

Digest, *Jewish Ethical Aspects of Neonatology*
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This paper will discuss whether it is permissible from a Jewish perspective to allow parents and/or the medical community to refuse treatment of an infant born with a certain disorder or defect. In my introduction, I present two influential medical cases, which influenced the way neonatology is practiced today.

Chapter one will give us a summary of the general problems that face neonatologists. First, I give a historical overview of infant murder (infanticide). Second, this section discusses some of the serious disorders, syndromes, and conditions that afflict newborns. Third, I detail the challenges facing doctors that practice neonatology, exploring the ethical criteria and procedures by which they deal with them.

Chapter two reviews contemporary medical ethical literature regarding end of life decision-making for very sick neonatals. First, I explore how ethicists define euthanasia. Second, I outline different moral considerations that medical ethicists use to determine the best course of action in any given case and some of the limitations of each moral criterion. Third, I show how ethicists determine who should make end of life decisions for neonatals.

Chapter three deals with the traditional Jewish viewpoint of neonatal euthanasia. First, I analyze what Judaism says about euthanasia, whether or not it is permitted. I demonstrate some of the Jewish values that are involved in making any decision by presenting stories from our biblical, Talmudic, and rabbinic traditions. Third, I show how some liberal commentators have challenged traditional wisdom regarding euthanasia. Finally, I explore the issues regarding an infant and how it is different from a full grown adult.

In my conclusion, I present some of the similarities and differences between the approaches of secular medical ethics and Jewish medical ethics. I also provide my opinion as a Reform Jew, showing that science gives us better information to make more accurate decisions. Finally, I hope that this thesis suggests ways that rabbis can make decisions regarding cases such as the ones that were presented in this paper.

Jewish Ethical Aspects of Neonatology

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TABLE OF CONTENTS

<i>Introduction</i>	1
<i>Chapter 1: Medical and Ethical Dilemmas In the Treatment of Defective Newborns</i>	4
<i>Chapter 2: Euthanasia and Withholding of Treatment As Discussed in Medical Ethics Literature</i>	18
<i>Chapter 3: Traditional Jewish Viewpoint</i>	35
<i>Conclusion</i>	53
<i>Bibliography</i>	58

Introduction

On April 9, 1982, Baby Doe was born with Down's syndrome and esophageal atresia, a disorder of the digestive system, in which the esophagus does not develop properly.¹ Doctors recommended that the infant undergo immediate surgery to rectify the disorder, but knowing that the child had Down's syndrome, the parents refused. The parent's decision to withhold treatment and essentially allow the baby to expire caused uproar from Bloomington Hospital where Baby Doe was born to the local welfare department, country and state courts, the United States Supreme Court, White House, both Houses of Congress, and various lobby groups.

In a similar case, the parents of Baby Jane Doe also decided to withhold treatment of their newborn baby. Baby Jane Doe was born with a spinal defect and doctors wanted to place a shunt in her spinal cord to prevent hydrocephalus (water head).² Without closure, the baby would suffer and eventually die from recurrent meningitis infections which would enter from the opening in her spine. The parents, hearing that the baby would potentially be mentally retarded, refused the surgery. The New York court system did not allow the parents to starve the child to death, ordering that the child have adequate food and antibiotics, while upholding the parent's refusal to have surgery. The court maintained that the parents were obligated to keep the child comfortable until death. The defect was healed naturally three months later as skin grew over the spinal defect and healed it.

¹ Jonathan D. Moreno, "Ethical and Legal Issues in the Care of the Impaired Newborn," *Clinics in Perinatology* 14:2 (1987): 345.

² See CEJA Report I—A-92, "Treatment Decisions for Seriously Ill Newborns," American Medical Association.

Both Baby Doe and Baby Jane Doe sparked a debate in all sectors of the religious, medical, and political communities. In the case, religious organizations tried to take over the authority of the parents in order to "save" the child from death. Some organizations tried to gain custody and adopt the children. Their efforts did not prevail in either case; the authority remained in the parents' control.

The medical community, mainly the American Medical Association, was forced to set policies regarding this issue. In addition, the United States Congress and Reagan Administration asked to obtain the medical records of the Baby Doe and Baby Jane Doe cases. In reaction, certain members of Congress proposed an amendment to the Child Abuse Prevention Act, "that defined withholding medically indicated treatment from disabled infants as medical neglect."³ On July 26, 1984, the Baby Doe provisions were passed by a voice vote on the Senate floor. A few months later, on October 9, 1984, President Reagan signed the amendment into law.

My thesis will discuss whether or it is permissible from a Jewish perspective to allow parents and/or the medical community to refuse treatment of an infant born with a certain order or defect. My hope is to present a Reform Jewish criterion for responding to such an issue while taking into consideration medical dilemmas that face physicians,

³ Amendment to the Act: "[T]he term Withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."

Ibid., 2.

ethical discussions surrounding the issue of Neonatal Euthanasia and withholding treatment, and finally the traditional Jewish viewpoint.

Chapter 1-Medical and Ethical Dilemmas in the Treatment of Defective Newborns

Neonatal ethicists do not begin their study with the Baby Doe cases or even in the twentieth century. Instead neonatal ethics embarks with an evaluation of the cultural history of infanticide, or infant murder.⁴ Historically, infants have been put to death for a variety of reasons which include physical abnormalities such as size or shape, illegitimacy, population control and undesirable sex.⁵ In fact, the Bible (Isaiah 57:5) and the Koran (Surah 16:58-69) prohibit the killing of children for reasons of ritual or sex choice, suggesting that there was a practice of infanticide in biblical and post-biblical times.⁶ Plato in his work, *The Republic*, supports the throwing away of what he would call sickly babies. In Roman times, kings ordered the drowning of monsters. Even in the twentieth century, infanticide in China and India has been used as a means of population control.

From medieval times through the eighteenth and nineteenth centuries, abandonment of infants was not uncommon.⁷ In 1624, England passed a law to curtail the practice by requiring the death penalty for those who killed their babies; however, the law was ineffective. In the eighteenth and nineteenth centuries, there seemed to be an increase in infanticide due to the industrialization of England and Europe. Factory workers were sexually abused by their bosses and other workers.

⁴ Moreno, 346.

⁵ BA Kellum, "Infanticide in England in the Later Middle Ages," *History of Childhood Quarterly* 1 (1974) and R Sauer, "Infanticide and abortion in nineteenth century Britain," *Population Studies* 32 (1978).

⁶ Moreno, 347.

⁷ *Ibid*, 347.

Many techniques have been devised to carry out infanticide.⁸ In addition to abandonment, exposure and starvation, many active means have been cited throughout the centuries, such as strangulation, burning, and poisoning. In colonial America, a popular device among new mothers was to cover the infant in bedclothes making the death seem accidental.⁹ All of these techniques are still in use today, including those modern technological advances such as legal injection. Although it is practiced by some, infanticide in the twentieth and twenty-first centuries has largely been curtailed due to a combination of court and legislative action, changing social values, and economic stabilization and growth.¹⁰

In Christian law and most legal systems around the world, a person who intentionally kills another is subject to severe punishment. Parents who have neglected to provide their children with life-saving and sustaining treatment are liable for their actions according to the child abuse and neglect laws. Despite what our laws may dictate, however, in cases where infants are born with severe handicaps and may live a limited lifespan and where the parents decide to withdraw or withhold treatment, the courts have sided with the parents.¹¹

Physicians, caregivers, and hospital officers are also liable for giving permission to parents and other staff to withdraw or withhold care from infants, especially those born with defects or disorders.¹² In addition to holding hospital staff accountable, the courts have also determined that the parents do not have the absolute right to make decisions for

⁸ Moreno, 347.

⁹ NEH Hall and PC Hoffer, "Murdering Mothers," *Infanticide in England and New England* (New York: New York University Press, 1981) 1558-1803.

¹⁰ Moreno, 347.

¹¹ *Ibid.*, 348.

¹² C Damme, "Infanticide: The worth of an infant under law," *Medical History* 22 (1978) and J Robertson, "Involuntary euthanasia of defective newborns: A legal analysis," *Stanford Law Review* 27 (1975).

their infant. Courts have also respected the opinion in most cases of state's interest for the continued life of the child, where quality of life considerations play an important role. However, the courts have determined that quality of life considerations should not be decisive.¹³

A number of cases have challenged the courts to reexamine their procedures when it comes to physically handicapped infants.¹⁴ In the introduction, I discussed the impact of Baby Doe and Baby Jane Doe cases on society and the legal system. The courts have failed to come up with a standard pattern for decision making in cases where infants are born with severe handicaps but need additional life-saving surgery to prolong the life of the patients.

One such case was Baby boy Houle, who was born on February 9, 1974 at Maine Medical Center with several gross external malformations as well as tracheoesophageal fistula, which led to several complications including pneumonia.¹⁵ The father, after being confronted with the decision of whether or not to do corrective surgery to save the child, directed the hospital staff not to proceed.¹⁶ In reaction to the father's decision, several physicians and medical administrators pushed for charges of child neglect to the superior court judge. Judge David Roberts declared *parens patriae* jurisdiction and ordered the surgery to be performed.¹⁷ He argued, "at the moment of live birth there does exist a human being entitled to the fullest protection of the law...the most basic right enjoyed by

¹³ JE Herr-Cardillo, "Defective Newborns and Section 504 of the Rehabilitation Act: Legislation by administration fiat?" *Arizona Law Review* 25 (1983).

¹⁴ *Ibid.*, 348-349.

¹⁵ Robert J. Boyle, "Paradigm Cases in Decision Making for Neonates," *NeoReviews* 5:11 (2004) 477.

¹⁶ R. Weir, *Selective Nontreatment of Handicapped Newborns*, New York, Oxford, 1984.

¹⁷ Literally, "parent of his country." Used when the government acts on behalf of a child or mentally ill person. Refers to the "state" as the guardian of minors and incompetent people.

right enjoyed by every human being...the right to life itself.”¹⁸ The surgery was performed; however, Baby Houle died following the surgery.

Following the case of Baby Doe in Bloomington, Indiana, the Federal Department of Health and Human Services (DHHS) issued a notice in May of 1982 mandating that hospitals risk losing funding if they withheld nourishment and treatment from handicapped newborns.¹⁹ As a basis for their mandate, DHHS applied Section 504 of the Rehabilitation Act of 1973, which prohibits institutions that receive federal funds from discriminating against people with handicaps. DHHS wrote, “it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if: (1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.”

Several doctors objected to this statement issued by DHHS. However, the issue became more heated when President Reagan ordered DHHS to issue a harsher policy.²⁰ Apparently, President Reagan was touched after he watched a film “Who Should Survive?” The program featured a child with Down’s syndrome that was not given nourishment or life sustaining sustenance by the directive of the parents in order that the child would die. Following President Reagan’s directive, DHHS additionally required that all delivery, maternity, and pediatric wards post a sign with the May 1982 order and

¹⁸ *Maine Medical Center v Houle*, no 74 to 145 (Supreme Court, Cumberland County, Maine) 14 February 1974.

¹⁹ *State ex rel. Infant Doe v Baker*, No 482 S 140 (Ind. May 27, 1982).

²⁰ *Moreno*, 351.

added a twenty-four-hour-a-day toll-free hotline number to receive complaints of any individuals who may be suspected of discriminating against handicapped newborns.

