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The Reaper in the "Nursery": A Defense of Parental – Elective Euthanasia of Severely Ill Newborns

by Douglas Davison

(Philosophy 1100)

*Authors Note*

*"Jesus loves the little children*

*All the children of the world  
Red and yellow, black and white,  
All are precious in his sight*

*Jesus loves the little children of the world*

*Jesus loves the little children*

*All the children of the world There are those who need some help  
to walk, to talk, to see, to hear  
Jesus loves the little children all so dear"*

First verse original composition of Clarence Herbert Woolston

Second verse creation of Dawn Davison at the birth of her child, 1995



The author at 4 hours old



The author's cousin, Sam Richard Comstock, born 1994 with Trisomy 13 (Edwards Syndrome), lived three days

The scope of this essay is wide and full of such a large quantity of philosophical profundity such that it is easy to lose sight of its purpose. It is to shed light on the plight of infants with severe illnesses that limit quality of life. It is to these children that this essay is dedicated.

Camus' assertion that the "central problem of philosophy is that of suicide"<sup>1</sup> is undoubtedly incorrect. The central problem of philosophy is whether someone ought to have you killed. Nowhere else is this of greater importance than in Neonatal Ethics, a subdivision of medical ethics that addresses the treatment of congenitally defective newborn children. Firstly this essay will look at the philosophy behind the debate of infant euthanasia, especially the potential dangers inherent in modern day Preference Utilitarian theories of personhood. Second we advance a parental-elect model of infant euthanasia. The latter portion of this essay introduces such a policy already implemented in Europe, and evaluates the merit of this system in decisions of termination.

### Preference Utilitarianism

*Preference Utilitarianism* is rooted in the classical foundations of *Hedonistic Utilitarianism*, yet the former attempts to liberate the latter from the critique that happiness cannot be assumed the greatest good. Munson elaborates "Someone may value knowledge more than health, whereas someone else may value physical pleasure over knowledge or health ...there can be no clear cut procedure for determining what action is likely to produce the best outcome for an individual."<sup>2</sup> Resolving this conundrum "has led some thinkers to replace considerations of intrinsic value with considerations of actual preference. What someone wants, desires or prefers can be determined ...by consulting the person directly."<sup>2</sup>

### Singer-Tooley Model

Modern Preference Utilitarian's have attempted to develop a theory that endorses infant euthanasia as ethical. Leading this endeavor are the philosophers Peter Singer and Michael Tooley (their theory will be referred to as the Singer-Tooley model.) The model is an extension of their combined animal ethics. They contest that the ability of an organism to make preferences denotes its moral status as a "person". Attempts to claim personhood is denoted by one's genetic status as a human<sup>3</sup> are a *speciest* attempt to elevate humans over organisms whose sentience is relevant to moral decision making.

In order to make preferences, one must have the features of personhood. To Singer, these are "the characteristics like rationality, autonomy, and self-consciousness that make the difference" between persons and nonpersons.<sup>4</sup> Infants, having no "conception of self as a continuing subject of experiences" are not persons. Second, there is no significant developmental differentiation between 40-week-old fetuses from a born babies. Birth does not confer status of personhood.

"A prematurely born infant may well be less developed in these respects than a fetus nearing the end of its normal term. It seems peculiar to hold that we may not kill the premature infant, but may kill the more developed fetus. The location of the being - inside or outside the womb - should not make that much of a difference to the wrongness of killing it."<sup>4</sup>

<sup>1</sup> Camus, Albert. *The Myth of Sisyphus and Other Essays*. New York: Random House, 1991. Print.

<sup>2</sup> Munson, Ronald. *Intervention and Reflection*. 9<sup>th</sup> ed. Boston: Wadsworth, 2012. Print.

<sup>3</sup> See Noonan, *Abortion is Morally Wrong*.

<sup>4</sup> Singer, Peter. *Practical Ethics*. 2<sup>nd</sup> ed. New York: Cambridge University Press, 1993. Print.

