the strongest candidate in the euthanasia debate for ethical permissibility. However, in order for there to be proper patient consent, the patient must first be autonomous, which includes having the ability to make informed medical decisions.⁵ Newborns obviously lack this autonomy. It is clearly impossible for newborns to express their desires regarding euthanasia. Therefore, if euthanasia were to be considered for them it would be non-voluntary euthanasia, which applies when the patient is incompetent and

⁵ This need not be contemporaneous autonomy. The development and recognition of advance directives allows wishes expressed in a previous state of autonomy to control medical treatment during the present state of an incompetent patient.

unable to express wishes regarding euthanasia (Brock 1993, 205). In non-voluntary euthanasia, patient autonomy is replaced by a more appropriate decision making standard meant to aid surrogate decision makers in the decision making process. One of these decision making standards, the best interest principle, will be discussed in greater detail to show how it applies to the decision making processes regarding newborn euthanasia.

The lack of patient autonomy in newborn euthanasia is what makes it different from adult euthanasia. However, this does not mean that the two do not share similar motivating factors in terms of the decision making process. As Stephen Hanson puts it, the requirement of an autonomous request on the part of the patient in the case of adult euthanasia serves two primary roles: the first is to minimize external coercive influences on the patient, and the second is to inform the physician about the patient's beliefs regarding his/her best interest (Hanson 2009). Because they are not themselves autonomous, newborns cannot be coerced, but their guardian or decision maker can be (Faden and Beauchamp 1986, 235-297). Undue amounts of external influence or direct coercion "can render even intentional and well-informed behavior nonautonomous" (Beauchamp and Childress 2009, 133). This possibility raises many issues about the decision making process involved in newborn euthanasia, specifically issues such as who should be making the decisions and what the decision maker should consider when deciding.

In the United States, parental consent and authority over the treatment decisions of children has become an established norm of newborn and pediatric care. This practice is based, in part, upon the broader concept of informed consent regarding all treatment decisions where such consent is practically attainable (i.e., not emergency situations where there is no time to

obtain it). This includes surrogate decision making, or decision making for others.⁶ However, since I aim to explain when it is ethically permissible for physicians to provide euthanasia as a medical option, I must attempt to do so in a way that upholds the practice of informed consent and allows parents or guardians to make the final value-laden decision of whether to euthanize the newborn. Therefore, in order to ethically provide euthanasia as a medical option, doctors must have some criteria by which to evaluate cases consistently and fairly. This criteria-based evaluation may enable physicians to minimize the influence of their own individual perspectives and values so that they may approach potential cases with a minimum of personal bias. It may also reveal socially-ingrained biases that influence medical perspectives beyond practitioners' individual values and perspectives. The criteria-based evaluation process that I develop and advocate employs a list of components necessary for a minimally decent QOL, which starts with the best interest principle and the second of Hanson's roles for respect for autonomy; namely, a communicative role whereby the physician becomes informed of the patient's (or here, the parents') preferences (Hanson 2009).

Hanson believes that when doctors agree to actively kill a patient as a result of an autonomous request from that patient, they are partially acting out of respect for what the patient believes is in his own best interest. This is because according to Hanson, patients have a unique

⁶ Parents' rights to raise their children have been acknowledged by the United States Supreme Court as a constitutionally protected right, the limitation of which can only occur after a balancing of such limitation against state interests. See *Troxel v. Granville*, 530 U.S. 57 (2000) (holding a Washington visitation law allowing third parties to petition for visitation was unconstitutional because it violated parents' rights to control the upbringing of their child); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (holding that compulsory education of Amish children past the 8th grade was a violation of parents' right to freedom of religion and their right to control the upbringing of their children).

insight into what is in their own best interest. In cases of newborn euthanasia, it is impossible to receive an autonomous request from the newborn that would represent what the newborn believes is in his/her best interest. Instead, it is up to the parents to decide what would be in the best interest of the newborn. The term “best interest” has both legal and ethical interpretations.

Commenting on the ethical interpretation, Allen Buchanan and Dan Brock explain the best interest principle as a decision making standard that is concerned with determining how a patient’s various interests affect the overall net “good” to that patient (Buchanan and Brock 1998, 123). They claim that some interests have a greater effect on this overall good than others, requiring the decision maker to weigh the relative importance of the patient’s various interests by “subtracting the costs from the benefits for each option” (Buchanan and Brock 1998, 94). An important question then becomes what *are* the relevant interests, i.e., what are the factors that parents of seriously ill newborns should be considering.

Ronald Dworkin separates interests into two main groups: experiential and critical (Dworkin 1994, 224). Experiential interests are interests we have in maximizing pleasure and minimizing pain. Parents may see it in their child’s best interest to relieve uncontrollable pain or constant physical discomfort caused by the newborn’s illness or disability. Critical interests are the values that we hold and what we consider to be important to us. An adult patient may have a critical interest in living long enough to see his daughter get married, despite the potential pain or discomfort that would be involved. In the case of newborns, critical interests must be characterized differently, as newborns have not yet developed any values. The main critical interest of newborns is in their future quality of life, a quality that may be seriously affected by

their illness or disability. Buchanan and Brock nicely associate QOL with the best interest principle:⁷

The best interest principle is clearly patient centered because it focuses primarily upon the current and future interests of the incompetent individual. As such, it must take into account quality-of-life judgments...Whether a particular life-sustaining treatment is in a patient's interest depends upon whether life under the conditions that would exist if the care in question were provided would be worth living for the patient. Quality-of-life judgments are unavoidable because whether life would be worth living for the patient depends not only upon the length of time that life would be extended but also upon the character of the life for the patient during that period (Buchanan and Brock 1998, 123).

From an ethical perspective, the application of the best interest principle to seriously ill newborns implies the use of QOL judgments.

The legal perspective has a unique relationship with the best interest principle. The case of *Superintendent of Belchertown State School v. Saikewicz* is a primary example of the use of the best interest principle in situations where a patient is currently incompetent to make his own medical decisions and has never been competent to do so in the past (like newborns) (373 Mass. 728, (1977)). The court spends time considering *how* to properly determine a never-competent patient's best interests (*Saikewicz* 1977, 750-51). The first option is to use a "reasonable person

⁷ Here Buchanan and Brock use QOL in the context of withdrawing/withholding life-sustaining treatment (WLST). I consider WLST and euthanasia to have relevantly similar consequences and considerations to justify the use of commentary on the procedures of one in the context of the other. Others have done a better job at arguing for the similarities between the two (Rachels 1986; Perret 1996)

standard,” which is understood to be an interpretation of what the best interest of the patient would be based upon what a majority of reasonable individuals would choose in this case. The court views this option as insufficient because it believes that the primary test in this case should be a substituted judgment standard. A substituted judgment standard is a more subjective test meant to determine what the patient would chose to do if she were competent. However, in the case of *Saikewicz*, the individual had never been competent; therefore, due to the individual’s profoundly mentally incompetent and non-communicative status, the court was forced to admit that it would be “necessary to rely to a greater degree on objective criteria, such as the supposed inability of profoundly retarded persons to conceptualize or fear death” (*Saikewicz* 1977, 750). Nevertheless, the court concluded that the substituted judgment standard was the proper standard to use because it wanted to ensure that the personal decisions concerning the conduct of individual affairs remain, to the greatest extent possible, with the individuals (*Saikewicz* 1977, 750; *Custody of a Minor*, 385 Mass. 697, 710 (1982)). However, when the Supreme Court revisited the *Saikewicz* substituted judgment standard in the context of a do-not-resuscitate order for a four month old child, it admitted that “in cases involving a child who is incompetent by reason of his tender years, we think that the substituted judgment doctrine is consistent with the best interests of the child test” (*Custody of a Minor* 1982, 710). The court went on to say that when applying the two standards to a newborn the two standards required examination of the same set of criteria and relied upon the same sets of reasoning (*Custody of a Minor* 1982, 710). The court therefore admits that application of the objective best interests standard is proper in the context of newborns.

There is certainly some debate in the legal community regarding the use of QOL judgments. The most famous example was *In re Baby Boy Doe* in 1982. Baby Doe was born with

Down's syndrome and a complication of tracheoesophageal fistula. The fistula required an operation to allow the baby to properly feed. However, the two consulting physicians differed as to the appropriate course of action regarding the treatment of the child. One believed that even if the surgery were successful, the child would have a sufficiently poor QOL to warrant initially pursuing only comfort care measures instead of the surgery. The other physician believed that Baby Doe should have the surgery despite the mental retardation associated with the Down's syndrome. The parents were presented with both options and chose to forgo surgical treatment. The Indiana Supreme Court upheld their decision (Scott 2009, 803). The decision was appealed by the hospital and was on its way to the U.S. Supreme Court when Baby Doe died and the case was rendered moot. However, as a result of the case, the Secretary of Health and Human Services issued regulations to prevent hospitals from not providing care to seriously ill newborns. These regulations culminated in the 1984 Child Abuse Amendments which stated that medical neglect includes "the withholding of medically indicated treatment from a disabled infant with a life threatening condition" (42 U.S.C.A. § 5102). Nevertheless, the amendment allowed for the withdrawal/withholding of treatment in cases where the newborn is "chronically and irreversibly comatose" or where treatment would be "virtually futile" and "inhumane."

Despite the regulations of the Child Abuse Amendments and wariness with regard to QOL judgments in the decision making process regarding seriously ill newborns, there is a legal consensus that the rights of competent patients should be afforded to incompetent patients as well (Meisel 1993). This means that with regard to medical decision making, never-competent patients like Joseph Saikewicz or any newborn have the same rights as competent patients. However, never-competent individuals must have surrogate decision makers. When making decisions for incompetent patients, Meisel claims we should use three standards, listed here in

descending order of preference: the subjective standard, the substituted judgment standard, and the best interest standard. The subjective standard simply involves respecting any sort of explicit wishes or directives previously expressed by the incompetent patient. Since newborns cannot make such expressions, we cannot apply this standard to them.⁸ The substituted judgment standard involves attempting to ascertain what the patient would have wanted in light of her values, interests, desires and beliefs. For newborns, this standard is inapplicable for the same reasons as the subjective standard.