The hotline had limited results. In one case, the parents took their infant out of the hospital against medical advice, and in another the medical team was so distracted by the investigation that they neglected to provide adequate care for the newborn baby.²¹ Eventually, after appeals to the federal courts culminating at the Supreme Court, the policy was struck down in a plurality opinion authored by Justice John Paul Stevens, who argued that the 1973 Rehabilitation Act does not include parents of newborn infant. Stevens focused his opinion on technical legal considerations rather than ethical considerations or infants' rights.

Although a Supreme Court decision was handed down, several ambiguities still remain. First, the decision mentioned only Baby Doe rather than all cases, which means that the 1973 statute could indeed apply to some cases where newborns are born with severe handicaps, especially if the court in the future were to find a legal basis. Second, since members of the Supreme Court such as Chief Justice Warren E. Burger did not join with Justice Steven's plurality opinion and provided no reason of his own, no real argument can be used to say that the Supreme Court has definitively decided on this issue.²²

A coalition of liberal and conservative U.S. senators formed in 1984 to fix some of the shortcomings of the 1973 Rehabilitation Act regarding the protection of handicapped newborns²³ Working with individuals from all aspects of society from right

²¹ JA Strain, "The American Academy of Pediatrics comments on the "Baby Doe II" regulations," *New England Journal of Medicine*, 309:7 (1983).

²² TH Murray, "At last, final rules on Baby Doe," *Hastings Cent. Report* 14:1 (1984).

²³ Moreno, 353-355.

to life to medical groups, the senators decided to amend the Child Abuse Prevention and Treatment Act. The bill was passed by both Houses of Congress and signed into law by President Reagan in 1984. After working on some loop holes that were identified, on April 15, 1985, P.L. 98-457 was published. Medical neglect would not be defined as "withholding of medically indicated treatment from a disabled infant with a life-threatening condition."²⁴ Withholding treatment is defined as "the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication), which, in the treating physician's (physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions..."²⁵ Issues of quality of life were not mentioned and people assumed that having an abnormality was a bad quality of life.

These cases had a profound impact on the practice of neonatology. As technology becomes much more sophisticated and effective, more and more infants born prematurely are being saved by neonatologists. As a decade went by, the ethical issues were no longer whether or not one should save an infant born with severe handicaps and malformations, but whether or not to treat a very low birth weight infant knowing that the child may have severe cognitive problems as well as physical issues.²⁶ The same technology that has increased the chances of survival for low birth weight infants also has been criticized for prolonging the dying process or allowed infants to live short life spans with severe handicaps, both cognitive and physical.

²⁴ Public Law 98-457

²⁵ The following are exceptions: (1) The infant is chronically and irreversibly comatose; (2) The provision of such treatment would merely prolong dying, not be effecting in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (3) The provision of such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.

Three approaches in infant care are taken by neonatologists throughout the world.²⁷ In the United States, medical facilitators continue to practice an aggressive treatment environment. This environment is called by ethicist Nancy Rhoden the *wait until certainty* approach.²⁸ Neonatologists begin treatment without question on almost every infant who is thought of having any chance to survive when they are born. Physicians who take this approach would rather err on the side of maintaining life knowing that some will survive and lead healthy lives while risking that some will have severe handicaps or simply prolong their life. According to Dr. Kinlaw, "the aggressive approach is in accordance with a society in which individualism is a strong value and consumer rights have gathered increasing support particularly since the 1960's. In addition, the United States is a very litigious society, in which legal action to support individual rights, especially in health care, is routine."²⁹ In 1986, a survey was conducted to see what impact the Baby Doe regulations had on doctors.³⁰ The study found that neonatologists and pediatricians were aggressively treating newborns to the point of overtreatment. Most neonatologists; however, believed that the Baby Doe regulations were not necessary and did not improve the quality of life for infants.

Although the United States takes an aggressive approach to neonatal care, there are other approaches to treating infants.³¹ One would be the *statistical approach*. In this

²⁶ Kathy Kinlaw, MDiv, "The Changing Nature of Neonatal Ethics in Practice," *Clinics in Perinatology*, 23:3 (1996): 418.

²⁷ Kinlaw, 418.

²⁸ A Caplan and CB Cohen, eds., "Imperiled Newborns," *Hastings Center Report* 17 (1982): 5-32 and NK Rhoden, "Treating Baby Doe: The ethics of uncertainty," *Hastings Center Report* 16 (1986): 34-42.

²⁹ Kinlaw., 418-419.

³⁰ AE Kopelman and LM Kopelman, "Neonatologists, pediatricians, and the Supreme Court criticize 'Baby Doe' regulations. In AL Caplan, RH Blank, JC Merrick, eds., *Compelled Compassion* (Totowa, NJ: Humana Press, 1992) 241, 248.

³¹ Rhoden, 34-42. For further information on strategies taken around the world, please see: "Physicians' Attitudes and Relationship with Self-reported Practices in 10 European Countries," *Journal of the*

approach, any infants born under a certain age of gestation and weight would most likely not be eligible for NICU care. For example, in countries such as Sweden, Netherlands, other Scandinavian countries any infant born under 25 weeks gestational age and 600 g, might fall into the category of being ineligible for NICU care.³² However, they would be given comfort care, such as warmth, touch, nutrition and extra oxygen. Just as the aggressive approach errs on the side of saving potentially normal newborns while prolonging the suffering and death of some newborns, this approach avoids “creating” severely handicapped infants while costing the lives of potentially healthy infants.

Another approach is the *individualized approach*.³³ This strategy initiates care on an infant who has a chance at survival but evaluation on whether or not care should continue takes places at the earliest stages. This approach is typically taken by doctors in Great Britain.³⁴ If an infant is born at 25 weeks gestation at under 600 g, the doctors would begin care and reassess the infant’s intraventricular hemorrhages, pulmonary hemorrhages until more information is revealed in the process. This approach also has raised concerns among neonatologists and pediatricians, mainly regarding the structure of assessment and how to define lines of success and failure. Despite some fallbacks, this strategy takes into consideration some of the ethical decisions necessary in moral responsibility for decision makers.

American Medical Association, 284:19 (2000). This article through statistical data explores the practices and tendencies of doctors in the case of neonatals in other countries. The article demonstrates how neonatologists disagree on which approach to take to care for infants.

³² Also see “The Groningen Protocol—Euthanasia in Severely Ill Newborns,” *New England Journal of Medicine*, 352:10 (2005). This article explores the practices of neonatologists in the Netherlands. Their practice is very similar to those in Scandinavian countries.

³³ Rhoden, 34-42.

³⁴ Also see, “Physicians’ Attitudes and Relationship with Self-reported Practices in 10 European Countries,” *Journal of the American Medical Association* 284:19 (2000).

According to Dr. Kinlaw, the ethical perspective is integral to the question of moral responsibility in decision-making.³⁵ Whether or not doctors decide to treat an infant born at 23, 24, or even 25 weeks gestational age, decision-making requires ethical justification. Any decision made by the medical care giver should take into consideration the moral justification of their decision. In the case of technology, doctors may feel "morally" obligated to use it at the expense of the patient due to its availability. "Ethically, this is an unexamined, nondefensible stance. The decision to use technology, just as the decision to forego the use of technology, should be clearly backed by ethical reasoning. (Even in the emergency situations, the general maxim *to treat* must have an ethical foundation.)."³⁶ Instead, the doctors should help families explore what is in their best interests by finding out what are their family's value or belief systems.

Under the current system, the decision as to what is in the best interests of the infants is made by the primary physician, the parents, and to some extent other members of the health care team.³⁷ In today's society when personal autonomy is valued more than ever, parents are given more and more authority to make decisions for infants. Typically, society believes that the parents will make the best decision for their children. However, several obstacles exist that may obstruct their point-of-view. In early stages of the life of an infant, the parents may be in shock and unable to understand the complexity of the situation or absorb the information. Second, doctors tend to use language that may be intimidating or hard to understand. It creates barriers between the knowledge of the doctors and the parents, which creates more tension and lack of comfort with the situation. Third, parents potentially have to make decisions that will have long-term

³⁵ Kinlaw, 419-420.

³⁶ *Ibid.*, 420.

effects on the infant and the family. The family may not realize how their lives may change in the future such as quitting and/or switching jobs and the resources necessary to take care of the children. Parents will need an unending line of support and resources to cope with these changes.

Communication with parents is crucial to the decision-making process. Dr. Kinlaw argues that the transparency model introduced by physician-ethicist Dr. Howard Brody and further discussed in neonatal care by Professor Nancy King is very helpful.³⁸ This process requires the physician and health care team to speak in a language that is understandable to the parents. Every step of the process including the trial and error process of treatment is exposed to the parents. The hope is that the parents will begin to understand the complexity of every day decision-making for the doctors. Therefore, in a time of crisis and urgency, the parents will not be shocked by difficulty of their own decision-making. Dr. Kinlaw concludes her article by saying that "respecting family autonomy does not mean leaving parents alone in their decision-making process. Public discussion about the expectations and limitations of neonatal intensive care would avoid the reactive focus on the few cases that capture media attention and assist clinicians and individuals families who deal with these difficult decisions."³⁹

As has been stated in this chapter, communication is vital to avoiding conflicts between the medical staff and parents. Recently, neonatologists were asked to describe

³⁷ *Ibid.*, 422-423.

³⁸ H Brody, "Transparency: Informed consent in primary care," *Hastings Center Report* 19:5 (1989): 5-9 and NMP King, "Transparency in neonatal intensive care," *Hastings Center Report*, May-June (1992): 18-25

³⁹ Kinlaw, 427. Cross Reference in this same volume, Peabody and Martin, "From How Small is Too Small to How Much is Too Much," *Clinics in Perinatology*, 23:3 (1996).

some of the most challenging communication issues.⁴⁰ Three issues were most prevalent in the survey. First, parents, especially new ones, have a hard time understanding some of the long-term effects of taking care of an infant with severe disabilities. The physician needs to take into consideration that any method he or she uses will be hard for the parents to hear, no matter how delicately it is communicated. Second, parents want as much information as possible; however, it becomes difficult to absorb it because of a lack of knowledge of medicine and biology. According to Fox et al, "this leads to mutual frustration, with claims by parents that 'They didn't tell me' and by physicians of 'They didn't hear me.'"⁴¹ Finally, even though physicians are considered experts by parents, they; nonetheless, may not trust the doctor when it comes to the care of their newborn baby. This reaction is frustrating for doctors and leads to more miscommunication.

In addition to these three reasons, doctors and especially parents become more frustrated when care of their infant is transferred from doctor to doctor.⁴² Moreover, when doctors are uncertain about data and results and are honest about it to parents, it becomes frustrating and leads to a lack of trust.

Parents of very low birth weight infants also complain that doctors are very poor with communication, more so than other specialties.⁴³ To combat this problem, Fox et al offer three strategies: giving bad news, sharing information and working toward a decision and responding empathetically. Each of these strategies requires training. In the

⁴⁰ Susan Fox, JD, MA, Platt, et al, Perinatal/Neonatal Communication, *Clinics in Perinatology*, 32:1 (2005).

⁴¹ Fox et al, 158-159. Also see, Thorne SE, Robinson CA. "Guarded alliance: health care relationships in chronic illness," *Image (IN)* 21:153-7 (1989).