It is only when the child has gained awareness of self and an ability to make preferences known that they have obtained personhood.

From the non-person status of infants Singer sets up a “replacement theory”.

“A woman planning to have two children has one normal child, and then gives birth to a haemophiliac child. The burden of caring for the child may make it impossible for her to cope with a third child, but if the disabled child were to die, she would have another.” “The loss of happy life for the first infant [disabled twin] is outweighed by the gain of a happier life for the second [the replacement]. Therefore, if killing the haemophiliac infant has no adverse effect on others, it would be...right to kill him.”<sup>4</sup>

### Critique of the Model

The non-status view of neonates lies upon faulty logic. Firstly, it equates all suffering with the same parity. The neonate, family members (such as siblings) and medical professionals all could potentially suffer from termination decisions. The theory could even endorse that the mental anguish of bystanders hearing about these “Baby Doe” cases in the news would have to be factored in. What if a child will foreseeably have a life full of physical and emotional dysfunction that he or she not ought live, but the collective public displeasure at its being killed forced this child to exist for sake of the utility of the group? Conversely, what if a child had a prognosis for a high quality physical life, along with likely healthy emotional existence, yet his parents, while loving of their other children, do not want this child?

The theory suffers from being a side effect of the resoluteness of both of these philosophers to reject “‘possibility of resolving the issue of abortion’ in terms of rights.”<sup>5</sup> In building a theory that demonstrates it is not seriously wrong to kill a fetus, they have supported a personhood theory with traits that even infants up to several years of age lack. “The lesser worry is where the line is to be drawn in infanticide ...there is no serious need to know the exact point at which a human infant requires a right to life.”<sup>6</sup> By defending the seriousness of killing animals, the Singer-Tooley Model has thrown the baby of a rational defense abortion out with the bath water. Certainly the conservative attack that “we are extending the period of abortion into the neonatal stage” sits in the back of the minds of any liberal defense of infant euthanasia.

The theory is also prone to a “slippery slope” attack. Tooley writes “In the vast majority of cases for which infanticide is desirable, its desirability will be apparent within a short time after birth.”<sup>6</sup> But if neonates lack a serious right to life, then is it wrong to kill infants for reasons other than quality of life? Conservatives are quick to throw out a “reductio ad hitlerum” (a fallacy comparing another's belief to Nazism) but legitimate concern should be raised over whether this policy would allow termination for societal utility reasons. Societal endorsement that neonates are persons at birth with full legal rights would prevent “eugenic” or social utility practices from developing.

<sup>5</sup> Weiss, Roslyn. “The Perils of Personhood.” *Ethics*, vol. 89, no. 1, Oct. 1978, pp. 66-75. *JSTOR*, www.jstor.org. Accessed 7 Aug. 2016.

<sup>6</sup> Tooley, Michael. “Abortion and Infanticide.” *Philosophy And Public Affairs* 2.1 (1972): n. pag.

## True Personhood

Does the argument that neonates have personhood hold water? This demands careful consideration, and some concessions to the Tooley Singer Model. I am in agreement with Singer that there is little different developmentally from a fully developed fetus and a neonate. Also, we are in agreement that an infant lacks self-consciousness and autonomy.

However, the *social* construct that is placed around birth is too strong. What is your birthday? Your siblings? What was it like the day your first child was born? It is clear from the reality that we celebrate *birthdays* and not *conception* days that fetuses lack standing as persons, but the social bond of birth is too strong to deny there is a moral transition period beginning the moment one exits the womb. To Walters, "Personalist thinkers must not abstract higher-brain functioning from the rich social context which we humans slowly develop and gradually lose brain capacities."<sup>7</sup>

Birth in and of itself is not constitute fully a proof of one's personhood. It can be argued that nothing is inherently special about passage through a birth canal, and it does little to separate the species *Homo Sapiens* from the wider group of mammals that have similar births.