Therefore, in the decision making processes regarding newborns, the only remaining option is to use the best interest standard. As mentioned in the previous discussion regarding the ethical nature of the best interest principle, QOL judgments are a fundamental factor in the decision making process regarding newborns. This fact is supported by the AMA's stance on the role of QOL in the decision making regarding seriously ill newborns, which says:

Care must be taken to evaluate the newborn's expected quality of life from the child's perspective. Life-sustaining treatment may be withheld or withdrawn from a newborn when the pain and suffering expected to be endured by the child will overwhelm any potential for joy during his or her life. When an infant suffers extreme neurological damage, and is consequently not capable of

⁸ It should be noted that there are degrees of incompetency, even in cases of never-competent patients. While a patient may never be able to make a medical decision for themselves, they may nevertheless be able to express their opinion regarding the nature of a treatment. For example, while a mentally handicapped individual may always require a surrogate decision maker, he could potentially provide verbal responses to simple questions such as "does this hurt" or "how do you feel". However, newborns represent an extreme point on a spectrum of incompetence since physicians and decision makers can only glean like or dislike of a set of conditions from purely physical feedback, which provide a limited amount of information to inform the decision making process.

experiencing either suffering or joy, a decision may be made to withhold or withdraw life-sustaining treatment” 2.215 Treatment Decisions for Seriously Ill Newborns (AMA Report 1994).

Due to the fact that newborn euthanasia cannot involve or rely on an autonomous request by the patient, if never competent newborns are to be accorded the same rights and protection from intolerable suffering as competent adults, a surrogate decision maker would have to be allowed to make the request for euthanasia on their behalf.⁹ The newborn’s parents would be the appropriate surrogate decision makers for their child. They make this decision based upon their belief of what would be in the (current and long-term) best interest of the child¹⁰, which requires them to make QOL judgments about both the current and future state of the child. However, the best interest principle is meant to be used as a guiding decision making standard by both physicians and parents. In order for the parents to make an informed decision whether to euthanize their child, they must be given appropriate information by their physicians. Since the parents are basing much of their decision upon assessments, expectations and predictions of QOL, physicians are therefore required to provide QOL information to the parents.

Throughout the thesis I limit the decision making period of newborn euthanasia to the twenty eight day “newborn” period of the child’s life. This is admittedly an arbitrary limit that

⁹ This statement does not assume that adults have the right to euthanasia. It does assume two other propositions. The first is that there is a right for competent patients to control their medical treatment including situations of extreme pain. This right was recognized by the United States Supreme Court (*Cruzan v. Director, Missouri Dept. Of Health*, 497 U.S. 261 (1990)). The second is that euthanasia is one avenue of control that is theoretically (though not currently legally) open to competent patients.

¹⁰ I use “child” here instead of newborn simply because I am considering the newborn’s long-term interests that extend beyond my stated scope of the neonatal period.

has associated with it the advantages and disadvantages of any arbitrary deadline. Without such a deadline, social policy concerns arise regarding the potential abuse of the opportunity to perform non-voluntary euthanasia based on QOL assessments throughout the lifespan. Furthermore, the greater amount of time that a child is given to become part of a broader social network the greater the risk that the decision making of the parents can be improperly influenced by emotional and other benefits that those around the child gain from the child's continued life, despite the fact that the child does not receive any benefit in return and is forced to continue to live below a minimally decent QOL.¹¹ However, when the deadline is too short, there is the serious concern that parents will be rushed to make a decision without being given the due time to properly digest and scrutinize the information being provided to them. The emotional and psychological pressure that parents face after the birth of seriously ill and impaired newborns is likely to pose a serious restriction on the parents' abilities to make decisions in a rational manner. Therefore a deadline that does not provide for sufficient time to make an informed and reasoned decision is also problematic. In short, a balance must be struck between these two sets of concerns that provides ample time for parents to make a properly informed decision but does not allow for the potential negative consequences that can arise when parents are given too much time. Establishing this balance requires an analysis of the circumstances surrounding such decision making that is beyond the scope of this thesis. Instead, I adopt the twenty eight day

¹¹ I should note that this risk does not imply that parents should not consider the effect the child's continued life has on the members of a family or a broader social network. In fact in the fourth chapter I mention that such considerations *should* be taken into account when deciding whether to euthanize. This includes both positive and negative consequences. However, what should be avoided is giving the factors more weight than the best interests of the newborns.

period because it is a recognized arbitrary point within a child's life that *arguably* provides enough time to parents make a rational decision while avoiding the concerns that arise from providing too much time.

The purpose of this background chapter was to establish the necessity of QOL information in the overall decision making processes regarding newborn euthanasia. The next chapter will look at QOL judgments from a physician's perspective, specifically in relation to the decision to provide newborn euthanasia as an option. I will argue that in order to maintain a more informative position that does not rely upon their personal value sets, physicians must provide their assessment of the future QOL of the newborn in relation to a set of components required for a minimally decent QOL. By referring to this set while still maintaining a non-prescriptive stance regarding the parents' ultimate decision to authorize euthanasia, physicians can adhere more closely to the preferred informed consent model of medical decision making mentioned earlier.

3.0 QUALITY OF LIFE

It can be said with little controversy that a primary goal of medicine is the preservation of life. However, as evidenced by the consensus regarding the permissibility of withdrawing or withholding of life-sustaining treatment for competent and incompetent patients, medicine is not committed to an unqualified preservation of life. Instead, it is fair to say that, as a result of concern about future QOL by patients and families, medicine promotes the best QOL possible or, in turn, provides the opportunity of forgoing treatment that would otherwise promote unsatisfactory QOL. This section will try to give a broader understanding of the concept of QOL, which will then allow us to have a better sense of how QOL can be used in cases of severely ill-newborns.

Since we are interested in what exactly QOL involves, it may be appropriate to first consider the difference between life in a biological sense and the quality or experience of life. The former of the two pertains to the physical components of the body, their function and relationship of these components and functions to one another and to the outside world. In medicine, these components of life are often the primary focus of acute care (Veatch 1995, 484-493). Doctors attempt to stimulate muscles, mend bones, and cure infections. However, patients must see the treatment and outcomes associated with such acute care through the greater context of their lives. This involves considering the social, financial, psychological, emotional and

physical aspects of a person's life. All of these factors have an additive effect on the subjective experience of the patient's life, i.e., the patient's own experience of her life. This subjective experience of life is often expressed in such commonplace sayings as "things are going fine" or "life couldn't be better". It is important to note that these individualized statements represent a personal, or subjective, experience of life. This should be contrasted with an objective or at least intersubjective approach towards QOL that this thesis is interested in. An objective QOL may not necessarily match the subjective experience of a person's life; nor does their discord preclude the possibility of making ethical decisions regarding medical treatment. However, often times these personal statements of one's experience are understood to be one-and-the-same as a person's QOL since objective or intersubjective analysis of another person's QOL is not necessarily what we are asking when we say "how are you." Regardless of the conceptual differences between objective QOL and a person's subjective experience, statements like "fine", "best", or "miserable" are so common that they force us to ask what exactly is included in the concept of QOL that leads us to believe these statements to be sufficient answers to our inquiries of others. I have already mentioned the social, financial, mental, and physical factors that may be included, but this does not provide us with a good sense of what QOL is.

In order to determine what is included in such experiences of life, it would be useful to consider what a high QOL of may include. After analyzing the components of a high QOL, we can begin to understand the underlying abilities and capacities on which they stand and eventually work down to the most basic components of a minimally decent QOL. Dan Brock states that a high QOL includes at least four components: (1) the capacity for self-determination, (2) the opportunity for choice amongst life plans, (3) personal well-being and (4) the subjective experience that things are going well (Brock 1997, 95).

According to Brock, people have a general interest in having the capacity for self-determination, which he broadly considers to be the capacity to form, revise, and pursue in their actions their own concept of a good life (Brock 1997, 107). Here Brock emphasizes that self-determination is understood in terms of guiding actions towards a specific end; “a good life” or a high QOL. A person’s ability to act in a self-determined manner can be limited in two major ways. The first is through external societal factors that have no bearing on a person’s capacity for self-determined action but nevertheless impede or preclude any attempts to do so. The slave examples that are discussed later in this chapter are an example of this sort of limitation and examine the effects that it can have on a person’s QOL. The second way a person could be prevented from acting in a self-determined manner is if he lacked the capacity to do so. A person whose capacity for self-determination is limited to a certain range of decisions, or is completely non-existent, is less well-off than a person whose capacity is fully intact. This lack of capacity can (but does not necessarily) have a negative effect on the overall QOL of the individual. The reasons why this negative effect does not necessarily follow from a limited or non-existent capacity for self-determination are mentioned below in the discussion regarding the interplay of Brock’s four components. However, the point remains that people have a general interest in having the capacity for self-determination and a lack of such capacity can have a negative effect on their overall QOL. Therefore, it is worth examining the capacity for self-determination more closely in order to identify possible components of a minimally decent QOL.

The capacity for self-determination is composed of two necessary elements: first a set of some capacities to reason, deliberate, make decisions, or otherwise will or act toward an end and second, a guiding set of values and/or conception of the good that informs this reasoning and willing. The capacities for rational thought and communication are some of the cognitive

faculties that are used in decision making processes. Values or a conception of the good serve a role similar to the weights on a scale; they determine the benefits or harms, goods or evils, of particular options (Buchanan and Brock 1998, 25). Both of these elements are made up of some even more fundamental abilities. For example, both the cognitive capacities and the set of values of an individual depend upon a person's ability to be self-aware and conscious of his own experiences over time. Awareness of our experiences provides us with a greater understanding of cause and effect, which helps us develop our capacities for rational reasoning and understanding. Furthermore, one of the main ways that we develop our own values and conceptions of the good is by being aware of the values around us, including the values of those people close to us as well as the values of the society we live in, and comparing them to the ones we already hold. Therefore, the capacity to be aware of one's self and of one's surroundings appears to be a foundational capacity that is part of a certain threshold level of QOL that I have labeled as a minimally decent QOL. Elaborating on this level of QOL and applying it to practical medical decision making is the primary goal of this thesis.¹²

¹² By starting from the capacities that are part of a high QOL and working down to the capacities needed for lower and lower levels, I open the door for the possible counter-argument that every capacity can be broken down into even smaller more "fundamental" elements; much like matter can be broken down into atoms and then again into sub-atomic particles and so on. However, I believe that such an argument misses the point. I am trying to establish a threshold level of a minimally decent QOL and the capacities that make up that level. My goal is much different from what is assumed to be the goal in the counter-argument; namely establishing the most fundamental capacities of human life. It may be true that the components of a minimally decent QOL can be broken down even further, but that does not change the fact that they are the components of that level without which the QOL of the individual can be said to be sufficiently poor to justify an act of euthanasia.