⁴² *Ibid.*, 159.

⁴³ *Ibid.*, 159. Also see, Wocial LD, "Life support decisions involving imperiled infants, *J Perinat Nurs*, 14:2 (2000): 73-86. Platt FW, McMath J, "Clinical hypocompetence: the interview," *Ann Intern Med* 91 (1979): 898-902.

end, doctors will build better trust and communication with parents, hoping that the medical staff and parents will avoid legal battles.

In this chapter we have discussed whether or not to treat very low birth weight infants and who should make those decisions. In 1984 following the Baby Doe debate, the American Academy of Pediatrics Joint Policy Statement of Principles of Treatment of Disabled Infants held that "present or future lack of available community resources are irrelevant."⁴⁴ In the 1990's, doctors saw a transition from Baby Doe to Baby *Dough*.⁴⁵ Infants born under a certain weight or gestational age may not be economically justifiable to treat, meaning the outcome does not justify the means and expenses. Some doctors in the late seventies and early eighties warned about the potentially sky rocketing figures in cost that they would encounter. However, most doctors continued to neglect these figures. Fast forward a couple of decades and now the figures have exploded. Eventually, states began to measure how cost-effective it would be to use certain strategies in medicine. Oregon created a plan that drew the line by pairing 709 conditions and treatments and prioritizing their cost-effectiveness.⁴⁶ Care of an infant less than 500 g and less than 23 weeks of gestational age was priority number 708. Infants who were treated in this category were not to receive state funds for their care. The Department of Health and Human Services denied Oregon's proposal on the grounds that it does not take into account those cases that may have a positive income.⁴⁷ This outcome is indicative of our nation's reluctance to put a price on human lives, even though it may be

⁴⁴ Peabody and Martin, 483. Cross reference, American Academy of Pediatrics (Wehrle P, Buonomo J, Sweeney R, et al): Joint Policy Statement, Principles of Treatment of Disabled Infants, *Pediatrics* 73:559-560 (1984).

⁴⁵ Peabody and Martin, 483.

⁴⁶ A Capron, "Oregon's disability: Principles or politics?" *Hastings Center Report*, Nov-Dec (1992): 18-20.

⁴⁷ Capron, 18-20.

inevitable. Health care costs are exploding and not having a serious discussion on this issue, according to Peabody and Martin, is negligible on the part of the U.S.⁴⁸

Due to climbing health care costs, the United States government has been pushing for fiscal constraint in the health care industry.⁴⁹ This issue, however, has become global, one that affects most countries in the world. Studies have been conducted to understand the issue and methodologies to deal with it. Some studies show that society is not being cost effective with care of very low birth weight infants, while continuing treatment at the expense of society. Other studies show a different result, that over time doctors have learned to be more cost effective in providing resources. Overall, according to Zupancic, et al, the studies are inconsistent and doctors globally do not have a consistent way of examining the costs of healthcare both short and long term. However, one thing is for certain. Intensive care of infants is significantly more cost effective and favorable than other well-accepted medical interventions, such as coronary artery bypass grafting and renal dialysis.⁵⁰

Throughout this chapter, we have discussed some of the ethical issues confronting neonatologists. It began with a historical sketch of medical care of infants born with abnormalities to how we care for them presently. With on-going progress in technology and medical care, these questions will continue to confront neonatologists. In particular, neonatologists will have to come up with mechanisms to deal with cost and effectiveness.

⁴⁸ Also see, Jay P. Goldsmith, et al, "Ethical Decisions in the Delivery Room," *Clinics in Perinatology*, 23:3 (1996). John A. F. Zupancic, et al, "Economics of Prematurity in the Era of Managed Care," *Clinics of Perinatology*, 27:2 (2000).

⁴⁹ A. F. John, Zupancic, et al, 483-486.

⁵⁰ Zupancic, 494, also see, Tengs TO, Adams ME, Pliskin JS, et al: Five-hundred life-saving interventions and their cost-effectiveness. *Risk Anal*, 15:369 (1995).

Tough ethical decision-making lies ahead for neonatology; however, many of the issues are being raised.

Chapter 2: Euthanasia and Withholding of Treatment as Discussed in Medical Ethics Literature

In chapter one, we discussed some of the issues confronting neonatologists and how they are attempting to deal with them. In this chapter, we will discover how various ethics committees and ethicists approach difficult cases that are presented to them in the neonatal intensive care unit. Second, we will take a look at a particular case and how different ethicists suggest we should approach cases similar to it in the future. In particular, we want to see if these committees come up with consistent recommendations for doctors and what impact that may have on issues of authority, whether it be the parents, doctors, or both.

Certain approaches to end of life such as euthanasia and withholding and withdrawing care are practiced throughout the world, but do not go without much debate between those that advocate for it in appropriate circumstances and those that are opposed to it in any case. Caregivers in neonatal intensive care units should be aware of the potential criminal liability and complex moral issues with their practice of passive euthanasia. Furthermore, the definition of euthanasia and its varied practices remain ambiguous. Therefore, before we delve into issues concerning the practice of neonatal euthanasia, it may be useful to define such approaches as euthanasia, specifically, passive euthanasia and see if it can be used in cases of very sick newborns.

Euthanasia can be derived from Greek for good ("eu") and death ("thanatos"), "good death". Recently, the term has been used to practice mercy killing, for those that suffer unbearable and suffering. Ethicist Mark Sklansky, a pediatric cardiologist and associate professor at the University of Southern California, Keck School of Medicine,

defines euthanasia as referring "to the action, motivated by mercy, and in effort to avoid prolonged or futile suffering, of deliberately bringing about the death of another individual in as painless a way as possible."⁵¹ Euthanasia can be practiced in two ways, actively or passively. Active euthanasia refers to those cases when death is actively caused by another individual. Passive euthanasia refers to those cases when there is an absence of intervention that would have prolonged life. "...passive euthanasia usually refers to withholding or withdrawing life-supporting therapy."⁵² Withholding treatment or withdrawing life-support, however, is not always considered a form of euthanasia by all communities. Rather, in some cases, it can be defined as the act of simply removing an impediment to death when the doctors can no longer do anything to cure the patient, which will be discussed in chapter three where we will examine the Jewish point-of-view. Prolonging life, on the one hand, can be positive in the sense that it provides the patient time to heal but, on the other hand, can simply delay someone's inevitable death.

Euthanasia can be further defined according to degree of expressed consent.⁵³

Voluntary euthanasia refers to cases in which patients expressly request their own death. Involuntary euthanasia refers to those cases when caregivers or the patient's agent acts in the best interests of the patient. Newborn infants, however, are unable to express their will to live or die. Therefore, ethicists have offered the term non-voluntary, meaning without the patient's will, to specifically describe cases of neonatal euthanasia because there is no means of knowing what their desire is.

⁵¹ Mark Sklansky, "Neonatal Euthanasia: Moral Considerations and Criminal Liability," *Journal of Medical Ethics* 27:5-11 (2001): 5.

⁵² *Ibid.*, *Ibid.*

⁵³ *Ibid.*, *Ibid.*

Although ethicists and caregivers may be able to agree on definitions of neonatal euthanasia, which is not always the case, different moral considerations may lead caretakers to take different courses of action. By understanding and considering different moral principles such as autonomy, beneficence, non-maleficence, and justice, it will help clinicians approach those moral questions that are related to neonatal euthanasia.⁵⁴

The moral principle of autonomy allows "competent" individuals to refuse treatment even if it is against the individual's best interests.⁵⁵ Neonates lack the ability to make such decisions for their futures; and therefore, the moral principle of autonomy plays no significant role when considering neonatal euthanasia.

Beneficence on the other hand seeks to act on behalf of the person's best interests.⁵⁶ The goal is to maximize the individual's best interests by making decisions on their behalf when they are unable to do so for themselves. Neonates, however, are unable to form their own opinions of what is in their best interests, leading caregivers to make what are called "substituted judgments". Nonetheless, whether or not beneficence is the best moral principle with which to determine whether to prolong a defective newborn's life is not and will not be clear in most cases.

Non-maleficence, which is the reverse of beneficence, can be defined as the morally correct action which does not promote harm, pain, and suffering, otherwise known as "*primum non nocere*".⁵⁷ *Primum non nocere* is a Latin word and medical slogan that means "first do no harm". This is a fundamental precept of Hippocrates (ca.460-ca. 377) which is taught to all medical students to remind them of the possible

⁵⁴ T Beauchamp, J Childress, *Principles of biomedical ethics* (New York: Oxford University Press, 1979).

⁵⁵ Sklansky, 5-6.

⁵⁶ *Ibid.*, 6.

⁵⁷ <http://www.medterms.com/script/main/art.asp?articlekey=61110>.

harm that might be done through any intervention. With advancements in technology which have helped caregivers prolong life of individuals also comes the risk of prolonging suffering. With this approach, any medication which will prolong life should also be evaluated for its efficacy in healing the patient and what degree of suffering the medicine causes the patient to feel. Both non-maleficence and beneficence in cases of adults and children can conflict with one's autonomy because these methods do not take into account one's personal desires for treatment. However, in cases of neonates, it is impossible to determine their wishes; and therefore, the moral principles of non-maleficence and beneficence become much more valuable as moral criteria.

Finally, the moral principle of justice seeks to speak for the fairness, rights and duties of the patient.⁵⁸ The goal of this principle is that all patients are approached in the same way and given the same rights, despite our own feelings regarding their treatment. In cases of very sick neonates, the principle of justice ensures that they are attended to in the same way that a healthy infant would be cared for in the hospital. This principle often comes into conflict with the principle of beneficence because even though it may dictate we do what is more "humane", the principle of justice tells us to remember the rights of the individual. This idea may be appealing for those who like to recognize the neonate's right to life.⁵⁹

By considering each of these moral principles when confronting cases of critically-ill newborns, the hope is that we will come to a fair conclusion. However, more often than not these principles come into conflict with one another and demand different courses of action. So far in this paper, we have assumed that it is morally justified to

⁵⁸ Sklansky, 6.

practice passive euthanasia. According to Mark Sklansky, four basic moral questions are implicit in any discussion about euthanasia. First, "can euthanasia ever be morally justifiable?"⁶⁰ There are those people who find it immoral in any circumstances. These people find that life is sacred and should be treated as such. Practicing any kind of euthanasia, therefore, is considered immoral because it makes life unsacred. Often, people who take this position are religiously based; however, there are people who believe in sanctity-of-life principles who find their basis from morality and social order foundations, outside of any religious convictions or principles.

Another argument against the practice of neonatal euthanasia is that while there are cases when it would be appropriate and morally justifiable, one runs the risk of making a mistake if it becomes a common practice.⁶¹ In any given case, according to this argument, there is always hope. By prolonging life even at the risk of prolonging suffering, with time doctors may find an effective treatment to cure the infant's illness. In other words, we prolong suffering because in the long run there is the potential for more happiness if the child survives and lives a full life.

A third objection against practicing neonatal euthanasia can be found in the "slippery slope" argument.⁶² Advocates of this argument recognize that while there are cases when neonatal euthanasia is morally justifiable, condoning it may lead to abuse. The threat is that euthanasia will move from non-voluntary to involuntary: "the legal machinery initially designed to kill those who are a nuisance to themselves may some day

⁵⁹ P Foot. Euthanasia. In: J Ladd, ed. *Ethical Issues relating to life and death* (New York: Oxford University Press, 1979): 30.