The burden of the "Liberal" according to Tooley, is "To show that these events involve changes, or are associated with changes, that are morally relevant."<sup>6</sup> Joseph Fletcher describes these changes as the "*sin qua non*" or condition that is necessary for "indicators of Humanhood" to develop. He compiles a list of twenty traits, among them self-awareness, sense of time and futurity, communication, and control of existence. The impetus to these traits according to Fletcher is neocortical function.

"As far as I can see I will stand by my own thesis or hypothesis that neocortical function is the key to humaneness, the essential trait."<sup>8</sup> "Without the synthesizing function of the cerebral cortex...the person is nonexistent no matter how much the individual's brain stem and mid brain continue to provide feelings and regulate autonomic physical functions."<sup>8</sup>

Yet many mammalian species have neocortices. If one is to propose the idea that members of the species *Homo Sapiens* are persons based solely on having neocortices they are liable to the criticism that other animals have this neurological apparatus also.

What is unique to one's species is the biochemistry (genome and proteins) that comprises individual members of the species. But the fallacy of genetic personhood means we cannot rely solely the biochemistry for denoting personhood. However, there is a relationship between the biochemistry and the structures it creates. The biochemistry builds the neocortex, which in turn enables the body to act out the traits we cherish in our own species, and do not see in others. They exist almost symbiotically to create the duality of the person from the chemistry.

This modification of Fletcher's definition of personhood is non-speciest. Members of the species *Homo Sapiens* who do not have neocortices such as infants with significant neurological defect (as in the case of hemorrhagic brain damage or anencephaly) will not be considered persons. But it relegates non-human animals as non-persons, as they lack the biochemistry to create human

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<sup>7</sup> Walters, James W. *What Is A Person*. Urbana: University of Illinois Press, 1997. Print. Rpt. in *Moral Problems In Medicine*. 2nd ed. N.p.: Prentice Hall INC., 1972. N. pag. Print.

<sup>8</sup> Fletcher, Joseph. "Four Indicators of Humanhood: The Inquiry Matters." *The Hastings Center Report* 4.6 (1974): n. pag. Digital file.

brain structures.

However, higher brain functioning does not necessarily permit humankind free reign over animal species, and does not negate considerations of sentience from moral discernment. Animals have legitimate ethical claims and concerns that ought to be taken seriously. The author is in agreement with Singer over continued unjustifiable practices such as factory farming. Far from Kant's "indirect duties towards animals", where "by doing our duty toward animals ...we indirectly do our duty toward humanity"<sup>9</sup> a split model of animal ethics endorses that when possible, humans should work together to safeguard animal welfare for their sake. Yet Kant is correct in his belief that when vital human claims come up against the preferences of animals, they are always "merely means to an end" And "That end is man"<sup>9</sup>

### Infants as Rights Bearers

Sufficiently demonstrating that infants have personhood, we now turn to the question of rights. Neonates are persons, and have the full rights-bearing status they are entitled to. But does this include a right to life? Can we assert this right of life, and still find legitimate cases where it is not absolute? Yes, infants do have a right to life, yet this is integrally coupled life having qualities that are integral to the *good life*. If it can be established that the severity of the defects is one that would preclude the child from having at least a fair shot at having a high quality of life then the right of life is superseded in favor of termination. All have a right to life provided the life that is lived is filled with the *qualities that make that life worthwhile*.

This makes the right an alienable one. Believing designates the philosophy as a "moderate" sanctity of life ethic.

"Moderate proponents of a sanctity of life ethic hold that there is a prima facie, not absolute, obligation to protect and preserve human life. Designating the obligation as prima facie implies that there can be...exceptions to the general rule."<sup>10</sup>

Arras and Fenton, argue that in the debate over the limits of medical resource allocation, there are *ideal rights* and *institutional rights*.