Brock's second component of a high QOL refers to the broader social structure of the individual's environment. Not only is it important for a person to have the capacity for self-determination, but it is also preferable for him to live in a society that provides various opportunities and choices. If an individual were born into society as a slave but was nevertheless well taken care of, it may be reasonable to say that his QOL suffers due to the fact that he cannot fully make effective his capacity for self-determination. The slave may very well have the requisite abilities needed for the capacity of self-determination, but his slavery would prevent him from freely performing actions based on his own values or conception of the good. This severe constriction of opportunity and freedom at least would cap, if not lower, his overall QOL. As evidenced by the slave example, there is an interesting relationship between the first and second of Brock's components of a high QOL. As I have explained it, self-determination is a capacity that is composed of certain fundamental abilities. However, its impact on the overall QOL of an individual is in part dependent upon the opportunities that the individual has. Ideally, we would prefer a society in which people are free to choose and pursue their own life plans, thereby maximizing the importance of self-determination in relation to QOL. I do not mean to imply that self-determination's value is wholly dependent on the opportunities provided to an individual by their society. Instead I believe it to have a certain base or intrinsic value that is independent of the external circumstances of the individual. However, it seems plausible to say that self-determination is at least *more* valuable to a person whose society provides him with opportunities than it is to someone whose options are severely limited.

There is another way that we can setup the slave example in order to highlight other important points about the relationships between Brock's four components, as well as the notion of subjective and objective values/interpretations of QOL. Imagine that the slave, despite his lack

of opportunities, has a subjective feeling that his life is going well (the fourth item of Brock's list). Can we still reasonably say that *despite* his subjective interpretation of how things are going, his overall QOL suffers because of his lack of opportunity? What if the slave were suddenly freed and forced to make a living for himself that resulted in him living in conditions far inferior to the ones he experienced as a slave? His subjective interpretation of his QOL could then cause him to bemoan the fact that he had been freed, since his life was much more comfortable as a slave. This example shows that the importance of each of Brock's components to the QOL of an individual may not be the same for all persons. In fact, one of the main advantages of these four components is the fact that they are composed of items the values of which can be objectively and/or subjectively determined. I will return to this distinction as well as its implications on our understanding of QOL shortly, but briefly we can say that it is objectively preferable for a person to live in a society that affords a reasonable assortment of opportunities to its citizens. However, this does not mean that a person whose society does not afford such freedoms is guaranteed a poor QOL. Instead, he may have a subjectively high interpretation of his QOL despite his lack of opportunity. Similarly, the presence of a disability that limits one's range of opportunities also does not guarantee a poor QOL.

The third component of QOL that Brock cites is personal well-being, which can be understood roughly as what is good for a person. A person's well-being encompasses his physical state (e.g., health, safety), as well as other aspects of his condition, including social, psychological, emotional, environmental and economic or material factors. Well-being has been considered both as objectively ascribable to (or true of) a person and as a subjective experience. Moreover, when considered as a subjective state, well-being may depend not only on the subject's perceptions, but also on his values. Thus when ascribing some degree of well-being, or

an increase or decrease in well-being, to a person it may be important to know something of his values. Even an increase in pain, which seems a classic instance of a reduction in well-being that can be objectively ascribed to the person experiencing the pain, may nevertheless be perceived as an increase in well-being by a masochist. Receiving a gift of a million dollars may not increase the well-being of someone who values above all else working for and meriting every advantage he receives. Even if the previously destitute person can now avoid starvation and thus is, objectively better off than before, he may not consider the gift to increase his well-being. The interplay of these objective and subjective understandings of well-being can be seen in three classic conceptions of well-being: the hedonist, the preference satisfaction view, and the ideal theory approach.

The hedonist approach is focused on our experiential interests, i.e., the maximization of pleasure and the minimization of pain. Hedonists consider conscious experience to be the measure of a good life. The relevant experiences are sometimes summarized as happiness, pleasure, or satisfaction. For example, the hedonist approach values the sensational pleasure derived from eating delicious foods. When considering the value of more abstract actions such as doing philosophy, the hedonist conception focuses on the satisfaction that is experienced as a result of the act, as opposed to the value of the act itself. Furthermore, the overall satisfaction that we can derive by maximizing pleasures and minimizing pains causes hedonists to experience happiness. These experiences can also have weight relative to one another. The short term experience of pain derived from the dentist's office can be outweighed by the long term satisfaction of having healthy teeth. In one sense, then, the hedonist approach is thoroughly subjective; it is the experiencing person's perception of pleasure or pain that determines whether his well-being is enhanced or decreased. In order to ascribe increased or decreased well-being to

a person on the hedonist view, one would have to assess or make assumptions about whether the person is experiencing an increase or decrease of pleasure. In considering the well-being of newborns, the hedonist approach is primarily concerned with the types of pleasurable/painful experiences that the newborn's current and future states afford.

The second conception of well-being is the preference satisfaction view. Brock distinguishes the preference approach from the hedonist approach by stating that the preference approach is focused on the desire to have certain states of affairs obtain, rather than on the feeling that one experiences once they obtain (Brock 1997, 96). The difference between the hedonist and preference satisfaction approaches can best be revealed in cases where a state of affairs obtains without the specific knowledge or experience of the one who prefers/desires it to obtain. For example, a writer's desire to have his work influence other writers may not be satisfied until well after his death. Nevertheless, on a preference satisfaction view, we can say that it is "in his interest" for his literature to have such a posthumous influence, even though he derives no actual pleasure or satisfaction from its doing so. On a hedonist account we could make no such claim; if he is not alive to enjoy the pleasure of influencing others, his well-being is not increased thereby.

Furthermore, most preference theories have to account for the possibility of preferences and desires changing throughout the course of a person's life. A person's initial preferences may be based on false reasoning or information, which could potentially *harm* the QOL of the person if they obtained (Buchanan and Brock 1998, 32). Or a person's values and preferences/desires based on them could simply be revised during the course of his life. In the case of newborns, it makes little sense to apply a preference/desire approach when assessing their immediate QOL. This is because newborns do not have the capacities necessary to form preferences or desires.

Any preferences or desires that they do have can be understood through the hedonist approach, i.e., an assumption that they prefer to avoid pain and maximize pleasure. However, when considering the future QOL, and thus well-being, of a newborn, it is important to consider whether he will develop the capacity to have preferences and desires (beyond pain avoidance and pleasure seeking) and perhaps what the nature of those preferences/desires are likely to be. The practical and ethical challenges of predicting the development of those capacities and/or the preferences/desires themselves are discussed later.

The third approach to well-being is called the ideal theory approach. In contrast to the two previous approaches which rely on a person's own valuation of his life, ideal theories take an objective stance regarding the concept of well-being. Here I use Norman Daniels' objective conception of well-being whereby well-being may be assessed and attributed to a person "independent of the individual's own assessment, for example, independent of the strength of his preference" (Daniels 1981). According to an ideal theory approach, the value of a specific component of well-being is independent of an individual's subjective determinations. Even if a particular person does not value the opportunity to choose among different options, an ideal theory of well-being might hold that the presence of some range of options increases well-being. Similarly, even if a person does not enjoy having a high degree of "creature comforts" (e.g., easily controlled environmental conditions, plentiful and diverse food, multiple types of entertainment), an ideal theory of well-being might hold that someone living under such conditions has a higher degree of well-being than another person who cannot easily temper the effects of weather change, who has only minimal nutrition, and who has no time for activities beyond those necessary for subsistence. Moreover, even if the person living at subsistence level is tremendously happy—and thus has a high level of well-being on a hedonist view—an ideal

theory of well-being may find his state sorely lacking in well-being (or deems him to have only minimal well-being).

In the ideal theory approach to well-being we see the interplay of well-being and self-determination. While they can sometimes conflict, as when someone chooses to act in a way that is contrary to his (objectively ascribed) best interests (or well-being), exercise of the capacity for self-determination is typically considered a component of well-being.¹³ There may be varying degrees to which persons choose to *use* this capacity for self-determination that may result in varying degrees of impact that the capacity has on the person's life. Different people may value being self-determining more than others. And people's lives differ in terms of the scope of opportunity afforded for the exercise of the capacity of self-determination. Nevertheless, the value of the capacity in terms of a person's well-being is considered to be independent of the degree to which it is exercised.

The fourth component of a high QOL that Brock identifies, the subjective belief that things are going well, is closely related to the concept of well-being. Indeed, it seems almost identical to the hedonist or preference-satisfaction conceptions of well-being because for them it is the individual's own perception or assessment of his life that matters. This fourth component of QOL specifically incorporates the individual's own perspective, the subjective perspective, on his life. While the other components—the capacity for self-determination, material conditions and opportunities, and an objective determination of well-being—can be assessed somewhat independent of the individual's own values and view of his life, with this fourth component Brock makes clear that the person's own experience of his life matters to its quality.

¹³ Here we also see the relationship between QOL and well-being; remember that self-determination was the first component of QOL that Brock identified.

When a hedonist considers his own well-being he assesses the amount of pleasure and pain that his life provides. When the pleasures clearly (in his subjective estimation) outweigh the pains, he may experience the added bonus pleasure of experiencing happiness. As a result, the hedonist may have the subjective belief that his life is going well. The hedonist approach provides the simplest and most direct example of the relationship between Brock's third and fourth components, although the same analysis could be made with reference to a person's estimate of the degree to which his preferences are satisfied. However, the subjective belief that things are going well does not always require the presence of the third component. If we consider the slave example mentioned in the discussion of the second component, we can see that the subjective experience that life is going well depends upon the other three components of QOL as well. More accurately, it depends upon the individual's perception of, and the value he attributes, to the other three components of their QOL. Some individuals would be satisfied with the taken-care-of slave scenario. They do not value opportunity or the freedom to make important choices as much as they value a guarantee of their own personal well-being. As a result, their subjective perception of their situation would be much more positive than that of an individual who resented the confinement of slavery. This example indicates the true power and value of the fourth component of QOL. It recognizes that a component of the quality of one's life is one's experience or subjective assessment of that life, which in turn reflects one's relative valuation of the other three components of QOL. This understanding of the relationship of the components of (a high) QOL makes sense of how a person with ideal physical health may state that he has a poor QOL and a person with severe disabilities to believe that he has a good QOL without running the risk of some contradiction. In short, it represents the inherently subjective portion of QOL.

