

2023

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### Recommended Citation

Payne, Chloe G. (2023) "The Ethical Dilemma of Whether or Not to Withhold Life Sustaining Treatments for Newborns," *OUR Journal: ODU Undergraduate Research Journal*: Vol. 10, Article 11.

DOI: 10.25778/mey3-qr81

Available at: <https://digitalcommons.odu.edu/ourj/vol10/iss1/11>

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# THE ETHICAL DILEMMA OF WHETHER OR NOT TO WITHHOLD LIFE SUSTAINING TREATMENTS FOR NEWBORNS

By Chloe Payne

## I. INTRODUCTION

Every day millions of babies all over the world are born, but not all of them are fully healthy and able to be discharged on their birth date. Babies with congenital anomalies, a lack of oxygen at birth, extremely small birth weights, brain injuries, and other health issues are transferred to neonatal intensive care units. The length of a newborn's stay in a neonatal intensive care unit (NICU) is dependent on a number of factors including the severity of their condition, weight, parents' finances, and the hospital's available resources. For some infants, days in the NICU can turn into months as their conditions stay the same or worsen. Throughout a newborn's time in a NICU, healthcare teams composed of physicians, surgeons, nurses, and other healthcare professionals implement numerous interventions. For critically ill infants, some interventions can be the difference between life and death. Interventions such as mechanical ventilation, cardiopulmonary resuscitation, and more are life sustaining interventions that "have the potential to replace or assist vital organ functions and prolong life for several days, weeks, and even months, in patients who may have little or no chance of survival without each support" (Divatia, 2020). Those interventions require informed consent from the newborn's parents. Some parents do not want those life sustaining interventions to be initiated. There are also parents who wish to discontinue treatments for their newborn at a point in which the infant is surviving off them for a long period of time. Other parents want physicians to continue implementing interventions for as long as their baby is alive. It

is crucial for parents to have those options and be involved in decision making alongside physicians due to the legality and ethics of newborns receiving life-sustaining treatment (Shaw, 2020).

In the advancing technological era that we live in, the decision to withhold or continue life sustaining treatments is becoming more prominent as new life saving treatments are created. Healthcare workers across the world in all specialties – especially physicians and nurses – need to be familiar with this ethical issue as they may end up in a situation where their patient is receiving life sustaining treatments and they have to educate and comfort the people who are delegated to make the decision regarding whether or not to continue treatment for the patient. Furthermore, even though this decision is delegated to the parents of a newborn, all family members of a baby in the NICU are impacted by the decision. Therefore, this topic is relevant to all family members of critically ill newborns. Families of ill infants, nurses, physicians, and more need to be aware of the pros and cons of each argument regarding whether to continue life sustaining treatments. This decision can be the difference between life and death, so it is essential for all factors to be considered for educated decisions to be made. There is never a definite answer as to how long one will survive though, so parents have to base their decisions off facts from medical providers and the topics presented in this essay.

## II. CONTINUING LIFE SUSTAINING TREATMENTS

The decision for life sustaining treatments to be continued can be attributed to numerous factors including the miracle of the life, resources for disabled, potential psychological effects on parents post loss, potential health issues post loss, and religious beliefs.

### **Miracle of Life**

When aggressive treatments are implemented in the NICU, some babies survive and can be discharged home. At six years old, I witnessed first-hand one of those miracles when my sister was born.

On October 03, 2006, a lack of oxygen at birth led to my sister, Claire, turning purple in my mother's arms. Moments after she was born, she was rushed to the NICU by a nurse and was immediately hooked up to numerous machines and medications in an incubator. After just a few short hours in the NICU, physicians told my parents that my sister most likely wouldn't live past two days and they asked for consent from my parents before implementing interventions including cardiopulmonary resuscitation, surgeries, and more. As a result of the extensive care that Claire received in the NICU, she lived and my parents were able to take her home. Due to the oxygen deprivation, Claire now has cerebral palsy, is non-verbal, and cannot complete many activities on her own. My parents have to help her with basic activities that we take for granted like bathing, toileting, and eating. Even though she will never be able to live by herself, complete basic activities independently, or speak, she appears happy. Claire's constant smile, laughter, and presence are irreplaceable in the eyes of my family. My parents do not at all regret the decisions they made for my sister the week that she was born because of how much they value my sister's life. There are other people in the world like my sister who now have disabilities as a result of their birth and are still alive having received lifesaving treatments in the NICU. The limitations that those people experience differ, but their lives are extremely valued by the people around them.

### **Resources for Disabled**

In addition to the beauty of life even with limitations, people may decide to continue life sustaining treatments for their newborn with the anticipation that there are resources in the community for the disabled if their newborn survives. Resources such as Medicaid, the Federation for Children with Special Needs, the Council for Exceptional Children, Parent to Parent USA, and the National Youth Leadership Network can assist parents of disabled children and the disabled in multiple ways (Fabian-Weber, 2022). Medicaid, for example, can provide the disabled with a set amount of caregiving hours each week that a Certified Nursing Assistant (CNA) will take care of them, necessities such as diapers, prescription medications, physical therapy, occupational therapy, transportation to healthcare offices, inpatient services in a hospital, and more (Mandatory & optional Medicaid benefits, (n.d.)). Ultimately,

there are resources available to assist the disabled and their parents in regard to healthcare needs, caregiving needs, emotional needs, and more.