⁶⁰ *Ibid.*, *Ibid.*

⁶¹ Sklansky, 6.

⁶² *Ibid.*, *Ibid.*

engulf those who are a nuisance to others.”⁶³ Two other concerns are derived from this argument. First, making it permissible to practice neonatal euthanasia in certain circumstances may make it easier for something else down the line to be condoned.⁶⁴ Second, allowing certain forms of neonatal euthanasia to be practiced may lead to a decline in the moral fabric of society in respect to human life and its sanctity.⁶⁵

In the first question, we examined whether or not neonatal euthanasia can ever be justified. In our second question, we will assume that there are certain cases where neonatal euthanasia would be permitted. Despite some of the concerns stated in the previous argument such as sanctity of life issues, possibility of the wrong diagnosis/prognosis and slippery slopes, in some cases, caregivers still think neonatal euthanasia may be the right thing to do. And if this is so, “what forms of euthanasia are justifiable...passive, active, and/or both?”⁶⁶ In North America⁶⁷ and especially in Europe⁶⁸, there are certain cases when caregivers practice passive euthanasia but never active euthanasia. As Sklansky asks in his article, two fundamental questions have to be asked before proceeding. “First, is there an intrinsic moral distinction between killing and letting die? Second, if there is no moral distinction, are there still moral reasons to justify one form of euthanasia but not the other?”⁶⁹ Although caregivers tend to see a distinction between active and passive euthanasia, most people do not see a fundamental

⁶³ Y Kamisar, “Euthanasia legislation: some nonreligious objections,” In: T Beauchamp, S Perlin, eds. *Ethical Issues in Death and Dying* (New Jersey: Prentice-Hall, 1978): 221.

⁶⁴ C Schneider, “Rights discourse and neonatal euthanasia” *California Law Review* 76 (1988):178.

⁶⁵ T Beauchamp and J Childress, 113.

⁶⁶ Sklansky, 6-7.

⁶⁷ S Wall, J Partridge, “Death in the intensive care nursery: physician practice of withdrawing and withholding life support” *Pediatrics* 99 (1997): 64-70.

⁶⁸ Please see the following references: Royal College of Paediatrics and Child Health. *Withholding or withdrawing life saving treatment in children. A framework for practice*. London: RCPCH, 1997.

HMChaffie, M Cuttini, G Brolz-Voit, L Randag, R Mousty, A Duguet, *et al.* “Withholding/withdrawing

moral difference between the two. When removing patients from machinery, the distinction between allowing someone to die and killing them starts to blur and depends on the case; even when caregivers have in their minds a clear distinction, it may not matter morally:

“If a doctor deliberately let a patient die who was suffering from a routinely curable illness, the doctor would certainly be to blame for what he had done just as he would be to blame if he had needlessly killed the patient...it would be no defense at all for him to insist that he didn’t do ‘anything’. He would have done something very serious indeed, for he let his patient die.”⁷⁰

On the other hand, those who believe a moral distinction is quite clear see killing a terminally-ill patient as more immoral (active euthanasia) than letting someone die (passive euthanasia).⁷¹ For those who advocate a clear moral distinction, it becomes complex when mixed with some of the realities of cases. Earlier, we discussed some of the moral deliberations that need to take place when taking care of sick newborns. We remember that certain moral considerations may lead us to different conclusions regarding treatment. In the case of a very sick newborn, for example, the moral principle of beneficence may indicate to us that the best practice in this case is to provide active euthanasia, not passive euthanasia. “...we would never consider allowing a horse or dog to die in agony if it could be killed painlessly. Once we see that the case of a dying horse

treatment from neonates: legislation and official guidelines across Europe,” *Journal of Medical Ethics* 25 (1999):440-6.

⁶⁹ Sklansky, 6.

⁷⁰ J Rachels, “Active and passive euthanasia,” *New England Journal of Medicine* 292 (1975):78-80.

⁷¹ Sklansky, 7.

is really quite parallel to the case of a dying infant, we may be more ready to drop the distinction between killing and letting die in the case of the infant too."⁷²

However, as Sklansky points out, even though there may be no moral distinction between letting someone die and actively killing someone, there nonetheless may be a greater social good in some cases of permitting the practice of passive over active euthanasia.⁷³

"...the disutility of introducing legitimate killing into one's moral code (in the form of active euthanasia rules) may, in the long run, outweigh the utility of doing so, as a result of the eroding effect such a relaxation would have on rules in the code which demand respect for human life...rules permitting killing could lead to a general reduction of respect for human life..."⁷⁴

Another argument that places passive euthanasia as a better alternative to active is that it may inevitably save the lives of patients in the long run.⁷⁵ It is quite possible according to Sklansky that if we were in the practice of allowing both forms of euthanasia, then more patients would die. Only allowing passive euthanasia provides doctors time to re-diagnose the neonate and possibly come up with a better treatment plan. And, as we know from the case of Baby Jane Doe, there are some circumstances when the problem fixes itself. Morally, we should feel compelled to leave room for hope.

Now that we have described that passive euthanasia may be used in certain cases, the next question should be "which patients should be considered for neonatal

⁷² Peter Singer, "Unsanctifying human life," In: J Ladd, ed. *Ethical Issues relating to life and death*. (New York: Oxford University Press, 1979): 53.

⁷³ Sklansky, 7.

⁷⁴ Beauchamp T. A reply to Rachels on active and passive euthanasia. In: Beauchamp T, Perlin S, eds. *Ethical issues in death and dying*. (New Jersey: Prentice Hall, 1978): 253.

⁷⁵ Sklansky, 7.

euthanasia?"⁷⁶ Furthermore, what moral criteria should be used? Sklansky offers the following criteria, each of which will be discussed in the following paragraphs: personhood, costs of treatment, quality of life, and best interests. Unlike those that argue against any practice of euthanasia based on the sanctity of life argument and therefore see the human being ultimately as a creation of two human beings, people who advocate using personhood look at the particular human being's characteristics "which represent the moral essence of being a person."⁷⁷ Rather than look at the human being as a biological creation, personhood looks for the moral traits in a person.⁷⁸ As a qualification to this principle, Michael Tooley suggests that a person must be able to envision his or her future and have a certain amount of clarity of what that future may be.⁷⁹ The problem with this point-of-view is that this approach contradicts many of society's moral institutions; and furthermore, not knowing or being aware of life's desires, the neonate would have no right to life.

In order to still use this approach with neonates, some have argued that one should not look at it from a moral point-of-view but rather from a social one.⁸⁰ As Sklansky argues, the personhood approach protects societal interest:

"...it is difficult to determine specifically when in human ontogeny persons strictly emerge. Socializing infants into the role person draws the line conservatively. Humans do not become persons strictly until sometime after birth...Unlike persons strictly, who are bearers of both rights and duties, persons in the social sense have rights but not duties. That is, they are not morally agents, but are treated with respect (ie, rights

⁷⁶ *Ibid.*, 7-8.

⁷⁷ *Ibid.*, 7.

⁷⁸ M Tooley, "Decision to terminate life and the concept of person," In: Ladd J, ed. *Ethical Issues relating to life and death* (New York: Oxford University Press, 1979): 64-5.

⁷⁹ Tooley, 13:91.

are imputed to them) in order to establish a practice of considerable utility to moral agents: a society where kind treatment of the infirm and weak is an established practice...The social sense of a person is a way of treating certain instances of human life in order to secure the life of persons strictly."⁸¹

Although personhood in the biological sense denies the right to life for all newborns, in the social sense it provides an argument for saving a neonate. The goal from a social point-of-view is to determine whether or not the infant can develop into a person in the biological sense; and therefore, after surviving illnesses that almost killed the child, be able to fulfill in life the original meaning of personhood.

Our second moral criterion is the costs of treatment. Physicians do not have infinite resources at their discretion, meaning that decisions have to be made how finite resources will be allocated for medical treatment. Some ethicists argue that costs of treatment should be one element of the discussion regarding treatment of critically ill newborns. However, as Mark Sklansky argues, it may be inappropriate to discuss such issues at the bedside.⁸²

Whether or not an infant will have a quality of life after aggressive treatments should certainly be a part of the discussion regarding future care.⁸³ If the infant will only experience suffering and little or no pleasure in life, then prolonging treatment may be perceived as cruel and unnecessary. In other words, are we prolonging life while not considering the inevitable? However, there are those infants with severe pain and suffering that have grown into adults and would rather have lived than not lived at all.

⁸⁰ Sklansky, 7.

⁸¹ HT Engelhardt Jr., "Medicine and the concept of person," In: Beauchamp T, Perlin S, eds. *Ethical issues in death and dying*. (New Jersey: Prentice-Hall, 1978): 277-8.

⁸² Sklansky, 7.

⁸³ *Ibid.*, 8.

Furthermore, it is impossible for us to place value on a quality of life. For this reason, some ethicists and caregivers have suggested that quality of life cannot be used as independent criterion. However, it may be used as one of many criteria to determine whether or not to allow an infant to die.

Finally, one of the most widely accepted criterion criteria is "the best interests of the patient."⁸⁴ The goal of best interests is to help caregivers put their own biases away to do the right thing for the patient. One problem with infants is that the answer is not always clear what should be done; nevertheless, it provides parents and caregivers an opportunity to think about the best course of action. Also, any definition of "best interests" is unavoidably subjective or culturally-based.

After carefully considering some of the moral criteria for determining who should be allowed to die passively, then we need to discuss our fourth question, "Who should decide?"⁸⁵ In most cases, the decision of whether or not to withdraw or withhold treatment is made jointly by parents and caregivers.⁸⁶ If a decision cannot be reached between parents and caregivers, then hospital may consult an ethics committee. Ultimately, if the ethics committee cannot come up with a recommendation that satisfies both parties, then the court system may need to intervene. Sklansky argues "[f]rom a moral perspective, life-and-death decisions for defective newborn infants should be made by that individual (or set of individuals) most likely to make the choice that best promotes the best interests of the infant."⁸⁷ Three separate aspects of decision making should be consulted: parents, physicians, and infant care review committees.

⁸⁴ *Ibid.*, *Ibid.*

⁸⁵ *Ibid.*, *Ibid.*

⁸⁶ S Wall, J Partridge, 64-70.

⁸⁷ Sklansky, 8.

Parents are typically the most important and appropriate decision-makers for their child.⁸⁸ The assumption is that parents exhibit a certain love for their children which makes them most suitable to act in the best interests of the infant. Therefore, society should grant the parents ultimate decision-making when it comes to their own child. However, there are times when the parents are unable to act in the best interests of their child. The stress of a defective newborn may be too overbearing for the parents to make rational decisions and, in addition, both emotional and financial stresses build when a defective newborn is in the hospital for an extended amount of time for treatment. This heavy burden may lead the parents not to act in the best interests of the infant.