Brock's four components of a high QOL provide us with a better understanding of the concept of QOL. Moreover, when QOL is broken down into its various components, it is clear that these components are not separate and independent factors. Instead, they have a complex interconnected relationship that is often dependent upon many other more fundamental capacities and abilities. Many of these relationships (and the subsequent QOL of the individual) depend on the value that is ascribed to each component of QOL either by the individual or by the society at large. This attribution of value to the various components of QOL is of primary interest to this thesis. I have stated before that this thesis is concerned with creating and defending the use of a list of components of a minimally decent QOL. In order for such a list to have any sort of clinical value in helping doctors determine whether an act of newborn euthanasia is ethically permissible, it would have to be objectively ascribable as relevant to all newborns. In other words, its components would have to be valuable no matter what the future life plans or values of the newborn may be. Furthermore, because the components of Brock's conception of a high QOL are dependent upon more fundamental abilities and capacities, it is to these abilities and capacities that a list of the minimally decent components of a QOL should pay closest attention. If Brock's list is meant to describe a good or high QOL, then the more fundamental elements that that list relies upon stand as strong candidates for a minimally decent QOL. I now turn to a discussion of such fundamental elements and the components of a minimally decent QOL.

3.1 COMPONENTS OF A MINIMALLY DECENT QUALITY OF LIFE

A focus on human capacities or abilities as a support of some policy or theoretical framework is not an uncommon approach in scholarly literature. Martha Nussbaum uses a list of what she calls

“central human functional capabilities” as a guide for what she believes should be included in the basic constitutional guarantees of any modern society (Nussbaum 2000, 70-86). The goal of constructing the list is to enable choice of social and political institutions that will promote “at least a threshold level of these human capabilities.” While her list is too long to reproduce here, and her use of these human functional capabilities is different from mine, Nussbaum’s list reflects many of the QOL considerations that ground Brock’s four components of (a high) QOL.¹⁴ For example, Nussbaum states that “the central capabilities are not just instrumental to further pursuits: they are held to have value in themselves ...but they are [also] held to have a particularly pervasive and central role in everything else people plan and do” (Nussbaum 2000, 74 - 75). Here Nussbaum is commenting on the individual value of the capabilities. Each item on her list has an objectively ascribable value that is independent of the life plans of each individual. Nussbaum argues that since these capabilities hold such an objectively ascribable value, they represent the types of central human capabilities that should be protected and nurtured by any socio-political structure. However, she also admits that the value of these capabilities is determined by the role that each of the capabilities plays in an individual’s life plan. Nussbaum’s recognition of both objectively ascribable value and a value particular to the life plans of the individual closely resembles the objective and subjective components of Brock’s list. Therefore, there is no surprise that Nussbaum’s list and Brock’s list are referential to each other. For example, Nussbaum includes in her list “bodily health” and “bodily integrity.” Bodily health is defined as simply being in a good state of health, which includes proper nourishment and shelter. Bodily integrity can be summed up as having independence and control over one’s body, i.e.,

¹⁴ This is partially due to the fact that Brock and Nussbaum both draw upon some of the same sources, most notably Amartya Sen’s work in the economics of quality of life (Sen 1980; 1985).

having proper freedom (from interference) with regard to one's body and having proper respect be given to that freedom by other members of society. While these two capabilities encompass a wide scope of various rights and capabilities, they are part of all four of Brock's components of a good QOL. Bodily integrity draws heavily on the notion of self-determination and societal opportunity. In order for a person to have control over her body she must have the capability to act in a self-determined fashion and live in a society that permits the effective use of self-determination. Both bodily health and integrity also make up key components of a proper understanding of a person's well-being. A person's well-being is threatened when she is in poor health or cannot control what occurs to her body. Furthermore, as was discussed in the previous section, the subjective feeling that things are going well is tied closely with all of the other components of QOL. This means that since bodily health and integrity are associated with the first three of Brock's list, they subsequently have a direct effect on the subjective experience of the individual.

Another example of the resemblance between Nussbaum's and Brock's lists is Nussbaum's sixth item, "practical reason." She defines practical reason as "being able to form a conception of the good and to engage in critical reflection about the planning of one's life" (Nussbaum 2000, 79). This definition nearly mimics Brock's broad understanding of QOL. It also exemplifies the emphasis on capabilities and actions since practical reason is expressed as another capacity that we can use to gain control of and improve our QOL. Just as bodily integrity and bodily health involve actions and abilities, so too does practical reason depend upon other cognitive faculties. Some of these faculties can be found in Brock's list of the requisites of decision making (Buchanan and Brock 1998, 23). The abilities to reason and deliberate, as well

as having a concept of the good or a set of preferences of which one is aware, are all “central human functional capabilities” that are a part of the capability of practical reason.

A final point to make about Nussbaum’s list, one that applies to any objective capabilities approach including my own, is that the list was not created with a strict mindset of universal applicability. While the goal is to create as objective a list as possible, there are, without a doubt, degrees of social context and diversity that must be accounted for. For example, as Nussbaum states, it would be difficult to imagine a list of central human functional capabilities without the right of bodily integrity. However, the degrees of importance of other items on her list such as relationships with other species and literacy are “differently constructed by different societies” (Nussbaum 2000, 77). Nussbaum claims that this type of mutability is in fact one of the strengths of such a list. It tolerates a certain level of social pluralism. Nussbaum’s interpretation of her list can best be likened to a “loose-constructionist” interpretation of the U.S. Constitution, which holds that the authors of the Constitution did not mean for their work to be interpreted literally but instead allowed room for adjustment and revision. Indeed since Nussbaum is attempting to have her list apply to the political make-up of societies, the analogy to the Founding Fathers of the U.S. Constitution makes some sense. Regardless of the success of the analogy, my point is to highlight the social flexibility of an objective capability approach. The goal of such a list is to create as encompassing and applicable a list as possible while maintaining and respecting the mutability and revision caused by social diversity.

My main purpose in discussing Nussbaum’s list is to show how a capabilities approach can draw and depend upon the concept of QOL. Most, if not all, of the capabilities on Nussbaum’s list in some way affect and define the QOL of an individual. However, since her use of human capabilities is meant to serve a much broader purpose, Nussbaum’s list cannot readily

be used as an example of the components of a minimally decent QOL. To examine an example that is much closer to my stated goal, I now turn to Earl Shelp's components of minimal independence (Shelp 1986, 49). First, it is important to explain how Shelp uses the term "minimal independence" in the context of newborns. Shelp believes that it is the duty and goal of all parents to raise their children so that the children's lives become "useful to him or her and to others" (Shelp 1986, 49). This duty applies to all parents, except for those cases where it is clear that a threshold level of minimal independence of the newborn cannot be achieved. In these specific cases where a "competent medical opinion is that a particular newborn is physically and/or mentally impaired to the degree that these capabilities are not attainable, even with technological assistance, then parents and society are not obliged to attempt the impossible" (Shelp 1986, 48). While the language here hints at the withdrawal/withholding of life-sustaining treatment, later on Shelp cites the inability of newborns to achieve minimal levels of independence as one of four cases where infanticide or newborn euthanasia is ethically permissible (Shelp 1986, 175).¹⁵

An issue that arises from Shelp's position is that if a commitment to their child's independence is truly a parental duty, the applicability of that duty does not end when the child has developed beyond the stage of a newborn. For example, if a severely impaired twelve year

¹⁵ The other three cases are (2) the foreclosure of the attainment of capacities sufficient for personhood, (3) the survival of the child would impose a burden on the newborn such as to render life a net disvalue, and (4) the survival of a severely impaired child would impose immense and/or incommensurate burdens on others. While this list is clearly relevant in the context of newborn euthanasia and QOL issues (in fact (3) is exactly the type of case that I am considering), it is his definition of minimal independence that most closely resembles my list of the components of a minimally decent QOL, which is why I give it the most attention of the four.

old boy has lived a life of complete dependence due to a lack of almost all autonomous motor and cognitive functions Shelp's argument may still apply as a justification for euthanasia. Of course there may be other counter-veiling considerations that may eliminate this exception, but nevertheless there is nothing in Shelp's argument that precludes the possibility of applying a minimal independence standard to children still under their parents' (or perhaps even the state's or an institution's) care that have gone beyond the newborn stage; perhaps it applies even to individuals who have advanced into what is typically considered to be an "adult" age. This is an issue that I mentioned briefly at the beginning of the thesis and will discuss in more detail later on. It is an issue that applies to Shelp's position in a similar fashion as it does to mine.

As I mentioned earlier, there are legitimate concerns that stem from the establishment of arbitrary age limits on when euthanasia can be provided as a medical option. However, it is also true that when considering the best interest of some older yet still-impaired children, the discontinuation of treatment or even euthanasia may be warranted. Examination of the considerations necessary to address the fixing of any sort of arbitrary deadline regarding such decisions is beyond the scope of this paper. What we *should* hope to foster is a framework of decision making that gives parents sufficient time to make an informed decision regarding the future of their newborn, which includes impressing upon them the consequences of a prolonged and delayed response. Among these consequences is the possibility of the child becoming enmeshed in a web of social relations that does not actually benefit the child but only those around the child. In such a case where the child is not aware of his surroundings or those closest to him, decision makers may be prevented from acting from the best interests of the child and may instead base their decisions on the value the child has to those around him instead of the value of the child's life to himself.

Regardless of its applicability to older children, Shelp's use of the threshold level of minimal independence is still intended to be used in cases of seriously ill newborns. We can now examine in greater detail what exactly he considers independence and minimal independence to entail. First, and in a similar fashion as Nussbaum, Shelp claims that the concept of "independence" (and subsequently minimal independence) is socially constructed term and lacks a universal definition. Instead it is subject to the "historical, cultural, scientific, physical, and economic" conditions of a society as well as the specific circumstances of the family (Shelp 1986, 48). Like Nussbaum, Shelp believes this context dependence and flexibility to be an advantage. It allows each individual family to interpret the estimated future of the newborn in light of broader societal values and personal familial values. With these qualifications in mind, Shelp claims that a child's minimal independence includes "a capability to relate, communicate, ambulate, and perform tasks of basic hygiene, feeding, and dressing" (Shelp 1986, 48). We can immediately recognize the first two capabilities as capacities mentioned by both Brock and Nussbaum in the context of capacities important in the QOL of an individual. Furthermore, the "tasks" that Shelp mentions are all conducive to the well-being of an individual since they pertain to the physical and perhaps mental and social health of an individual.