"The 'ideal' conception of human rights identifies the basic conditions that all human beings require in order to lead minimally decent lives ....it must be possible ....to assign specific duties to fulfill these abstract rights." "The 'institutional' conception, which provides the detail and specificity that the ideal conception lacks." "Institutional rights tackle allocation decisions by specifying in detail who gets what from any right claim, and who has to provide it."<sup>11</sup>

<sup>9</sup> Kant, Immanuel. "We Have Only Indirect Duties To Animals." *The Moral Life*. By Louis P. Pojman and Lewis Vaughn. 3rd ed. Oxford: Oxford University Press, n.d. N. pag. Print. Rpt. of "Duties To Animals and Spirits." *Lectures on Ethics*. Trans. Louis Infield. N.p.: n.p., n.d. N. pag.

<sup>10</sup> Shelp, Earl E. *Born To Die? Deciding The Fate Of Critically Ill Newborns*. London, Collier Macmillan Publishers, 1986.

<sup>11</sup> Cochrane, Alasdair. "Evaluating 'Bioethical Approaches' to Human Rights." *Ethical Theory and Moral Practice*, vol. 15, no. 3, June 2012, pp. 309-22. JSTOR, www.jstor.org.cod.idm.oclc.org. Accessed 27 Aug. 2016.

From Arras and Fenton, it is easy to make the jump that the right of life of severely ill children is a concrete example to the ideal right of life. If one's right of life in the adult stage is predicated on resource allocation, why not first predicate one's right to life on quality of life at the neonatal stage?

### Parental Authority Model

Parents are decision-makers in decisions of treatment or termination. Parents ultimately will be in the role of caretaker for the extent of its development. Yet, doctors do not have a passive role in the decision. They must fully inform the parents of the symptoms of the child's illness and disclose and encourage their preferred treatment to them. Shelp comments "Neonatologists ought not to tell parents which morally permissible option to choose. This may mean that some parents will choose life and others will accept death for their severely impaired newborn. Either course holds potential for either good or grief."<sup>10</sup>

An example of such a doctor is the case of Dr. John Lorber, a British physician who treated cases of Spina Bifida. This illness arises when the spinal column does not close in utero and at birth the neonate's nerves and meninges from the spinal cord are exposed in a "hole" in their back called a myelomeningocele. The child must immediately have an operation to close the back to prevent infection, and have throughout life numerous corrective neurological and orthopaedic procedures. Spina Bifida neonates typically have symptoms of hydrocephalus, where due to the damage in the spinal column a protein called cerebrospinal fluid does not flow between the brain and spinal column causing a pressure buildup in the cranial cavity. These children lack motor control and sensation in the lower extremities, along with nerve signals that typically control bowel and bladder continence. As a result, maladies such as pressure sores and kidney infections from bladder reflux are common ailments of sufferers of the disease. The latter half of the 20<sup>th</sup> century brought the advent of new therapeutic technologies such as shunting to constantly drain cerebrospinal fluid back into the abdominal cavity, and surgical interventions to relieve orthopaedic, and bowel and bladder dysfunction. Today, many patients with Spina Bifida can live into extended ages, and can have lives with self-satisfaction and independence on par with their able bodied counterparts, despite the glaring challenges to the quality of life they suffer.

At the advent of these treatments, Lorber was a physician in Sheffield England. He and his colleagues published a paper outlining "That Spina Bifida must be operated on as soon as possible, since otherwise further-and irreparable-nerve damage could result from the drying of the [myelomeningocele]." "For twelve years every infant with Spina Bifida in Sheffield was treated in this manner."<sup>12</sup> Yet Lorber began to rethink his endorsement of immediate treatment after longitudinal research from Sheffield was compiled, particularly that of the 848 neonates treated, exactly half of them were alive some years later, and that of the 424 survivors "seventy three had a moderate handicap, 345, or over 85 percent were severely handicapped. Those in this latter group had at least two, but usually more, of the following conditions: no bowel and bladder control ...frequent kidney infections ...which may lead to renal failure, paralysis ...that they are unable to walk without crutches ...or other appliances and must rely on a wheelchair for part of the day; pressure sores on feet knees and buttocks; hydrocephalus treated with adrainage tube."<sup>12</sup> Lorber began endorsing a selective treatment policy where Sheffield doctors should "concentrate its