If parents are unable to act in the best interests of their child, then one can argue that physicians would be next in line as the best decision-makers.⁸⁹ After all, physicians have superior medical knowledge about the infant's prognosis and ability to have a quality of life. Furthermore, some claim that physicians tend to approach the cases in an objectified manner that does not involve the same emotional intensity that parents have. However, physicians may not be best suited to make a decision for the infant for the following reasons. First, some physicians are drawn to non-treatment in some cases because of their bias of normalcy, what they define as viable enough for an infant to live. In today's world of high costs for medical care, certain doctors have been rewarded by health insurance organizations when they do not provide excessive care.⁹⁰ Furthermore,

⁸⁸ Sklansky, 8..

⁸⁹ *Ibid.*, *Ibid.*

⁹⁰ R Shapiro and R Barthel, "Infant care review committees: an effective approach to the Baby Doe dilemma?" *The Hastings Law Journal* 37 (1986): 848.

doctors are not unexposed to certain emotional stress, whether it be financial or over an attachment to the patient.⁹¹

When neither parents nor doctors are able to make an objectified decision for the infant, they can turn to the Infant Care Review Committee. The Infant Care Review Committee (ICRC) was conceived to provide them with consultations, not decisions. The ICRC included "a practicing physician, a practicing nurse, a hospital administrator, a social worker, a representative of a disabled group, a lay community member, and a member of the facility's organized medical staff as chair."⁹² One of the positive things that the ICRC brings to parents and physicians is the ability to provide unbiased, educated, and unemotional advice. The only setback may be that committees and organizations sometimes are slow to recommend a course of action and often in the neonatal intensive care unit decisions need to be made quickly. Ethicists also want to emphasize that decision-making should ultimately lie in the parent's and physician's hands while the ICRC can serve an advisory role to resolve disputes and ensure the best interests of the infant are being determined.

Ethicists such as Michael Gross have taken a different approach to neonatal issues than what has been previously mentioned in this chapter.⁹³ As we discussed in the previous chapter, he examines and critiques the three approaches (aggressive treatment, initial treatment but reevaluation and statistical cut offs) used by neonatologists throughout the world when caring for very sick newborn babies. In particular, he examines their efficacy by taking a look at the case of baby Messinger. Baby Messinger,

⁹¹ R Weir. *Selective non-treatment of handicapped newborns: moral dilemmas in neonatal medicine*. (New York: Oxford University Press, 1984): 257.

⁹² R Shapiro and R Barthel, 848.

a severely ill preterm infant, was born with a 50-75% chance of mortality and a 20-40% chance of severe cerebral hemorrhage and neurological damage in addition to the potential of significant respiratory complications. After consultation with the parents, the attending physician instructed her assistant to intubate the baby only if he was "vigorous" and "active". Even though the baby was born with severe complications and hardly seemed to be viable, the instructions were ignored. The father, outraged by the hospital's actions, physically removed his son's life support and the child died in his parent's arms.⁹⁴ Messinger was charged with manslaughter and later acquitted.

After examining the case of baby Messenger, most ethicists concluded that the parents hold the best interests of the child and therefore should be given greater authority in decision-making.⁹⁵ However, as we discussed earlier, parents are not always in the right position to make decisions for their children and often need outside support to help them determine what is in the best interests of the child.

Some countries, as we have discussed in chapter one, have adopted a strict statistical approach for extremely low birth weight (ELBW) infants. However, other countries, understanding that parents need to be involved in decision-making and often have the best interests of the child in mind, have adopted a modified version of this approach. Under this modified approach, The Danish Council of Ethics considers not only a minimal gestational age and a maturity criterion, but also respect for parental

⁹³ Michael L Gross, "Avoiding anomalous newborns: preemptive abortion, treatment thresholds and the case of Baby Messenger", *Journal of Medical Ethics* 26 (2000): 242-248.

⁹⁴ JJ Paris, "Parental right to determine whether to use aggressive treatment for an early gestational age infant: The Messinger case" *Medicine and Law* 16 (1997): 679-85.

⁹⁵ FI Clark, "Making sense of state vs. Messinger" *Pediatrics* 97:4 (1996): 597-83; H. Harrison, "Commentary: the Messenger case" *Journal of Perinatology* 16:4 (1996): 299-301; JJ Paris, MD Schreiber, "Parental discretion in refusal of treatment for newborns: a real but limited right," *Clinics of Perinatology* 23:3 (1996): 573-81.

wishes when making decisions.⁹⁶ For example, if a child is born younger than 24 or 25 weeks gestational age, then the infant is not treated, unless the caregivers can use "low technology modalities" and minimal respiratory help.⁹⁷ However, if the parents decide that they can take care of the infant and are well aware of some of the challenges down the road, parental wishes may override minimal gestational age. In the case of baby Messenger under these criteria, the infant would not have been treated even if the child met some of the other criteria because the parents did not want to care for a defective preterm infant.⁹⁸

Although this approach takes into account parental wishes, some ethicists object to it on grounds that it would be more just and cost-effective to initially resuscitate all infants and then constantly evaluate the case to see which babies are most severely affected.⁹⁹ As I wrote in the first chapter, this approach is advocated by Dr. Kinlaw.¹⁰⁰ However, according to Gross, even this policy has its shortcomings. Physicians may not know the outcome of ELBW infants until they are certain they have done everything they can, which may in the long run produce more healthy human beings. In summary, Gross has narrowed down his objections to this policy to the following points.¹⁰¹ First, in all cases where doctors and parents decide to terminate life support before absolute certainty, they deny the lives of potentially healthy human beings. Second, cost effectiveness should not enter the discussion. Finally, one may object to threshold protocols because of

⁹⁶ Danish Council of Ethics, *Debate outline: extreme prematurity, ethical aspects* (Copenhagen: Eurolingua, 1995): 28-9.

⁹⁷ Danish Council of Ethics, 6:19-21; T Jakobson, J Gronvall, S Petersen, GE Andersen. " 'Minitouch' treatment of very-low-birthweight infants," *Acta Paediatrica* 82, 3 (1993):934-8.

⁹⁸ Gross, 243.

⁹⁹ *Ibid.*, 244.

¹⁰⁰ Kathy Kinlaw, MDiv, "The Changing Nature of Neonatal Ethics in Practice," *Clinics in Perinatology*, 23:3 (1996).

¹⁰¹ Gross, 244.

the slippery slope argument. If we allow people to refuse treatment of ELBW infants, what will keep us from terminating late term pregnancies?

Instead, Michael Gross advocates that we should indeed consider late-term abortions to preempt the issues that occur when babies are born with ELBW.¹⁰² Gross is well-aware that in the US this practice would not be possible, except in a few rare cases; and furthermore, depending on your definition of the fetus and its rights, this may well be considered a case of active euthanasia, which is condemned and prohibited in most states.¹⁰³ In Israel where it is much easier to justify this practice, the rate of late-term abortions is one of the highest in the world.¹⁰⁴ If the parents of baby Messenger had the option of aborting the fetus before birth, they may well have done so to avoid some of the ethical dilemmas that occur after birth.

In this chapter, we have defined some medical terms that are often taken for granted. Then, after getting an idea of how to define different kinds of euthanasia and seeing what some of the issues are when trying to do so, we considered which moral approaches ethicists suggest should be taken when caring for infants. We learned that many of these moral criteria cannot exist independently, but rather all of them have to be considered when caring for an infant. We also understood that, although the parents usually have the best interests of the child in mind, they ultimately may not be in a position to act on them due to emotional stress that is caused by treatment in the NICU. In that case, we turn to the infant's caregivers and ethics committees for solid

¹⁰² *Ibid.*, 245.

¹⁰³ *Ibid.*, *Ibid.*

¹⁰⁴ ML Gross, "After feticide: coping with late-term abortion in Israel, Western Europe and the United States," *Cambridge Quarterly of Healthcare Ethics* 8:4 (1999): 449-62.

recommendations of what would be the best course of action, but decision-making ultimately lies with the parents unless the courts are forced to intervene.

In the next chapter, we will see how traditional Jewish law informs our care of ELBW infants. In particular, we want to see if any of the approaches that have been recommended by doctors and ethicists comply with Jewish law. Finally, we hope to provide parents and caregivers a guide for issues such as these, both from a traditional Jewish point-of-view, and from a Reform one.

Chapter 3- Traditional Jewish Viewpoint

Up until this point, we have discussed how hospital caregivers and medical ethicists have dealt with moral dilemmas confronting treatment of very sick newborns. Although varied in practice, when looking at each case, we discovered that both hospital caregivers and medical ethicists have developed criteria. In cases of adults and newborns, we also found that different kinds of euthanasia are practiced in certain parts of the western world.

In this chapter, we want to determine whether or not neonatal euthanasia would be permitted under any circumstances in Jewish tradition. In order to determine this, it is important to take a look at what Jewish tradition says about euthanasia. Jewish tradition defines suicide as a "rational, premeditated act of self-killing."¹⁰⁵ Judaism holds that every human life is sacred, emphasizing that our bodies belong to God.¹⁰⁶ As Owner, God has the right to impose certain prohibitions on what we do with our bodies.¹⁰⁷ Euthanasia, assisted suicide or mercy killing, is therefore prohibited according to Jewish law. Even if a person is at the end stages of one's life (*goses*), a person within 72 hours of death, the sources tell us that we are to treat the *goses* with the status of a living person. "The dying person is like a living person in all respects" (*Semachot* 1:1).¹⁰⁸ The Tanaitic text specifies what can be done to the *goses* (*Semachot* 1:2-4):

One may not bind his jaws, nor stop up his openings, nor place a metallic vessel or any cooling object on his navel until such time that he dies as it is written (Ecclesiastes 12:6): "Before the silver cord is snapped asunder."

¹⁰⁵ *Shulchan Aruch*, 345:2-3 and commentaries.

¹⁰⁶ Exodus 19:5; Deuteronomy 10:14; Psalms 24:1; also see Genesis 14:19, 22 (Hebrew word for "Creator" [*koneh*] is interpreted here as "possessor").

¹⁰⁷ See Deuteronomy 20:19-20; B. *Bava Kamma* 8:6, 7; B. *Bava Kamma* 92a, 93a; M.T. *Laws of Murder* 1:4 (Maimonides specifically talks about the theological basis for laws against suicide).

One may not move him nor may one place him on sand or on salt until he dies.

One may not close the eyes of the dying person. He who touches them or moves them is shedding blood because Rabbi Meir used to say: this can be compared to a flickering flame. As soon as a person touches it, it becomes extinguished. So too, whosoever closes the eyes of the dying is considered to have taken his soul.

Any action taken to hasten the death of a dying person is seen by the Tanaitic text as literally killing the patient, or committing an act of murder. The authors of the Babylonian Talmud and Jewish codes take a similar point-of-view. "Our Rabbis taught: He who closes [the eyes of a dying man] at the point of death is a murderer. This may be compared to a lamp that is going out: If a man places his finger on it, it is immediately extinguished."¹⁰⁹ Rashi points out that although this is a small effort, it nevertheless hastens death.

One of the greatest authorities on Jewish law, Moses Maimonides, interprets the text *Semachot* passage as follows:¹¹⁰

One who is in a dying condition is regarded as a living person in all respects. It is not permitted to bind his jaws, to stop up the organs of the lower extremities, or to place metallic or cooling vessels upon his navel in order to prevent swelling. He is not to be rubbed or washed, nor is sand or salt to be put upon him until he expires. He who touches him is guilty of shedding blood. To what may he be compared? To a flickering flame, which is extinguished as soon as one touches it. Whoever closes the eyes of the dying while the soul is about to depart is shedding blood. One should wait a while; perhaps he is only in a swoon...