I consider independence in general (not just the minimal independence defined by Shelp) to be a *part* of a person's overall QOL. This belief is supported by the relationship between self-determination and well-being in Brock's high QOL, as well as the role of independence as an indirectly stated item in Nussbaum's list of socially and politically protected human capabilities. Both Brock's and Nussbaum's work discuss a level of independence higher than Shelp's. For Brock, the relevant independence is the one obtained when a person has the capacity for self-determination and lives in a society that allows a person to act in a self-determined manner. For

Nussbaum, the ability to act freely and have control over one's body is a central concept throughout her list. However, the capacities on both of these lists depend upon more fundamental, or minimal, components of QOL. Since independence is a part of a person's overall QOL, it follows that some components of *minimal* independence may also be components of a *minimally* decent QOL. Therefore an analysis of Shelp's concept of minimal independence would be beneficial for my own concept of components necessary for a decent QOL.

While I believe that Shelp's concept is a fair representation of the use of a capabilities approach in the context of seriously ill newborns and that it offers valuable insight into the components of a minimally decent QOL, it cannot be said that *all* components of his concept are components of a minimally decent QOL. First, Shelp's argument replaces the concept of the QOL of the newborn with the concept of independence as the deciding factor in the decision making process regarding the appropriateness of newborn euthanasia. Despite his caveats and qualifications about the social construction of the notion of independence, his understanding of it places a strong emphasis on the idea that life must not only be worthwhile to oneself, but also not be overly burdensome on the lives of others. He argues that if society forces parents to support any and all seriously ill or impaired children, then it must be willing to provide whatever support those parents need in order to follow through with such a mandate (Shelp 1986, 49). Until society is willing to do this, it cannot require parents to support their seriously ill or impaired newborns. While this argument may be appealing in some respects, Shelp's approach is inherently flawed because in many cases the use of a minimal independence standard does not properly keep the best interests of the newborn in mind. More specifically, the capabilities encompassed by independence reflect only a *part* of the overall QOL of an individual. Having a minimally independent life may be sufficient for a minimally decent QOL, but it is not

necessary. For example, a large majority of children with even the most extreme form of spina bifida (meningomyelocele) whose movements are limited or who are completely paralyzed are nevertheless able to have meaningful relationships as well as communicate with others (Jong 2007; Chervenak 2006). This forces us to ask whether withdrawal or withholding of treatment, or newborn euthanasia, is permissible when the newborn lacks all or just some of the capabilities on Shelp's list. It would be difficult to claim that a child with meningomyelocele who is wheelchair-bound and depends on the aid of others is completely independent. However, is the child *minimally* independent? The answer is not so clear. More importantly, it seems difficult for Shelp to imagine that such a child who is considered by his criteria not to be minimally independent actually enjoys his life, which is the subjective component of QOL. This situation forces us to question the credibility of using minimal independence as a threshold for newborn treatment. Since Shelp's criteria reflect only a part of the concept of QOL, their use would allow for many newborns that would normally be treated without hesitation to be subject to scrutiny as possible candidates for euthanasia or termination of treatment. In short, when the criteria for newborn euthanasia are based on too narrow of an interpretation of the overall concept of QOL, their use may allow many newborns to die who may very well have experienced a minimally decent QOL.¹⁶

The question remains as to *which* of Shelp's criteria stand as possible components of a minimally decent QOL and which rely on a too "narrow" conception of QOL. I believe that a tentative division can be drawn between Shelp's first capabilities (communicate and relate) and the rest of his list (ambulate, basic hygiene, feeding, dressing). While I agree that all of the

¹⁶ This consideration applies just as much to the decision to provide newborn euthanasia as a medical option as it does for the decision to actually euthanize a newborn.

capabilities on Shelp's list may be relevant in an overall assessment of QOL, the first two of Shelp's criteria are more important than the rest because of the underlying capabilities that they rely on. By including the abilities to perform daily tasks in an independent manner, Shelp is pointing to the particular aspects of an overall QOL that he considers to be most important—namely, those abilities that make the life of an individual “useful to him or her and to others.” Without these capabilities and with the subsequent dependence on others that arises as a result of the absence of these capabilities, a person's overall independence and “usefulness” suffers. However, as shown by the meningomyelocele example above, at least in a society with adequate resources, a lack of these capabilities does not render a person's life lacking in subjective value, thus the overall QOL of the individual is not necessarily sufficiently low to justify euthanasia, even if their independence is found to be below the minimal threshold. In contrast, if it could be proven to a reasonable degree of certainty (something that is admittedly difficult to do) that a child lacked the capability to communicate and relate with others, not only would it be very difficult to claim that he has a minimally independent life, it would also be difficult to claim that he has a minimally decent QOL due to his inability to express likes, dislikes, values, and interests, which in turn would prevent him from shaping experiences based on these subjective factors.

This stronger effect on subjective experience of life from the lack of communicative and relational capabilities can be explained by the capacities that underlie the capability to communicate and relate with others. As I mentioned in the discussion of Brock's self-determination, the capabilities to communicate or relate depend upon a person's ability to recognize himself as a unique individual whose existence is separate from the existence of other people and objects in the world. Furthermore, they depend upon a person being able to, on at

least a very basic level, recognize and distinguish between positive and negative experiences, which in turn relates to the person's subjective experience of her life as being to some degree positive or negative. That subjective experience is much of what makes life worth living for a person, especially a person who does not have the capacity to develop her own critical interests. A person's belief that things are going well can have a wide degree of complexity associated with it. For example, a paralyzed man can consistently claim that his life is going well due to the enjoyment he derives from his vigorous intellectual activities. Similarly, and more importantly with regard to the cases of seriously ill or impaired newborns, a person who has severe mental and physical defects may be said to have a high QOL as a result of the consistent joy he derives from small daily experiences and activities like being taken through a park. I will discuss the relevance and weight of this subjective experience of life, Brock's fourth component of (a high) QOL, in the next chapter. Here my main point is that, as suggested in each of the above cases, individuals must, at minimum, first be able to (1) recognize themselves as separate and unique individuals in the world and then (2) be able to create at least very basic preferences regarding the experiences and/or values that make life worth living, as well as then have a reasonable prospect to have those preferences satisfied to some degree, in order to be a candidate for having a minimally decent quality of life. Once these first two fundamental capabilities are present, the subjective experience of QOL of an individual becomes a function of the other three components Brock identifies. Without these two capabilities, the notions of self-determination, well-being, societal opportunity, and subjective perception of one's overall QOL are meaningless.

Therefore I claim that the two most fundamental capabilities (and the first two components) requisite for a minimally decent QOL are (1) the capability for a person to recognize himself as a separate individual in the world, a consciousness distinct from the world

around him, and (2) the capability to develop at least very basic preferences regarding the experiences and/or values that make life worth living.

Once a person is able to identify himself as an individual and develop preferences regarding experiences, he must be able somehow to communicate these preferences to others, and thus to relate to others. Since we are considering the most seriously ill or impaired, there is a need for others to assist these individuals both in their daily tasks and in achieving a decent QOL. Since a decent QOL is dependent upon the preferences that an individual has regarding the types of experiences and/or values that make life worth living, these preferences must somehow be expressed to the people who are aiding the individual. This communication can take a wide range of forms from direct expression using language to the very most basic of non-verbal bodily motions responding to pleasurable stimulus. Regardless of the type of communication, some degree of it is needed in order for preferences to be understood. Therefore, a third capability—to (3) communicate on some level—is a capability (and third component) of a minimally decent QOL.¹⁷

Since this list of capabilities requisite for a minimally decent QOL is meant to be applicable to all children, it must take into consideration the social context into which each child is born. Just as Shelp and Nussbaum provided qualifications about their own lists, I too mention that any such objectively ascribable list must necessarily accommodate social variables. In the case of seriously ill or impaired newborns, one of the most relevant ways that this variable takes form is the degree of aid available to a child. It is an unfortunate truth regarding most societies,

¹⁷ I have purposefully left off the ability to “relate” to others in my list. Certainly the ability to relate to people plays a central role in many people’s QOL. However, it only serves to enrich those lives through the contact that it provides. It is not a requisite portion of a *minimally* decent QOL.

certainly our own here in the United States, that there is an uneven distribution of medical care and services. As a result, a child who is born in a poor or rural portion of this country may not be offered the same degree of assistance as one born in an affluent urban area. This difference in aid has a subsequent impact on the current and future QOL of the newborn. Therefore, the fourth component of a minimally decent QOL is (4) living in a society that has sufficient resources to provide the material support necessary to sustain the newborn's minimally decent quality of life, as well as a reasonable prospect of accessing those resources. It should be noted that this component is a more basic version of Brock's second component of a high QOL. While it is certainly preferable to be born in a society that provides for a vast range of life plans, it is *necessary* to be born in a society (and family) that can provide the level of care called for by the specific illness or impairment that may so severely limit QOL as to render it below the level of a minimally decent QOL.

The fifth (5) and final component of a minimally decent QOL is the subjective experience of life as a good or as worth living. Its presence as a component of a minimally decent QOL is justified for two primary reasons. The first reason is conceptual. Our usual understanding of quality of life includes, or even primarily refers to, the individual's own experience of his life, his subjective experience. A life can be judged as long or short, productive or not, all without reference to the individual's own experience and valuation of it. But the person's quality of life is inextricably bound to his experience of it. The second reason is normative. We as a society have committed ourselves to respecting a person's own interests, values and desires. From the individual's perspective, the value of all of the other components of a minimally decent QOL could be rendered meaningless if he considers his life to not be worth living. The other components would still retain their objectively ascribable value, but would be irrelevant to him.

We must respect the relevance of the subjective component of QOL since it is this component that reflects the degree to which or how an individual considers his own QOL.

The subjective assessment or valuation of QOL figures in both assessment of the QOL of seriously ill or impaired newborns and in decisions about whether to euthanize them. First, their own experience of their lives is an important (subjective) component of their QOL. Second, parents will need to make value judgments regarding the adequacy of the QOL of their children in order to determine whether that QOL is minimally decent as judged in light of their own value systems in order to make the final decision of whether to euthanize their child. It is ultimately the subjective interpretation by the parents of the information given to them by their doctors that should determine whether their child is euthanized. A respect for this parental authority mimics the respect given to the subjective component of a minimally decent QOL because it is the parents who provide, on behalf of their child, a subjective analysis of the particular value of the five components of a minimally decent QOL have with respect to their child. Just as a fully competent person is free to assess his own QOL, the parents of a seriously ill newborn are allowed to make the same assessment on behalf of their child.