<sup>12</sup> Singer, Peter, and Helga Kuhse. *Should The Baby Live?* N.p.: Oxford University Press, 1985. Print.

attention on the soluble problems of the less handicapped children, rather than attempt to keep all children irrespective of the problem they would face.”<sup>12</sup> Withholding treatment would be based upon five ‘adverse criteria’ that would present itself in the neonate in the successive hours after birth. These include “location of the opening of the spine [lower lesions such as ones in the sacral level have less disastrous symptoms], severe paralysis or spinal deformity, very bad hydrocephalus, and other major defects or brain damage.”<sup>12</sup>

Given that Lorber’s proposal endorsed physician selection without parental approval, it is obvious it had major faults. Yet it represents the ability of physicians to use symptoms to forecast expected qualities of life. It is the hope of this essay that other congenital illnesses can be categorized based on expected quality of life.

### Critiques of the Parental Model

Criticism can be leveled against the *Parental Authority Model*. Firstly, one could say that a parent’s mind is clouded, due to emotional turmoil after the birth of a chronically ill child. Robert Weir questioned the stability of the parents, calling into question the legitimacy of “emotionally devastated” parents who are “ignorantly informed” and “virtually ignorant of alternatives.”<sup>10</sup> Shelp argues “We are not told by Weir the level of parental incomprehension, or what type or to what degree emotional instability, is sufficient for neonatologists to assume decisional authority.”<sup>10</sup> If they are emotionally unstable and cannot comprehend their child’s illness, Shelp argues these parents are not able to appropriately decide *any* decisions for their child, let alone ones as important as termination. Furthermore, he questions what emotional devastation truly means. Do doctors or institutional review boards have the same amount of emotional stress to similar situations? The answer to this is unequivocally yes.

Secondly, the danger of solely allowing physician determination of termination lies in the *Vitalistic* bias of the medical community. The doctor may see their job as to preserve the life, not considering quality of the life the infant will live. Shelp clarifies this into what he sees as the

“neurological bias” “there is a tendency toward what might be called a neurological bias. Parents, neonatologists, and others seem to focus on the brains the organic indicator of whether the newborns life ought to be prolonged to the extent possible ...but there is a danger in normativizing neurological capacities and potential for decisions to save or let die. That danger is to forget, ignore or minimize the potential of other impaired vital organs to diminish quality of life. Cardiac, renal, hepatic and bowel abnormalities ...can be so severely restrictive or debilitating that continued existence may not be considered an advantage.”<sup>10</sup>

In Kantian the medical community has made the severely affected infant into a means of medical achievement. This affrontment to the second formulation of the categorical imperative denies respect for persons by making the infant into a means to an end of the advancement of medical research. Weir claims that:

“Rather than trying to assess treatment options in terms of the best interests of individual neonatal patients, they tend to view patients-especially those with the most serious, possibly exotic conditions-as relatively rare opportunities to advance the cause to neonatal medicine as a science.”<sup>13</sup>

It is not the goal of this paper to shame those in medical occupations who work to improve the lives of those with chronic illness. Yet it is meant to shed light on the unseen but always present *vitalism* inherent much of western medicine that is often co-opted by those who seek to push the bounds of medicine without thought to the very real consequences to the neonates being treated.

Legitimacy of physician authority in decision making can be questioned due to vitalism's focus on the "here and now". Immediately after birth of a severely ill child, medicine looks to stabilize its condition. Little regard is given to whether the child will be constantly hospitalized, socially marginalized and emotionally damaged. We ought to change this short-sidedness on the part of physicians. The most just way of accomplishing this is to give parents the power of decision-making in cases of termination of their children, due to them having the best knowledge of the future the child will have in the family, and being the stewards of the child's right of consent and treatment authorization.