¹⁰⁸ Talmudic translations from *Soncino Classics Collection*, Chicago, IL: Davka Corporation in conjunction with Judaica Press, 1996.

¹⁰⁹ BT *Shabbat* 151b

¹¹⁰ *Mishneh Torah* Judges, Laws of Mourning 4:5.

Maimonides reiterates that one should not do anything to hasten the death of the patient. Maimonides does not state like the Mishnah that one should not move the patient, but he might imply it when he says not to bathe or do anything that involves touching the patient.

Judaism also places great emphasis on saving a life (*pikuach nefesh*), so much so that one may violate Shabbat and Yom Kippur if there is a chance for survival.¹¹¹ The rabbis find biblical justification in Leviticus 18:5. "These are the commandments which one shall do and live by them." The rabbis add, "and not *die* by them."¹¹² Two important principles can be derived from this midrash.¹¹³ First, if we should not "die" by doing the commandments, then we should set aside those (commandments) that endanger life. Second, preservation of life according to the rabbis' interpretation of the Torah is of the highest values in Jewish tradition. Therefore, the practice of medicine, which aims to protect the sanctity of life, is defined as an instance of *pikuach nefesh*. Although the Torah never explicitly states that the practice of medicine is a commandment, the rabbis find their biblical justification through the exercise of Midrash. In Exodus 21:18-19, we read, "When men quarrel and one strikes the other with stone or fist, and he does not die but has to take to his bed if he then gets up and walks outdoors upon his staff, the assailant shall go unpunished, except that he must pay for his idleness and his cure." From this verse, the rabbis argue that physicians are permitted to practice medicine. Or, in a similar circumstance where one is injured and needs medical attention, the rabbis look to Leviticus 19:16: "Do not stand idly by the blood of your neighbor." The

¹¹¹ Mark Washofsky, *Jewish Living: A Guide to Contemporary Reform Practice* (New York, NY: UAHC Press), 220-224.

¹¹² BT *Yoma* 85b, also see Ramban *Torat Ha'adam*, 41-42, and *Shulchan Arukh*, *Yoreh De'ah* 336:1.

¹¹³ Washofsky, 222.

obligation of practicing medicine, however, is incumbent upon every Jew, not just a physician, to ensure that people have proper care. "The performance of medicine is a *mitzvah*. One who does so diligently is worthy of praise; but one who delays in securing medical treatment is like a shedder of blood."¹¹⁴ Ramban quotes Mishnah *Yoma* 8:6, which declares that we are to feed a patient suffering from *buleimos* on Yom Kippur on the order of a physician.¹¹⁵ Thus, if one can break Yom Kippur to save a life, medicine *must* be defined as an instance of *pikuach nefesh*. Maimonides derives his basis for medicine as a commandment to save a life from Deuteronomy 22:2: "And if your brother is not near you, or if you know him not, then you shall bring it to your own house, and it shall be with you until your brother seeks after it, and you shall restore back to him."¹¹⁶ Maimonides interprets this verse as obligating every Jew to save a person from terrible danger. No matter where our commentators derive the commandment to practice medicine, they all inevitably link practicing medicine to saving a life, a value that is paramount in Jewish tradition.

Although Jewish tradition prohibits suicide, there are exceptions to the rule. One major exception would be in the case of martyrdom.¹¹⁷ There are three sins which a Jew must never commit, even at the cost of his/her life. Those cases are when one is forced to commit murder of another, idolatry, and if one is forced to commit adultery or incest. By avoiding these transgressions and choosing death, one fulfills the commandment of *kiddush hashem*, sanctification of the Divine Name.¹¹⁸ The sources take special

¹¹⁴ Nachmanides, *Torat Ha'adam*, 41-42.

¹¹⁵ *Buleimos* is a sickness that is caused by hunger. The rabbis tell us that one can even eat something impure until the patient shows signs of life.

¹¹⁶ Rambam, *Commentary to the Mishnah*, Nedarim 4:4.

¹¹⁷ Dorff, 181.

¹¹⁸ BT Sanhedrin 74a-b and parallels; *Yad*, Hilchot Yesody HaTorah 5:1-4; YD 157:1.

consideration for those who are in extreme circumstances and commit suicide. The classic case in Jewish tradition is that of King Saul who falls on his sword instead of being captured by his enemies and facing a degrading death (I Samuel 31:4). Radak, in his commentary to this verse, states that Saul did not immediately die but was wounded. In his pain, he asks the Amalekite to hasten his death. Some commentators justify his act out of fear that if Saul would have been captured, the Israelites would have felt bound to save his life.¹¹⁹ Another argument is that Saul feared that if he was captured, he would be forced to commit idolatry. Thus, his death would be justified.¹²⁰ Others, however, reject the claims of many commentators and see this act as a case of classic suicide, forbidden by Jewish tradition.¹²¹

Jewish tradition also distinguishes between hastening one's death and simply removing an impediment that plays no therapeutic value except to keep the patient alive. The former is prohibited as "bloodshed" (*Semachot* 1:2-4 and commentaries); the latter is permitted. The major statement of this distinction is drawn upon from Rabbi Judah ben Samuel, the Pious, author of the 13th century work, *Sefer Chasidim*.¹²² He says, "It is not permitted to hinder the death of a person...if a person is dying and someone near his house is chopping wood so that the soul cannot depart then one should remove the (wood) chopper from there." The implication is that we are permitted to remove an impediment, since that factor is an unlawful presence in this particular case. Based on this statement, R. Moshe Isserles (Rema) in *Shulchan Aruch* Yore De'ah 339:1 rules that while it is not permitted to do anything that would hasten the death of the *goses* (such as

¹¹⁹ R. Shelomo Luria, *Yam shel Shelomo*, Baba Kama, ch. 8, no. 59

¹²⁰ *Hiddushey HaRitvah*, Avodah Zarah 18a

¹²¹ R. Yosef Karo, *Bedek HaBayit*, *Tur* YD 157.

¹²² *Sefer Chasidim*, no. 723.

moving him or removing a pillow and here he affirms the basic ruling in the *Shulchan Aruch*), "if there exists any factor which prevents the soul from departing, such as the sound of the woodcutter near the house or salt on the patient's tongue...it is permitted to remove that factor. This is not considered a positive act (*ma'aseh*) but merely the removal of an impediment." Isserles takes *Sefer Chasidim* one step further by classifying salt as a potential impediment.

Although some commentators permit the removal of impediments, most are very quick to define what that means.¹²³ In his commentary, Isserles does not permit the removal of a mattress from under the patient. Isserles distinguishes it as physical act, one that involves coming into physical contact with the patient. On other hand, he does permit one to physically remove salt from the patient's tongue. There seems to be a contradiction between the two—both require physical contact. Halakhic authorities try to solve the inherent contradiction. Some more stringent authorities decide that Isserles is wrong altogether and do not allow the removal of salt. David ben Samuel ha-Levi Segal, known as the Taz, writes in *Turei Zahav*, his commentary to the *Shulchan Arukh*, after summarizing Isserles and *Sefer Chasidim* that "it is forbidden to move a mattress...which is a positive act. This is the same thing as closing the eyes, even a little touch. How can he (Isserles) says it is alright. Therefore, it appears that we shouldn't allow a permit with removing salt because it is movement." Even though one is removing something on the body that should not have been there in the first place, the Taz sees any movement as a positive act, which hastens the death of an individual.

¹²³ Fred Rosner and J. David Bleich, eds., *Jewish Bioethics*, 278-283.

R. Yehoshua Boaz b. Baruch, the author of the 16th century *Shiltey Giborim*, a commentary to Alfasi, offers a third approach, which redefines the issue along the lines suggested by the *Sefer Chasidim*.¹²⁴

Certainly, to do anything which would cause a dying person not to die quickly is forbidden, for instance to chop wood in order to delay the soul's departure or to put salt on his tongue so that he not die quickly...In all such matters it is permissible to remove the causative factor.

Although he agrees that one should not impede the death of another, there are certain limitations of what one can do without hastening the death, or "shedding blood". "After many years, I found in the *Sefer Chasidim* (723) support for my contentions, as it is written there that if a person is dying but cannot die until he is put in a different place, he should not be moved." Salt, which does not bring any healing, only impedes the death of the *goses*; and should not have been put there in the first place. Therefore, while causing physical contact, removing it from the tongue is permitted because it reverses what was a prohibited act.

Shiltey Giborim's commentary turns our attention from "active" and "passive" to one of nature and purpose of our actions. The issue is whether or not the actions of the doctor are medically efficacious. The doctor should not apply any measures that have no therapeutic value. His actions are not considered legitimate "medicine"; they would only serve to impede death, something as we have discussed is forbidden according to Jewish law. Therefore, it is permitted to touch the patient to rectify the mistake that was made in the first place by the doctor or in our case, to remove the salt from the person's tongue.

Reform Responsum 5754.14 mentions that one can make an analogy between the birdfeathers, salt, and woodchopper and modern medical equipment that has to be turned

¹²⁴*Shiltey Giborim* to Rif, *Mo'ed Katan*, Chapter 3, #1237.

off in order to end life such as life support machines. "While the realia mentioned in this passage hardly resemble what we recognize as science, Isserles and *Sefer Chasidim* deal here with an issue familiar to all students of contemporary medical ethics."¹²⁵ As we have discussed in chapter two, ethicists distinguish between hastening someone's death on the one hand; and on the other hand, removing an impediment to death.¹²⁶ One cannot delay someone's death, but at the same time, you may not hasten the person's death. Whether or not an analogy can be made, the commentaries do tell us that one cannot hasten death in any way, but you can remove any device that provides no therapeutic value.

Whether or not the above commentaries support any form of euthanasia is difficult to determine. I have not found any experts on Jewish law who support the practice of "active euthanasia". Active euthanasia, as stated above, "refers to that class of euthanasia wherein the death is directly and actively caused by another person."¹²⁷ However, depending on your definition, some see the practice of "passive euthanasia" as permissible in certain cases. "Passive euthanasia refers to those cases of euthanasia wherein death occurs because of absence of an intervention that would have prolonged life; passive euthanasia usually refers to withholding or withdrawing life-supporting therapy."¹²⁸ This definition also may make authorities of Jewish law uncomfortable. A key word is missing—*unnecessary* prolongation of life. In other words, if passive euthanasia can be defined as the removal of any life-sustaining therapy that is no longer providing therapeutic value; and therefore, the prolongation of life is unnecessary; then

¹²⁵ W. Gunter Plaut and Mark Washofsky, eds., *Teshuvot for the nineties* (New York, NY: Central Conference of American Rabbis, 1997): 344.

¹²⁶ Sklansky, 5-11.

¹²⁷ Sklansky, 5.

authorities of Jewish law may feel more comfortable with the definition. Authorities such as Rabbis Elliot Dorff and Moshe Zemer use the term, passive euthanasia, in specific cases.¹²⁹ However, others, such as the authors of the Reform Responsa, prefer not to use this term because they feel it is not always clear how to draw the line between active euthanasia and "removing an impediment".¹³⁰

There are also those modern commentators that propose a reexamination of certain biblical and Talmudic stories that could be used to support active euthanasia, but have not been interpreted so by most authorities.¹³¹ These commentators, as Kravitz and others would argue, did not anticipate today's medical needs; and therefore it calls for us to find permission for the practice of active euthanasia in those *extreme* cases.