To conclude, there are five components of a minimally decent QOL of which three are capabilities. The two most important capabilities and components are (1) the capability of a person to recognize himself as a separate individual in the world, a consciousness distinct from the world around him, and (2) the capability to develop at least very basic preferences regarding the experiences and values that make life worth living. The third component is (3) the capability to communicate on some level. The fourth component is (4) living in a society that has sufficient resources to provide the material support necessary to sustain the newborn's minimally decent

quality of life, as well as a reasonable prospect of accessing those resources. The final component is (5) the subjective experience of life as a good or life worth living.

4.0 THE SUBJECTIVE ELEMENT OF QUALITY OF LIFE

This concluding chapter will take up the importance of the subjective element of QOL in general as well as its role in the decision making processes of physicians and parents in cases of newborn euthanasia. I will stress that when considering whether to euthanize a seriously ill or impaired newborn, the tension that exists between objective approaches to QOL (exemplified by components of a minimally decent QOL) and the view that the personal experience of life is all that should matter in QOL can be reconciled through a proper decision making framework that leaves to physicians decisions based on intersubjectively ascribable criteria and leaves to the parents the value-laden subjective assessments. I will first briefly discuss the importance of the subjective component of QOL overall by emphasizing its importance in practical tools used by the medical community. I will then return to its particular role in the components of a minimally decent QOL in light of this discussion.

4.1 SUBJECTIVE QOL AND THE DISABILITY PARADOX

It can be said with little controversy that the perceptions of our QOL by others do not always match our own personal assessment of our QOL. External perceptions and opinions certainly inform and have bearing on our own personal view of ourselves and our lives, sometimes to the unfortunate point where we become reliant upon external sources to largely define our personal

views of ourselves. However, much of what it means to live a good life is to believe that one's own life is worth living. This is a purely subjective assessment that is determined by the relationship between the individual's subjective experience of his own life and the value that the individual places on the various components of QOL. As shown above in the slave examples, the subjective element of QOL usually prevents external opinions of a person's QOL from serving as a complete representation of that individual's QOL. As mentioned before, the subjective component of QOL is unique in that it provides an individualized value to the other four objective components.

In perhaps no other area is the importance of the subjective component of QOL more pronounced than in the assessment of the QOL of people and patients with disabilities. In Gary Albrecht and Patrick Devlieger's article, we are introduced to the notion of what they call the "disability paradox" (Albrecht and Devlieger 1999). This paradox is characterized by the negative QOL assessments of individuals with a disability made by health care workers and the public who have no personal experience with disability and the contradicting positive personal QOL assessments by the individuals who actually have the actual disabilities. In essence, there is a conflict between the quality of life of disabled individuals as viewed by those without the disabilities and the subjectively assessed good or high QOL as expressed by the disabled individuals themselves. In order to explain this paradox, Albrecht and Devlieger adopt a broad interpretation of QOL. They state that they "understand quality of life for persons with disabilities in terms of the ability of the self to build and manage a balance between the body, mind, and spirit in searching for a state of well-being and to establish and maintain a harmonious relationship with the environment" (Albrecht and Devlieger 1999). While it is unclear how this interpretation of a QOL of individuals with disabilities differs from those without disabilities,

Albrecht and Devlieger are attempting to emphasize that many of the individuals they interviewed managed to successfully adapt to their disability or found new meaning through its effects on their life. In all, 54% of a total of 153 disabled individuals reported experiencing good or high QOL, despite their disabilities.

The subjective component of QOL has also been recognized in practical tools used in the medical community. One set of these tools is the economically focused health-adjusted and quality-adjusted life years (HALYs and QALYs). QALYs were originally created as a way “to accurately represent outcomes that can be generated most efficiently per dollar spent so that the total ‘good’ for a population is maximized” (Gold, Stevenson, and Fryback 2002). The reference to the maximization of “good” for a population is a strong hint at the utilitarian underpinnings of HALYs and QALYs. They were originally created by economists to help assess the overall health of a population as well as to identify disparities in health care and to maximize efficiency in health care costs. However, they have also been adapted to the micro level to aid patients in understanding the risks/benefits of certain treatment options (Gold, Stevenson, and Fryback 2002). HALYs, which is an umbrella term that includes QALYs, work by assigning a specific health-related quality of life value (HRQL) to an individual on a scale of 0 (death) to 1.0 (perfect health). How this value is assigned varies. In the case of QALYs, the HRQL is defined by “health states” that are comprised of specific “domains” such as physical, psychological, and social/role function (Gold, Stevenson, and Fryback 2002). Typically, the value of these domains is determined by the individual patient either through her own personal assessment of her current health state or through an assessment of health states described to her.

Another way of defining the HRQL is through the use of health questionnaires. QOL-related health questionnaires are meant to assess the effect of a person’s health status on her

QOL. For example, the Child Health Questionnaire has a system of scoring the responses to its questions in order to create the HRQL value (<http://www.healthact.com/chq.html>). The questionnaire has two versions, one for children (aged 5-18 years old) and one for parents. When comparing the questions asked in the two versions, it becomes clear that there is an underlying emphasis on the child's personal assessment of her QOL. In one question, parents are asked "how satisfied do you think your child has felt about: his/her school ability; athletic ability; friendships; appearance; family relationships; and life overall?" A similar question is asked to children using slightly different wording: "How good or bad have you felt about: yourself; your school work; your ability to play sports; your friendships; the things you can do; the way you get along with your family; the way life seems to be for you; your ability to be a friend to others; the way others seem to feel about you; your ability to talk with others; your health in general?"

Another set of questions in both versions of the questionnaire shift the perspective of the personal QOL assessment away from the QOL of the child and instead ask the parents and children to consider how the child's QOL affects the family unit. Specifically the questionnaire asks whether the child's health has affected the family's ability to perform activities together, whether it has caused tension and conflict, and whether it has limited their ability to be a "pick up and go" family. Each ends with the question, "In general, how would you rate your family's ability to get along with one another?" These questions represent the general idea that a personal assessment of QOL is not limited to how a person's health status affects only himself. Instead, the subjective element of QOL can also take into consideration the effect of a person's health status on those around them.

Albrecht and Devlieger's study, as well as the tools of HALYs, QALYs and the Child Health Questionnaire, provide empirical support to the importance of considering the subjective

component of QOL because of its ability to contradict objective assessments of QOL. They reinforce the idea that objective assessments of QOL are not sufficient when using QOL as a factor in medical decisions. These examples give an important broad understanding of the subjective component of QOL overall, but they do not explain its function as a component of a minimally decent QOL.

4.2 APPLYING THE COMPONENTS OF A MINIMALLY DECENT QOL TO THE DECISION MAKING FRAMEWORK

Subjective experience and assessment play two roles in relation to determining whether seriously ill or impaired newborns have a minimally decent QOL and, in turn, whether they may be euthanized. The first role for subjective experience is the newborn's capability to have a subjective experience, a component of a minimally decent QOL. The capability to have a subjective experience does not require the newborn to be able to eventually develop the complex value systems that most individuals use in assessing their QOL. Instead it should be understood as the capability to experience their lives and to experience their lives as having some (potentially variable) quality. These minimal assessments can best be characterized through the hedonistic approach towards well-being. The newborn must be able to experience basic stimuli (such as pleasure and pain) and somehow create preferences regarding those stimuli, which in turn represents a minimal personal assessment of QOL. Without the capability to have a subjective experience, the newborn will be unable to create even a rudimentary set of preferences regarding the experiences that make his life subjectively worth living.

Subjective experience or assessment enters decision making regarding the newborn's QOL and candidacy for euthanasia in a second way—namely, in the parents' assessment of the newborn's current and future expected QOL as being good enough to be a minimally decent life or not. Since newborns are not capable of determining whether their current or future health states make life a personal benefit or burden, we must rely on the parents' role as surrogate decision makers to serve as representatives of their newborn's best interests. This requires them to consider what would be a subjectively acceptable QOL and to, in part, base their decision whether to euthanize their newborn on such a determination. The decision to euthanize a newborn should be viewed as a collaborative process that requires both parents and physicians to understand and respect each other's rights and responsibilities. There is a strong need for participation and communication between the parents and the physicians.

The decision to provide euthanasia as a medical option is left to physicians and is dependent upon the outcome of a QOL assessment done in light of the objectively ascribable criteria of a minimally decent QOL. The final decision to actually euthanize the newborn is left to the newborn's parents and is a value-laden decision reflecting, at least, the information provided by the physicians and parent's personal value systems including what they believe to be an acceptable QOL. The components of a minimally decent QOL are meant to be intersubjective criteria that allow physicians to fairly assess all seriously ill or impaired newborns. However, as shown in the previous section, a complete assessment of QOL (especially for the purposes of medical decision making) is incomplete without taking into account the potential subjective interpretations of that life. Indeed there are scholars who argue that medical decision making on behalf of incompetent patients (surrogate decision making) should be devoid of QOL judgments because one person should not be deciding for another whether that other's QOL justifies

continued treatment (Ramsey 1978, 206-7). Yet, as Brock states, “the sound point that this objection confusingly makes is that quality of life judgments concerning a particular person should address how the conditions of a person’s life affects its quality or value to *that person*, and not its value to others” (Brock 1997, 103).¹⁸

4.2.1 Physicians’ Decision to Provide Euthanasia as a Medical Option

I will first discuss the role of the physician in the overall decision making framework of newborn euthanasia. In order to better understand this role, I will try to analogize it to the professional responsibilities of genetic counselors in a prenatal context. While this analogy is not perfectly fitting, there are valuable similarities between the two roles. One of the primary goals of genetic counseling is to educate parents about expected QOL that their future child may experience in light of genetic conditions with which the fetus has been diagnosed. When educating parents genetic counselors are guided by an ethos of value of neutrality (Biesecker 1998).¹⁹ Another term for this approach is “non-directive counseling.” The National Society of Genetic Counselors (NSGC) states that genetic counseling consists of “interpretation of family

¹⁸ This does not mean that medical decisions should completely ignore the effects a person’s health status has on those around them. Such effects are a serious factor to consider. However, justifications based on these concerns can lead to decisions that are contrary to the best interests of the patient.