This discussion of the euthanasia of individuals with chronic illnesses, and strong emotion amongst all. This emotional response seems to be highest among those within the disabled community. It is such a danger to "go against the grain" of public sentiment and encourage a euthanasia policy that Singer and Kuhse write in the preface of *Should the Baby Live?:*

“We think that some infants with severe disabilities should be killed. This recommendation may cause particular offence to readers who were themselves born with disabilities” and that "nothing in the views we express in this book in any way implies a lack of concern for disabled people in our community.”<sup>12</sup>

Singer has bore the brunt of attacks on the part of the disabled community and their able-bodied “defenders” from a comparison to Adolf Hitler, to assaults and death threats for his ethical positions. The author wishes to acknowledge that he genuinely believes that Singer harbors no ill will towards the disabled in his positions, despite the recognized shortcomings of these positions in denying “respect for persons.”

Throughout the second half of the twentieth century the disabled community worked tirelessly to gain greater freedoms and accommodation in society. There are individuals with disabilities who report a high satisfaction with their quality of life, and view it an outrage to imply that they *ought to have* been euthanized. Paralympic athletes such as Tatyana McFadden, Matt Scott, and Jean Driscoll are ambassadors for the acceptance of disabled people in society.

Yet it is fallacious to assume even that the most well-adjusted chronically ill individual's life doesn't have severe complications, and that a hefty percentage of them if asked, would report a low quality of life. Qualitative experiences of Lorber back up this assumption “I asked a group of young adult Spina Bifida subjects whether they would wish to have a child of their own treated if it was born with severe Spina Bifida; none would”<sup>12</sup>.

Criticisms involving the *qualitative* versus *quantitative* nature of decision making based on projected of quality of life can also raise concerns that some neonates who should have been euthanized due to poor quality of life prospects might be kept alive, and the inverse (that some who

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<sup>13</sup> Weir, Robert. *Selective Nontreatment of Handicapped Newborns*. New York: Oxford University Press, 1984. Print.

would go on to have high quality of life will be killed) can be raised. Warren T. Reich espoused the view that:

“The strict application of Lorber’s single symptom or set of symptoms at birth is probably too gross a criterion for judging fairly whether a human life should be preserved ...Many patients who would have only moderate sequelae, as well as some of the more severely impaired infants whose lives need not be without meaning, would be left to die.”<sup>14</sup>

This is a valid criticism. The aim of this paper is to defend selection and termination based their *duty* on the part of the moral community toward the most chronically ill neonates, not the consequences of the final decision. Inevitably there will be some cases of unjust death that Reich mentions. Yet, “With those decisions [termination versus continued treatment] we know that mistakes will be made, and there is no avoiding that...risks must be taken.”<sup>15</sup>

But, with the encouragement of doctors to terminate expected low quality of life cases, coupled with court injunctions that are obtained by hospital Institutional Review Boards in cases of parental neglect the issues that Reich warns can be expected to be at such minimal levels that it is counterweighted by the benefits obtained by euthanizing neonates with low quality of life prospects.

### Groningen

Infant Euthanasia while openly contested by American organizations such as the American Medical Association,<sup>16</sup> has been embraced in the 21<sup>st</sup> century by physicians in the European country of the Netherlands.

Around the year 2002, Dr. Eduard Verhagen began his quest to change Dutch Euthanasia law. At the time it was legal for children as young as 16 with terminal illness to opt for active euthanasia.<sup>17</sup> It is now legal for minors as young as 12 with parental consent.<sup>18</sup> Verhagen was instrumental in this change, but he is still determined to work toward his initial goal, to change this age restriction to allow active euthanasia of chronically ill newborns.