The first example that is often cited by those who support active euthanasia in extreme circumstances is the Death of King Saul.¹³² As mentioned above, most commentators justify his act as an extreme circumstance permitted in Jewish tradition. However, others, who see the practice of active euthanasia as permitted in Judaism under certain circumstances, emphasize that Saul's death was an act to spare himself pain and agony at the hands of his captors. Supporters, such as Leonard Kravitz, argue that this case can be used to support those terminally-ill patients in extreme pain and agony who want to hasten their death, rather than wait until their body finally stops functioning naturally.

¹²⁸ Sklansky, 5.

¹²⁹ Dorff, 198 and Moshe Zemer, *Evolving Halakhah: A Progressive Approach to Traditional Jewish Law* (Woodstock, Vermont: Jewish Lights Publishing, 1999) 351-356.

¹³⁰ *Teshuvot for the nineties*, 344-345; Abraham S. Abraham, *The Comprehensive Guide to Medical Halachah* (Jerusalem and New York: Feldheim Publishers, 1990) 177; Fred Rosner, *Modern Medicine and Jewish Ethics* (Hoboken: KTAV, 1991) 211, 212.

¹³¹ Leonard Kravitz, "Euthanasia", Walter Jacob and Moshe Zemer, eds., *Death and Euthanasia in Jewish Law* (Pittsburgh, PA: Rodef Shalom Press, 1994) 11-25.

¹³² I Samuel 31:4

The death of R. Chaninah b. Teradyon is the second case where some commentators have argued that suicide may be permitted according to Jewish law.¹³³ According to the story, R. Chaninah b. Teradyon died a martyr's death at the hands of the Romans during the Hadrianic period for teaching Torah to his students. R. Chaninah was wrapped in parchment from the *sefer Torah*, the Romans placed wet woolen rags around him in order to prolong the pain, and finally, lit him on fire so that he would slowly burn to death. By refusing to open his mouth he does not "hasten his death." "It is better that the One who gives life take it away than for a person to bring harm upon himself." One guard, in order to seek a place in the world to come, asks the rabbi, "Rabbi, if I increase the flame and remove the rags, will you guarantee me life in the world to come?", R. Chaninah answers, "yes," and the guard performed the act.

The guard commits two actions, which some Jewish ethicists have used to make analogy to modern medical ethics. The first, removing the rags is akin to "removing an impediment". The second, however, would be considered hastening his death because he increased the flames to bring about death. Perhaps, then, this is support for active euthanasia in Jewish law. In this case, R. Chaninah does not kill himself, but asks the guard to do it for him. The question, then, is whether Judaism allows a person to appoint another to hasten his death. One can deduce that if one is not allowed to kill oneself, then one is not allowed to appoint another to do it as well.¹³⁴ However, this does not solve whether or not R. Chaninah committed suicide because on the surface, it appears as if he

¹³³ BT Avodah Zarah 18a.

¹³⁴ See *Teshuvot for the nineties*, 362, see note 66. The operative principle is *sheluchō shel adam kemoto*, "one's agent is the legal equivalent of oneself". A person's legal representative, who carries that person's "power of attorney", is endowed with only those rights enjoyed by the one who appointed him or her. A corollary is the statement *ein shaliach ledevar aveirah*: "an agent cannot legally perform a transgression." Should I instruct my agent to do something prohibited by Torah, those instructions are null and void; BT Kiddushin 41b-42b and parallels.

did. The commentators solve this contradiction by stating that this case is one of martyrdom, for which, as I have described, a different set of rules apply.¹³⁵ According to traditional authorities, the Roman guard is not R. Chaninah's agent, but rather his executioner. In other words, he cannot appoint the guard to do anything. The guard is controlled by Roman authorities, not by R. Chaninah; and therefore, whether or not the guard wants to hasten the death of R. Chaninah is entirely up to him. If R. Chaninah did have any jurisdiction over the Roman authorities, then it would be considered a case of suicide. However, he does not and these set of facts distinguishes between martyrdom and in the case of a terminally-ill patient.

Leonard Kravitz argues that Rabbi Hananiah did "hasten his death".¹³⁶ R. Hananiah could have remained silent, he maintains, but he did not. Instead, when confronted with unbearable pain and an impending death, he chose to "hasten his death." Kravitz is making two important points. First, it was clear that Rabbi Hananiah was going to die. Second, in the face of unbearable suffering, he decided to "hasten his death" which, Kravitz argues, is permissible.

The third case that is often cited by some authorities as permitting euthanasia is the death of R. Yehuda Hanasi (Rabbi).¹³⁷ Rabbi becomes very sick and some of his students gather around him to pray for his recovery. At first, his maidservant becomes very sympathetic to their efforts. However, after discovering that the Rabbi is beyond healing, she prays that the rabbi die quickly. The maidservant sees that the prayers are only prolonging his suffering. Realizing that the students are not going to stop their praying, she drops a glass vessel from the attic of the house of the ground. The shattering

¹³⁵ See note 15.

¹³⁶ Kravitz, 14, 15.

sound immediately causes the Rabbi's disciples to stop their prayers and he subsequently dies.

Some read these stories as an example of mercy killing and therefore use this story to support the practice of active euthanasia for those who are suffering from a terminally-ill disease.¹³⁸ As is the case in the story of King Saul and R. Chaninah, most authorities of Jewish tradition do not perceive this as hastening his death, but rather as removing an impediment to avoid unnecessary prolongation of life.¹³⁹ However, Kravitz takes this one step further when he contends that the story tells us that one can determine another's level of pain and therefore act upon it if they so wish. "The story also suggests that one may act upon that observation, since in no way do we find actions of the maid condemned. Even though death was speeded from the suffering old man, we do not read in the *Talmud* text following that story that...namely that 'Jewish Law...cannot...purchase relief from pain and misery at the cost of life itself.'"¹⁴⁰

Kravitz argues that quality of life should play a role in determining the course of treatment for a terminally-ill patient. Unlike a *goses*, who will die within 72 hours, people can live with a terminal illness for months and even years without dying. For the person who may suffer unbearable pain and suffering, some such as Kravitz and Knobel maintain that it may be permissible to hasten the death of the terminally-ill patient.¹⁴¹ In defense of their argument, they direct us to look at the crime for capital offenses. The *Talmud* uses Leviticus 19:18 "Love your neighbor as yourself" to argue that this person

¹³⁷ BT Ketubot 104a

¹³⁸ Kravitz, 15-17.

¹³⁹ R. Nissim Gerondi, *Commentary to BT Nedarim 40a and Resp. Igrot Moshe*

¹⁴⁰ Kravitz, 16.

¹⁴¹ *Ibid.*, 19-22 and Peter Knobel, "Suicide, Assisted Suicide, Active Euthanasia", Walter Jacob and Moshe Zemer, eds., *Death and Euthanasia in Jewish Law* (Pittsburgh: Rodef Shalom Press, 1995) 45, 46.

should have a *mitah yafa* (a nice death).¹⁴² Rashi explains this term to mean *sheyamut maher* (that he will die quickly). Using the logic of *kal v'chomer*, Kravitz, Knobel, and others argue that if a person who is guilty of a capital offense can have a speedy death lacking any kind of suffering and pain, then all the more so should an innocent person of any offense be allowed to have a speedy death without pain and suffering. In conclusion, Kravitz defines who will be able to hasten their death¹⁴³:

Euthanasia, the *mitah yafah*, for me, is an option only in the case of someone who is terminal, *sheyamut*, that he will die and that he not suffer further, we think of *maher*-speedily. Euthanasia, we have said applies to one who is in process of dying and who is suffering; we must be sure of the first and unable to control the second. (Those strictures should obviate many problems). If that person be lucid and not wish the battle for life to continue, then his/her wishes should be followed as to when and how the end should come, whether that end comes by not doing something or by doing something...If, however, the patient not be lucid, then if he or she has left some instrument to indicate his/her intentions, a "living will" or a letter to the physician, then those instructions should be followed.

Kravitz notes that he goes far beyond where most Jewish medical ethicists are willing to go regarding end of life and euthanasia. He believes that the Jewish value of *veahavta l're'akha kamokha* "loving your neighbor as yourself," guides us to limit pain for a person with a terminal illness.

This argument is in direct contradiction to two key traditional Jewish concepts. First, as we have discussed above, God gave us our life and takes it back when it is our time to die. Second, as it is stated in Reform Responsum 5754.14:

¹⁴² BT *Sanhedrin* 45a, and Rashi.

¹⁴³ Kravitz, 21-22.

...the removal of an impediment is not an act of killing at all, even passive killing, [NOTE: the responsum rejects the use of the term "passive euthanasia"] but in fact a corrective measure taken against a situation that we have wrongly allowed to occur. For while Jewish tradition forbids us to kill a terminal patient it also forbids us to delay her death unnecessarily. It is therefore permitted to remove any factors which contribute to that delay. To permit mercy killing, however, would be to permit the taking of a life even in the absence of "impediments" (machines, medications, etc.) that serve no therapeutic effect other than to delay death. Such killing is qualitatively distinct from the removal of an impediment.

Some such as the authors of this Reform Responsum would not support Leonard Kravitz and Peter Knobel's claim that there is a difference between "removing an impediment" on the one hand and "mercy killing" on the other. Kravitz and Knobel do not see a substantial difference between the two and would feel comfortable in some cases with mercy killing, using the justification mentioned above.

Although most authorities on Jewish law and medical ethics would not permit mercy killing or hastening the death of a patient, they do, however, recognize that Judaism is very concerned about pain and suffering.¹⁴⁴ Jewish tradition does not require physicians and caregivers to resort to "heroic" measures to prolong life. In fact, quality of life does exist in Jewish tradition. The Gemara tells the story of a great sage Rabbi Yehoshua ben Levi who did not fear the deadly infectious disease, attaching himself to the sufferers of that disease and studied Torah with them.¹⁴⁵ He said, "Torah bestows grace upon those who study Torah and protects them." As death was approaching, the Angel of Death was instructed to carry out his wish. On his way to Paradise, Rabbi

¹⁴⁴ Moshe D. Tendler and Fred Rosner, "Quality and Sanctity of Life in Talmud and the Midrash," *Tradition* 28:1 (1993) 18-27.

¹⁴⁵ BT *Ketubot* 77b

Yehoshua ben Levi asked to hold the sword of the Angel of Death and he refused.

However, God orders the Angel of Death to allow him to use the sword. The imagery of the sword is symbolic of Rabbi Yehoshua ben Levi's request to hasten his death because life had become so burdensome.