¹⁹ Genetic counselors respect the autonomous nature of decision making and “adhere to the principles of benevolence and nonmaleficence that govern most health care providers and therapists...” (Biesecker 1998). However, just because genetic counseling focuses on value neutrality does not mean it is value-free. Genetic counselors are influenced by the values of “personal freedom, self-determination, and reproductive choice,” all of which “inform the practice of genetic counseling.” (Biesecker 1998).

and medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources and research; counseling to promote informed choices and adaptation to the risk or condition” (NSGC Code of Ethics, <http://www.nsgc.org/Advocacy/NSGCCCodeofEthics/tabid/155/Default.aspx>). They explain that “genetic counselors strive to...enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences”. As evidenced by the NSGC’s statements, genetic counselors have a strong commitment to empowering or informing the autonomous and informed decision making of their patients. Furthermore, they serve as more than just sources of information; they are a source of counseling and emotional support throughout the decision making process. The counselors understand that they should not coerce or unduly influence their counselees’ decisions. They are encouraged to choose the method of disclosure and degrees of information provided to the parents in light of the overall goal of informed consent and autonomous decision making. This means that counselors are encouraged to stress certain points regarding the nature of the disability in question (e.g., emphasizing the fact that certainly not all individuals with spina bifida have a low quality of life or that Tay-Sachs disease is a painful and inevitably fatal experience) in order to adequately inform their clients, meet their clients’ particular informational needs, and support their clients’ decisional processes and outcomes.

In order to achieve a proper balance of information in the decision making process, genetic counselors employ decision making tools that are “designed to assist individuals to make specific and deliberate choices on the relative risks, benefits, and consequences of available options” (Nagle et al, 2009). An example of such a tool is the Antenatal Screening Web Resource (ANSWER), which was meant to provide expecting parents with information about

some commonly diagnosed conditions and individual perspectives provided by people with those conditions (<http://www.antenataltesting.info/>). Tom Shakespeare, the coordinator of the project, states that “the best experts on life as a disabled person are disabled people themselves” (Ahmed et. al 2007). Information on the site includes background information on the individuals with the genetic conditions, as well as audio interviews regarding the quality of their life and how they have adjusted to living with the disability.

Many of the methods and guiding principles of genetic counseling should be adopted by physicians in the newborn euthanasia decision making process. Since the decision to provide euthanasia as a medical option must be as free of physicians’ personal biases as possible and informed primarily through the knowledge and experience of the medical community, it must try to avoid many of the value-laden factors that should properly be left to the parents. Physicians should adhere to a non-directive stance when providing information regarding the current and future quality of life of the newborn. Just as genetic counselors aim to promote autonomous and informed decision making, physicians faced with a possible situation of newborn euthanasia must make an effort to sufficiently aid parents through their clinical knowledge and experience. Further, it is conceivable that many of the decision making tools that genetic counselors already use can be employed to help parents faced with the decision of whether to euthanize. Even if these tools are not directly suited to the extremely low QOL that the newborns we are considering are likely to encounter, they at least provide a template for the development of more appropriate tools. Like the ANSWER website, tools employed by physicians communicating with parents about newborn euthanasia should take into account of subjective experiences associated with the newborns’ conditions.

The reason that doctors are given the responsibility of determining whether euthanasia is a medical option is due to their expertise and experience in medicine. The offer of euthanasia, like other medical options, is partially subject to the physicians' professional discretion. The general approach is to determine the current and expected future QOL of the newborn and compare that to the components of a minimally decent life. If the QOL assessment of the newborn falls below a minimally decent QOL, then doctors can offer euthanasia as a medical option.

One of the primary concerns raised in light of this approach is that it may initially seem unclear how many and which of the components a child needs to lack in order for them to fall below the threshold of a minimally decent QOL. For example, since I have stated that the first two components (capability to identify oneself as an individual in the world and the capability to create basic preferences) are "more important" than the rest, does that imply that missing one of these requires doctors to provide euthanasia as a medical option? Does it mean that it would take two or more of the other components to match the importance of the first? The succinct answer to these questions is that if even one of the components of a minimally decent QOL is missing it is ethically permissible to offer newborn euthanasia as a medical option. Each of the components of a minimally decent QOL is necessary but not sufficient to achieve the QOL threshold. Admittedly, some of the components seem to fit the idea of a threshold better than others. For example, a newborn lacking the ability to discern herself as a separate individual in the world seems to be a "stronger" candidate for someone who lacks a minimally decent QOL than a newborn lacking only the ability to communicate. However, without the ability to communicate the child is unable to express her preferences and desires to those around her. Since the newborns considered for newborn euthanasia are likely to rely on those around them to maximize pleasure

and minimize undesired experiences, without the ability to communicate the child's quality of life would substantially suffer. What seems most accurate to claim is that the complicated interconnected nature of the components makes it very difficult to envision examples where a newborn lacks only one of these components. When one is missing, all are affected. Even in situations where it would be possible to claim that only one component was truly "missing," the individual's QOL would still fall below the minimum QOL threshold. Therefore, the concern as to how many or which must be missing in order to justify offering euthanasia is driven by a misunderstanding of the interdependent nature of the components.

It should be remembered that like Brock's, Nussbaum's and Shelp's lists, the content of the components of a minimally decent QOL are a social artifact. While the components are objectively ascribable, the QOL assessments performed by physicians may differ when they are performed in different areas of the world or under different circumstances. This includes intra-national discrepancies. So, a newborn who would not qualify for newborn euthanasia in a relatively affluent and medically advanced portion of a country may qualify if she were born in an area of scarce medical resources. The likelihood of meeting the child's medical needs, or of providing the requisite constant care, affects the reasonably expected quality of the child's life. Thus material conditions, including the degree of medical and scientific advance of the society, and the ability of parents or society to fund such care, affect this assessment. This is an unfortunate social truth.

Another concern is that by providing physicians the power to serve as veritable "gatekeepers" to euthanasia, this decision making framework gives them a disproportionate amount of power regarding the treatment of newborns and undermines the authority given to parents as proper decision makers for their children. This concern is misplaced. The right to give

informed consent or refusal, or to give or refuse permission in the case of pediatric patients, does not grant an affirmative right to specific medical interventions. Parents do not have an absolute right to access whatever treatment for their child they see fit. Doctors' judgments regarding the appropriateness of medical treatment are a prerequisite to the offer of medical intervention and the opportunity to give informed consent. Since application of the QOL components depends upon sufficient medical expertise to be applied in particular cases, reserving the decision to offer euthanasia as a medical option to physicians is similar to reserving to them offers of other treatments that depend upon the medically-informed discretion of physicians. Furthermore, since these components are meant to be as objective as possible, the hope is that there will be a general uniformity in their assessment, which would prevent physicians from abusing their individual power to control access to the treatment for the newborn.

4.2.2 Parents' Decision to Euthanize the Newborn

The parents' role in the overall decision making framework is to provide the set of values for evaluating the acceptability of their newborn's current and future QOL, to evaluate the information provided by the physicians regarding the newborn's QOL in light of those values, and to make the final decision of whether to have their newborn euthanized. This set of values will determine whether the newborn's current or projected low QOL as assessed and described by the physicians justifies euthanasia. It is difficult to outline the various factors that parents should consider when performing such an evaluation. The factors will be similar to those the parents consider in making other very important decisions regarding themselves and their loved ones, especially their children. Much of what needs to be considered will depend on the nature of the QOL of the newborn. Therefore, decision making tools like the ANSWER website

mentioned above can be invaluable. However, at the very least, parents are responsible to determine on behalf of their newborn whether the QOL that the newborn will experience is an acceptable one in light of, or as judged by, the parents' conception of an acceptable quality of life and a projection of their child's actual ability to have that quality of life. This assessment can come *in spite of* and yet partly based on the objective determination provided by the physician.

In order to better understand the unique position that parents of seriously ill newborns find themselves in I will briefly examine Joel Feinberg's concept of a child's right to an open future. As will become clear through my explanation of the concept, the open future is almost completely inapplicable to seriously ill or impaired newborns. However, what the concept does provide is a way to begin a discussion regarding the particular considerations that set apart the decisions facing parents of seriously ill newborns from those made by parents of healthy children. Just as I examined Dan Brock's components of a high QOL in order to illuminate the components of a minimally decent QOL, I turn to Joel Feinberg's concept of an open future because it is intuitively accessible since it applies to a broader set of individuals, in this case children that have potential for much greater degrees of development than the particular set of seriously ill and impaired newborns considered in this thesis. I use this broader perspective to identify the factors that will *not* be a part of decision making processes regarding seriously ill and impaired newborns, which allows for greater emphasis on the particular factors that *will* be.

Feinberg enumerates various rights of a child that impose responsibilities on the child's parents (or relevant others). Among those are rights that derive from the dependent status of children, including rights to food, clothing, shelter, and protection. Another class of rights that children have, but cannot exercise until maturity or adulthood, are those autonomy rights involving free exercise of choice and self-determination (Feinberg 1980, 112-113). Because

children cannot exercise these rights until they are sufficiently mature to do so, the rights are said to be held in trust for them for the future. These rights, including reproductive rights and other rights of free choice, cannot be exercised in childhood, but may be violated during those early years if parents (or others) act in ways to preclude fundamental options or choices that might otherwise be pursued by the child in later life (for example, by sterilizing the child or brainwashing him so as to prevent free choice) (Feinberg 1980, 112-113). Protecting these rights held in trust is described as protecting the child's right to an open future. Feinberg states that when parents (or other decision makers) violate a child's right to an open future they are violating one or both of two concepts. First is the "emerging adult's" right of sovereign autonomy (self-determination). This includes both the *capacity* to govern oneself as well as the *right* to govern oneself. The second is the life-long well-being of the person (self-fulfillment). This means allowing children to naturally develop any tendencies and inclinations and allow them to plan, organize, and design their lives (Feinberg 1980, 142-144). The parents of a newborn that is healthy must consider how the various decisions they make throughout the child's life will affect her later on. What school should they eventually send her to? How strict or permissive should the parents be? What kind of activities should she participate in? When should she use the bathroom alone? When should she start driving? All of these are questions that seek, not only to protect the child's current welfare, but also to maximize the role of future autonomy and self-fulfillment for the child.