Unable to legally grant the wishes of infant patient Bente Hindriks’ (who due to the skin peeling and blistering caused by Hallopeau-Siemens syndrome, also called recessive dystrophic Epidermolysis Bullosa (rDEB), suffered excruciating pain and infection) parent’s to euthanize their child, he realized something must be done for children in situations such as Bente’s.

In 2005, Verhagen outspokenly admitted to euthanizing four infants, all with Spina Bifida. In the ensuing months he and colleague Pieter J. Sauer reviewed the literature and found

<sup>14</sup> Reich, Warren T. “Quality of Life and Defective Newborn Children: An Ethical Analysis.” *Decision Making and the Defective Newborn: Proceedings of a Conference on Spina Bifida and Ethics*. Ed. Chester A. Swinyard. Springfield IL: Charles C. Thomas, 1978.489-511. Print.

<sup>15</sup> Paris, John J., S.J. “Terminating Treatment for Newborns: A Theological Perspective.” *Quality Of Life: The New Medical Dilemma*, edited by James J. Walter and Thomas A. Shannon, pp. 151-60. Originally published in *Law, Medicine and Health Care*, 1982.

<sup>16</sup> See James Rachels, *Active and Passive Euthanasia*.

<sup>17</sup> “Euthanasia, assisted suicide and non-resuscitation on request.” *Government of the Netherlands*. Government of the Netherlands, n.d. Web. 24 July 2016.

<sup>18</sup> <<https://www.government.nl/topics/euthanasia/contents/euthanasia-assisted-suicide-and-non-resuscitation-on-request>>.

that from 1997 to 2004, three cases of euthanasia were reported to authorities, (as infant euthanasia is illegal in Denmark) but none were prosecuted. Yet a published national survey of doctors had found that "around 15 to 20 active cases of euthanasia occurred."<sup>19</sup> Clearly "a number of physicians [were] making decisions without...oversight."<sup>19</sup> Desiring to bring the practice into the light, the two published *The Groningen Protocol*, which systematically laid down procedures for use by doctors for actively euthanizing newborns. These guidelines helped both make treatment decisions, and lessen the possibility of prosecution. The Protocol addresses three categories of infants. First, "infants with low chance of survival, who will soon die after birth."<sup>19</sup> These are infants with "underlying and untreatable medical conditions, such as underdeveloped lungs or kidneys."<sup>19</sup> Second "infants sustained by medical care but have a bleak prognosis."<sup>19</sup> Third, and most important to this paper, is the category of infants described as having "a hopeless prognosis and experience unbearable suffering."<sup>19</sup> Within this group are infants with the "worst cases of Spina Bifida."<sup>19</sup> and "infants still alive after intensive care who have poor quality of life."<sup>19</sup> Additionally listed are a set of requirements that "must be fulfilled for the active euthanasia to be justified."<sup>19</sup>

- “1. The infant’s diagnosis and prognosis must be certain
2. The infant must be experiencing hopeless and unbearable suffering
3. At least one independent physician [other than the delivering neonatologist] must confirm that the two conditions are met
4. Parents must give informed consent
5. The termination must be performed in accord with the accepted medical standard”<sup>19</sup>

Additional qualifications related the necessity of post-mortem autopsy to assure the death was carried out within accepted legal framework was stipulated.

In a follow up study analyzing the Protocol, Verhagen found: “In the five years following the [Groningen Protocol], euthanasia had decreased from 15 to two cases ...For congenital malformations, euthanasia decreased from 15 to 0 cases.” The most plausible reasoning for the decline in the practice of euthanasia was due at least in part to “the transformation of the health care system (antenatal screening policy became a part of routine antenatal care in 2007)”<sup>20</sup>.