All the cases that we have considered thus far are related to adults. This paper is mainly concerned with the case of a very low birth weight and sick infant. Do we treat the infant the same as an adult? According to Jewish tradition, when an infant is born, he/she is given the same status as an adult. However, treatment of newborns may vary according to their viability. Jewish tradition tells us that a seven and nine month baby may live, but an eight month baby may not. Even if an eight month baby needed treatment, one could not override Shabbat.¹⁴⁶ Tosefta says, "He (eight month baby) is a like a stone. One does not move him [on Shabbat], but his mother may bend over him to suckle him." In the Talmud, due to the uncertainty of whether or not the child may or may not live, Rabban Simeon ben Gamaliel's did not consider a child viable until the thirty-first day after birth.¹⁴⁷ Although the Talmud advocates for treatment in certain situations, it would be much harder to support this knowing what we know today about medicine and neonatal. Therefore, the Conservative Movement's Committee on Jewish Law and Standards waived the old rule and advocated that a viable newborn should be treated the same as a viable adult.¹⁴⁸

Jewish tradition has also advocated the removal or withholding of care in the case of infants that are born with some kind of abnormality. "The sages say: Whatever does

¹⁴⁶ Tosefta *Shabbat* 15:5-7, BT *Shabbat* 135a, JT *Yevamot* 4:2, *Shulchan Aruch* OH 330:5.

¹⁴⁷ BT *Shabbat* 135b.

¹⁴⁸ http://www.rabbinicalassembly.org/teshuvot/docs/19912000/reisner_natology.pdf, Rabbi Avraham Israel Reisner, "Peri- and Neo-Natology: The Matter of Limiting Treatment," YD 339.1995.

not have the aspect of a human being is not [considered] a birth."¹⁴⁹ We do not know, however, what the Mishnah is referring to and medieval commentators try to settle it to no avail.¹⁵⁰ However, as we have made advances in modern medicine, we do know more about genetic abnormalities, which give us a more accurate picture of how long the infant may live. In other words, will the child have a viability that is worth saving the child? Are there situations where we could imagine allowing the child to die?

As I have presented earlier in this thesis, there are indeed cases where infants may not live beyond a week, month, or even a year with severe malformations. One such case would be an infant born with trisomy 13, where the infant is born with malformations in the brain and cannot support its own breathing, or trisomy 18 who also suffer from severe respiratory problems.¹⁵¹ Rabbi Avraham Reisner concludes that it is correct to classify cases such as these where the infants will not live longer than a year because they are unable to sustain their own vital organs as non-viable and withdraw any support being given at the time.¹⁵² However, he does not agree with the Talmudic position that these infants were never full births. If that were the case, Jewish law would tell us that there is not problem with removing care. "Rather, we should classify such newborn infants as born dying, and allow the latitude of non-treatment that we would consider appropriate at the end of life."¹⁵³ However, even for a severely premature newborn, where a chance of survival may exist, treatment should continue as it would for a full grown adult.

¹⁴⁹ Mishnah *Niddah* 3:2

¹⁵⁰ Maimonides, *Mishneh Torah, Issurei Biah* 10:11.

¹⁵¹ Presentation by Dr. Alan Fleischman, Director of Division of Neonatology at Weiller Hospital of Albert Einstein College, to the Subcommittee on Biomedical Ethics of the CJLS, 13 Sept. 1989 and D.W. Smith, "Recognizable Patterns of Human Malformation," vol. 7 in W.B. Saunders, *Major Problems in Clinical Pediatrics*, 3rd ed.

¹⁵² Reisner, 8.

¹⁵³ *Ibid.*, 8-9.

In cases such as Baby Doe in Indiana where a child was born with Down's syndrome (trisomy 21) or other disorders that do not severely affect the health of the infant, Reisner argues that full care should be pursued by the parents and caregivers.¹⁵⁴ In cases where the infant will not live beyond a year due to the inability to form viable organs, then I suggest that we see this as removing an impediment to death that would occur. In other words, if the child will not see any therapeutic value from the medicine and prolongation of life, then it is best to let life expire. In these cases, we should take into consideration viability and quality of life of the child for the reasons I just mentioned. There is no reason to prolong pain and suffering if there is no efficacy in improving the infant's life span above and beyond the first year of life. In cases such as Baby Doe and others where the parents chose not to do an elective surgery to prolong life above and beyond just a year after birth because the child was born with some kind abnormality, Jewish tradition would see this as "hastening the life" of those infants; and therefore, not following in line with "choosing life".

Knowing that each case is different, these situations need to be handled on a case-by-case basis. Parents should consult their rabbi to provide guidance from Jewish tradition. One thing is clear, however, that one may not remove care or refuse treatment of an infant simply because he/she is born with an abnormality. They are considered a viable life in every sense of the term according to Jewish tradition. However, if one is born with an abnormality, which has the characteristics of a terminal illness in that the infant will inevitably die within a specific amount of time, then Jewish tradition may tell us to remove life-sustaining care that is providing no therapeutic value while keeping the child on pain relieving medication and food and water nourishment.

¹⁵⁴ *Ibid.*, 9

In summary, when a very sick infant is born, Jewish tradition tells us to pursue aggressive care. We know this from the values of *pikuach nefesh* and the commandment to practice medicine to protect the sanctity of life. However, if the physicians and hospital staff determine that the child was born with a certain abnormality or has a disease that is terminal in nature, then we remove all life-sustaining machinery and medicine that has no therapeutic value. In other words, the infant is no longer a viable life and it is best to allow that life to expire. Decisions such as these are tough on the decision-makers, but crucial to following Jewish tradition and God's desires in the world.

Conclusion

In this paper, we began our discussion with a few case studies, Baby Doe and Baby Jane Doe, both of which had a profound impact on all levels of society regarding our practice of neonatology. Then in chapter one, we analyzed how neonatologists dealt with these cases and others, then taking a look at what confronts neonatologists today. In the future, neonatologists will have to make hard decisions of how to spend finite resources. Will the cost of healthcare for very sick newborns impact their decision on procedures in the hospital? Will neonatologists be forced to adopt some of the same procedures and criteria as their European counterparts have to reduce spending and utilize time effectively?

After understanding some of the issues that confront neonatologists, we analyzed how ethicists are dealing with these issues, providing, from a secular point-of-view, moral guidelines for treatment of very sick newborns. We learned that each of the moral criteria should be considered when deciding treatment for end of life issues regarding newborns. Although parents usually have the best interests of their child in mind, emotional and financial stress may hinder their ability to make those decisions for their child, forcing the medical ethics committees to make suggestions for health care workers and parents, and if it is an extreme case, the courts may be forced to intervene on behalf of the infant.

In chapter three, we analyzed what Jewish tradition would say about such cases. We learned that the values of *pikuach nefesh* and the commandment to practice medicine influence our decision of whether or not to pursue aggressive care. We also reiterated that God has ownership over our bodies, which is very different from the secular field of

ethics, which places emphasis on one's autonomy or right to choose what one wants to do with their body. If we are "borrowing" our bodies, then from a Jewish perspective, we take into consideration the principles of Torah before making decisions on whether or not to withdraw or withhold care from a very sick newborn. If, however, medicine cannot provide any therapeutic value and is simply prolonging suffering and life, we remove any impediments to death and allow the child to die as we learned from our study of removing any impediments to death.

Jewish tradition and secular medical ethics have many similarities and differences regarding their approaches to medicine. I already mentioned that secular ethics places special emphasis on the value of autonomy. However, it is impossible for an infant to make a decision regarding his/her life. Therefore, other moral criteria have to be taken into consideration. In particular, ethicists suggest that parents and caregivers should think about the best interests of the child. In Judaism, as I have already stated, our bodies do not belong to us, but rather to God. Our approach to medical ethics, therefore, is slightly different. The choice as to whether or not to withdraw or withhold care is not up to us; rather, it is up to God. How do we understand what God requires of us? We study our tradition and make the best decision possible, knowing that God commands us to practice medicine.

Efficacy of medical treatment plays a key role in decision-making in both secular medical ethics and Jewish tradition. Although some ethicists insist on the right to life from a secular point-of-view, most stress the therapeutic nature of medicine as a determination of whether or not to continue care. In Judaism, we also work from a similar criterion. If the doctors can do nothing more to save a patient and life is

ultimately terminal, from a Jewish perspective, one is not required to continue care, especially if there is no therapeutic value from the medicine. In fact, prolonging life may be frowned upon in most cases where it creates an impediment to death.

Up until this point, I have tried to present an unbiased perspective of each tradition. However, as a Reform Jew, I am compelled to end my thesis with a liberal one. What does it mean to approach these cases from a Reform perspective? As a Reform Jew, I try to balance the Jewish tradition (Torah and its commentaries, Talmud, codes, etc.) with what we know from a scientific perspective. Science tells us that we have to be open to change in the world with the times. Science makes us capable of making better decisions. Once we understand the cases better from a scientific point-of-view, then we can make a more accurate decision based on the moral values that are dictated from Jewish tradition.

In addition, Reform Judaism allows us to challenge tradition perspectives. Leonard Kravitz and Peter Knobel are two Reform Jews who confront our traditional understandings of euthanasia by reinterpreting stories from Talmud and Jewish tradition. Drawing from what they know from science and other secular disciplines, they offer new understandings of those stories often cited when discussing euthanasia. What this teaches us is that science sometimes forces us to reevaluate traditional understandings of Jewish tradition. As Reform Jews who see Judaism as an evolving religion, we should feel free to make such changes.

I would like to return to the case of Baby Messenger, which I discussed in chapter two. Baby Messenger was born with a 50-75% chance of mortality and a 20-40% chance of severe cerebral hemorrhage and neurological damage in addition to the potential of

significant respiratory complications. The attending physician, after consultation of the parents, instructed her assistant to intubate the baby *only* if the baby seemed viable after birth. Ignoring the order, the assistant took aggressive action despite the fact that the child was going to die. Leaving out the details of the rest of the case, if the parents approached a Reform rabbi inquiring how they should proceed, what would we say? What criteria should we use to determine our answer?

Our knowledge of medicine and science plays an important role in this case. The doctors have determined that the child may not live beyond a few days to a few months. Science helps us determine whether or not medicine will play any therapeutic value and whether the child will be viable enough to survive. From the facts of the case at the time, the doctors have determined that the child was not going to live a “viable” life, meaning that the child would not live beyond a year at the most. As Rabbi Reisner argues, we should see these infants that are born with severe abnormalities or complications as born dying. If the infant is born dying and knowing what we know from science, we should allow the child to expire, which in effect is removing an impediment to death. Prolonging life at this point would prolong suffering, and not allow the child’s soul to depart. Therefore, if the child was born unviable, I would advise the parents to let the child go, rather than prolonging life without any therapeutic value.

In this case, we analyzed what we knew from science and used what we hold as moral values from Jewish tradition to make the best decision for Baby Messenger. Each case is different. As we make more and more advances in technology and science, we may feel compelled to reevaluate our understanding of Jewish tradition. That is the beauty of Reform Judaism. We feel free to evolve when it requires us to. However, even

though each case is different, we still have a treasure of tradition to look for guidance, even if it is challenged by advancements in medical technology. In other words, we do not need to reinvent the wheel each time we confront these cases.

The values of *pikuach nefesh* and our duty to practice medicine to protect the sanctity of life, fighting until the last second, will always inform our decision-making as Reform Jews. However, we also consider if medicine is providing any therapeutic value, and as we make more and more advancements in medicine, we will become more learned about the right decision to make in any case. That is why it is difficult for me to make a general criterion for treatment of newborns. Each case may present something new and different from the previous case. However, we do know the values that guide us in making any end of life decisions for infants and they should be taken seriously with the consultation of a rabbi and healthcare team to make an educated decision for our congregants.

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