Parents of a seriously ill newborn are never going to be faced with these types of future autonomy-oriented decisions. They do not have to worry about violating their child's right to an open future because she does not and will not have the capacities necessary for an open future. The scope of the parents' decisions will be defined by the serious disabilities from which she

suffers. Those decisions are unlikely to ever evolve beyond a consideration of how her parents can continue maximizing her pleasure while minimizing her pain. These decisions may take various forms, such as whether a certain machine is cost-prohibitive or whether the family should move closer to a local care facility in case of emergencies. However, they are all defined by the unique needs that the child has and the parents' abilities to meet those needs. A choice to treat and care for such a seriously impaired child requires the family unit to be aware of the fact that nearly every other decision they make will require them to assess the effect the decision will have on their ability to meet the needs of the seriously impaired child. This potentially includes decisions regarding other children in the family, which means that a sibling who is developing normally may have his or her own future limited due to the needs of the seriously ill and disabled child. I stress that such a limitation on siblings' futures in light of a seriously ill and disabled newborn is not guaranteed and is furthermore not necessarily grounds for euthanasia. In many situations such a limitation could be seen by the parents as a necessary step needed to free up resources to provide for the future benefit of the seriously ill newborn. It is perfectly within the parents' rights to make such a determination, even if their healthy child's future may become limited in some respects. Perhaps a moral argument could be made that parents should not limit the future of their healthy children for the sake of a seriously ill and impaired newborn. However, preventing parents from re-distributing resources to the care of a seriously ill newborn that would otherwise have been used for a healthy child would be a serious limitation on parental judgment and rights. Furthermore, such an absolute ban could unduly weigh the welfare of older or more healthy children over the welfare of newborn and impaired children. Moreover, the presence of a seriously ill or impaired child in the family, and the demands of caring for him, could have positive effects on the family unit and particular members, including siblings. This

possibility should also be considered, though it is critical to avoid using such a child primarily as a means to benefit others (e.g., to teach siblings a moral lesson or to garner sympathy or special meaning in life).

Exploration of these questions and possibilities is beyond the scope of this thesis, but these are nevertheless considerations that parents of seriously ill newborns must face. Moreover, such balancing issues are not limited to siblings or to economic resources. All aspects of the family's life will be affected by the undertaking of the constant needs of the newborn. Parents should consider the stress that such total reliance places on their own lives as well as on the lives of others. Raising any child, whether they are healthy or disabled, carries with it a requisite amount of stress. However, due to the newborn's lack of development, parents must consider that a higher degree of stress derived from the constant required attention will endure for the entire life of the child. In sum, parents who face the decision of whether to euthanize their seriously ill and impaired newborn and who choose not to do so must be willing to commit to caring for a child that will have very little if any developmental changes and will likely never provide any large degree of interaction or affection.²⁰

²⁰ It should be noted that adoption is another alternative in situations where parents do not believe they can properly provide for the needs of the newborn but are unwilling to accept euthanasia as a medical option. In those circumstances the adoptive parents have, presumably, undergone a very similar QOL analysis as the birth parents and have concluded that they are (1) capable of providing for the newborn and (2) the newborn's QOL is worth saving. Again, the second determination is a decision that is informed by the values of the parents (in this case the adoptive parents). This can include those parents who believe that ANY newborn, regardless of QOL, should be saved. Furthermore, once the adoptive parents have taken on their responsibility for the child, they are precluded from newborn euthanasia even if the child is still within the twenty eight day period. The reason for this is similar to one of the policy concerns behind the twenty eight day period mentioned in the last section. Specifically, once

In light of this understanding of the pervasive effects that the needs of a seriously ill and impaired newborn may have on the family unit, we can now focus even more narrowly on the factors to consider when deciding whether a newborn should be euthanized. Before any of these broader effects are considered, parents should answer the preliminary question of whether they believe that, *considering only the disabilities and impairments facing the newborn*, the newborn's current and future QOL is sufficiently poor to justify euthanasia (or, stated differently, whether it is sufficiently high to justify continued life). As stated throughout this thesis, the QOL of the newborn should be judged from the newborn's perspective. If at this initial moment the newborn's parents decide that her QOL is sufficiently low based solely upon her subjective experience of her life in light of the impairments she faces, then parents must assess whether the broader set of factors justifies continued life. Of these other factors, the most important would be any available treatment options or avenues of care that would help boost the newborn's QOL back to a sufficiently high level. After these treatment options are considered, the parents should weigh the other factors, including the parents' ability to pay for the treatment as well as the impact that the newborn will have on the family. If, however, the child's QOL is initially determined to be sufficiently high, then parents should consider the same rough hierarchy of values, but only to see if external factors would cause the newborn's QOL to decrease below an acceptable level. Again, this includes the availability of treatment options followed by the parent's ability to provide for such treatment followed by the other concerns.

parents have committed to caring for the needs of the newborn, allowing them to change their mind and euthanize their newborn would be contrary to the high level of duty and responsibility that our society considers parents to owe to their children.

This hierarchy of factors is not meant to serve as the required steps of decision making. Instead it is meant to be a guide for parents in the decision making process. It is based on an underlying assumption of this thesis that the best interests and QOL of the newborn should serve as the moral compass in decision making, but that these must be assessed in light of the parents' own values and circumstances. It is certainly possible (and ethically permissible) that parents will weigh factors differently from the structure I have outlined. Some parents' value commitments will find even very minimal pleasure to make a life worth living; others will believe that only a greater degree of expected pleasure will afford a minimally acceptable quality of life. Some parents may weigh the likely absence of substantial pain more heavily than the likely presence of pleasure. Some parents will be highly risk averse with regard to the possibility of suffering. Some will be tolerant of such downside risks and more heavily weigh the positive likelihood of pleasure. Some parents will believe that even a life of great suffering and minimal pleasure has great value and is worth living, perhaps for metaphysical or religious reasons. Regardless of the parents' value systems, this preliminary question requires a subjective analysis of QOL and must be answered by the parents (or current guardian). Furthermore, it should be done so in the greater context of a setting that is supportive of the respective roles of doctor and parents, as well as one that is not coercive or unduly pressuring.

What I have offered may be a bleak portrayal of the circumstances surrounding the lives of those children below the minimum QOL threshold. Unfortunately, many aspects of this portrayal are true. However, it would be remiss on my part to create such a negative narrative without offering a sufficient counter-balance. My argument does not seek to make newborn euthanasia in situations of seriously ill and impaired newborns a foregone conclusion. It hopes to emphasize the respect that should be given to the various roles of QOL judgments that go into

the decisions surrounding newborn euthanasia. Joseph Kaufert and Tom Koch tell of a story about two speakers at an international conference on ethical decision making who gave a forty minute case study of an ALS (Amyotrophic Lateral Sclerosis) patient who decided to discontinue his own treatment so as to avoid the “inevitable” death that faced him as a result of his disease (Kaufert and Koch 2003). The presenters hailed this as a paradigm study of a situation when decision making procedures by the physicians followed proper medical and ethical guidelines to a conclusion that was ethically permissible and, in the presenters’ opinion, the correct ethical choice (Kaufert and Koch 2003). The presentation was given to an audience that had a large population of disabled individuals, many of whom were scholars and physicians themselves. The clinicians were surprised to discover that “what to the clinicians was a textbook case of ‘end-of-life’ decision making was, for their audience, a story in which a life was ended as a result of failures of information and assistance by presenters themselves” (Kaufert and Koch 2003). The disabled members of the audiences denounced the clinicians’ failure to provide adequate information regarding continued life on a ventilator. While ALS is in fact a terminal disease, the disability community argued that the approach taken by the clinicians “robs patients of alternatives (in a paternalistic fashion) and argues against an assisted life on the ground not that the disease will *eventually* be terminal but that life in the interim—which may last for years—will be insupportable” (Kaufert and Koch 2003).

I add the discussion of this case into this section of parental decision making because it neatly summarizes the major points regarding QOL that I have hoped to highlight in the preceding sections. More importantly, it emphasizes that parents of seriously ill and impaired newborns should not accept the QOL determinations provided to them by physicians as the only perspective on their child’s troubles. Instead, their guiding principle should be to balance the

information given to them by their physician with any countervailing perspectives on that QOL that they may personally hold or that they may glean through further study of the specific illnesses and disabilities facing their newborn. The ALS patient example highlights the danger of decision making that does not properly account for such a holistic approach towards QOL. Parents must be careful to take into account any information that they can gather on similarly situated newborns (and their subsequent lives) as well as any opportunities available to them through medical or social support centers that could potentially offset some of the burdens mentioned above. Only when parents have attempted to take this wide range of issues into consideration can they make a balanced decision.

This brings me to my final point in this section, which is that newborn euthanasia is not morally obligatory. The only possible situation where parents *may* be obligated to euthanize their newborn is if he was experiencing extreme physical pain to a point where medical intervention could not alleviate the symptoms. However, the problem with asserting this obligation is that it does not take into account the breadth of the values that we tolerate in our society. Tolerance for a plurality of values, as well as a great deference given to parental decisional authority, is the norm in healthcare decision making. Exceptions to these norms usually exist only when there is express harm being done to the child as a result of the decisions of the parents. Given that I hypothesize that in this case ending the child's life is the only way to end his suffering, and given the deference we give to vitalist positions regarding the value of life (used here to mean preserving physical life at all costs), it would be difficult to insist that a decision to euthanize is morally mandatory if parents asserted such an overriding valuing of continued life. Another situation in which one might assert that euthanasia is morally mandatory would be a case in which the newborn lacks the awareness necessary to derive any subjective benefit from his own

life. Nevertheless, since the newborn is not self-aware or capable to create preferences, he may never experience suffering of any kind. In light of the fact that no harm is done to the child and out of a respect for the accepted role of parents as the proper decision makers for their children, the decision to euthanize the newborn remains permissible and is not obligatory.

This thesis has attempted to argue that euthanasia should be available to seriously ill and impaired newborns and offers ethical arguments to support this conclusion within the contexts of the informed consent and best interest models of medical decision making. I have developed a set of guidelines for physicians that are based on a clearer understanding of quality of life and are meant to be used when determining whether to offer newborn euthanasia as a medical option in cases of seriously ill and impaired newborns. These guidelines are comprised of the components of a minimally decent quality of life, which allows them to be applied to all newborns. Finally, the thesis concluded with an explanation of the differences between the decisions to provide euthanasia as a medical option and to actually euthanize the child.

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