This raises criticism over the necessity of a legal euthanasia practice if abortion rates rise to the point that a majority of defective fetuses will be terminated before birth. Describing research done in 1977 regarding the integration in Britain of a new blood test to search for a-fetoprotein (AFP is indicative of a group of illnesses called Neural Tube Defects, of which Spina Bifida is the only one compatible to life) Reilly writes “In the United Kingdom, most women who were offered the AFP test took it, and most women who learned that they were carrying an affected fetus did terminate the pregnancy. In 1999, Wald [researcher of the study] reported that in just 20 years the annual number of live births of infants with [Neural Tube Defects] in the United Kingdom had decreased by 95%!”<sup>21</sup>

<sup>19</sup> Smith, James Lemuel. “The Groningen Protocol: The Why and The What.” *Intervention and Reflection*, by Ronald Munson. Excerpt originally published in *Intervention And Reflection*, Boston, Wadsworth, pp. 524-25.

<sup>20</sup> Verhagen, Eduard. “Neonatal euthanasia: Lessons from the Groningen Protocol.” *Seminars in Fetal & Neonatal Medicine* 19 (2014): 296-99. Digital file.

<sup>21</sup> Reilly, Phillip K. *Orphan: The Quest to Save Children with Rare Genetic Disorders*. Cold Spring Harbor: Cold Spring Harbor Laboratory, 2015. Print.

It is hoped that the use of abortive procedures will increase so that the number of parents that will have to make heart-wrenching termination decisions will decrease. Yet there will always continue to be a necessity for the practice. Firstly, quality of life is difficult to determine by ultrasound. Take a case of Spina Bifida. The level of lesion, and correlative quality of life issues cannot easily be determined by ultrasound. Will the child be wheelchair bound? Will they suffer no sensation of lower extremities, leading to health problems such as pressure sores? Do they have a neurogenic bowel and bladder, which can damage not only organs such as kidneys, but psychological and social progression of the child? All of these quality of life uncertainties remain question marks until birth. *Second*, there are some illnesses that are *caused by the birth process itself*. Among these are illnesses such as Nuchal Cord, and Cord Stricture. All of these illnesses are related to the umbilical cord being wound around the neonate, and, if wound tightly around the neck, depriving it of oxygen. Nuchal Cord has been found to cause “a decrease in fetal development” and “fetal heart rate abnormalities.” Cord Stricture is “difficult to detect during the prenatal period.” “If the infant survives, a series of medical conditions may follow, including a cleft lip, septal defects, and trisomy 18.”<sup>22</sup>

### Conclusion

The reader might be shocked by the conclusions put forth in this paper. The killing of infants seems an anachronistic and barbaric practice. But the relevancy of decision making in cases of reproductive tragedy thrusts a delicate issue into the consciousness of twenty-first century family life. Your family members, coworkers and friends may all have to make this decision someday. This burdensome reality motivated the author to write the paper. No child should have to look on its life as he has and demand out of a sense of justice that the alternative decision should have been made. Did his doctors imagine him on a hospital bed, with various tubes and instruments invading his body? Did they think about the many needles and scalpels that he would endure? What about the multitude of procedures he has lived through in order to maintain even a small portion of the health and bodily autonomy others have? The poor social health of his childhood and depressive symptoms he has battled throughout life because of chronic illness?

This essay had three goals. Firstly to refute any theory of traits-based personhood that would seek to deny the status of neonates as persons in both a moral and legal sense. We did this by evaluating traits that are required for personhood. Second, to advance a Parental Authority Model, and defended it from criticisms. Finally, we defended the Groningen Protocol.

At the outset of the 21<sup>st</sup> century, reflection will need to be done on the part of the medical community as to the way it treats seriously ill neonates. Will it continue to treat them as a means to an end? Or value them as beings-in-themselves, who demand justification for their continued experience filled with suffering? The “central problem of philosophy” must be wrestled with. And ultimately answered that in cases of severely defective infants, many times someone ought to have killed us.

<sup>22</sup> “Umbilical Cord Problems.” *Birth Injury Guide*. Birth Injury Guide, 2016. Web. 28 July 2016. <<http://www.birthinjuryguide.org/birth-injury/causes/umbilical-cord-problems/>>.