### **Psychological Effect on Parents Post Loss**

Furthermore, parents that make the decision to discontinue life-sustaining treatments end up having to mourn the loss of their baby which can be extremely damaging psychologically. Mourning the loss of anyone is extremely difficult and can lead to anxiety, depression, and an increased risk for suicide. Also, parents who choose to withhold treatment for their newborn may feel guilty for their decision which can cause further mental issues. A study regarding mental issues in parents after the death of their newborn or child found that “bereaved mothers have four times higher odds of depressive symptoms and seven times higher odds of PTSD symptoms compared with nonbereaved parents,” which exhibits how losing a newborn can be extremely detrimental to a parent’s mental health (Gold, 2016). Moreover, anxiety and depression from grieving the loss of a loved one leads to people not being in the right mental state to function properly at their place of employment. One article even expressed that the “Death of a loved one results in an estimated \$37.5 billion annually in lost productivity in the United States.” (Youngblut, 2013). Overall, the decision to discontinue treatment can have an extremely negative impact psychologically on parents while parents who decide to continue treatment for their newborn won’t have to go through the psychological effects of losing their newborn if the treatments are successful.

### **Health Issues Post Loss**

Parents who make the decision to discontinue life sustaining treatments which results in the death of their newborn are also at a greater risk for developing physical health issues compared to parents whose newborns survive after successful treatments because they decided to continue treatment. One study found that parents who are grieving the loss of an infant or child are at an increased risk for multiple sclerosis, diabetes, cancer, a myocardial infarction, and even death due to increased stress. Stress can cause illnesses because “Bereavement is a significant modulator of immune cell gene expression,

genes involved in innate antiviral responses.” (Brooten et al., 2018). Additionally, bereavement of a child is proven to increase the risk for hospitalization (Brooten et al., 2018). Ultimately, choosing to withhold treatment which typically results in an infant’s death can negatively affect parents both mentally and physically. On the other hand, parents who choose to continue treatment are at a decreased risk for the health problems discussed earlier because of the decreased risk for their newborn’s death.

### **Religious and Spiritual Beliefs**

The decision to continue life sustaining treatment is also impacted by one’s religious and spiritual beliefs. The Catholic, Jewish, Islamic, and Protestant faiths have complex perspectives regarding whether it is justifiable for treatment to be withheld. Those four religions believe that human dignity, the “recognition of the child as an individual,” and the infant’s well-being should be the center of the decision-making process (Oehmke et al., 2019). If those factors are not taken into account, withholding treatment is not at all justifiable. First, the Catholic perspective is that treatment should be continued if there are still medical indications for the preservation of an infant’s life – meaning that if there are ways baby can be further healed parents should consent to it. For example, if parents are told there are procedures that can help save their baby’s life then they should consent to having those procedures done regardless of how critically ill their baby is. Secondly, the Protestant perspective is that treatment should be continued if parents feel their newborn could have a future even if it means that they have limitations. This is due to the emphasis of viewing “the child as an individual” (Oehmke et al., 2019). Thirdly, the Islamic perspective is that treatment should be continued if the physician and parents believe it is “the best medical option to serve the welfare of the child” (Oehmke et al., 2019). Finally, the Jewish faith is ultimately against the limitation of life-sustaining treatment. Jews believe that “each human being has an indefinite value” and that “Life begins with the first independent breath and even very high risks for serious diseases constitute no convincing argument to omit life-saving activities.” (Oehmke et al., 2019).

### III. WITHHOLDING LIFE SUSTAINING TREATMENTS

The decision to withhold life-sustaining treatments could be based off the parents' values and opinions regarding quality of life for the newborn, quality of life for the family, the family's resources, the hospital's resources, and religious beliefs.

#### **Quality of Life of the Newborn**

When a newborn's prognosis becomes poor and parents have to decide whether or not to withhold treatment, quality of life for the newborn typically plays a major role in parent's decision making. For long term quality of life, some parents question whether their child will have intellectual disabilities and/or physical limitations if they survive and how that will impact their future. Questions such as whether the child will be able to live independently, walk, talk, attend school, get a job, and develop relationships in the future may arise when quality of life is considered. For short term quality of life, parents may question whether their newborn is in pain and is suffering due to the severity of their condition. Quality of life is subjective and is defined in multiple different ways which highly contributes to the debate of whether to withhold treatment. Furthermore, quality of life may be measured by success, independence, economic status, mental status, health status, and more but it differs based off who you ask. All of these considerations in regard to short term and long term quality of life are ones that may lead parents to the decision to withhold treatment (Delaney et al., 2022).

#### **Quality of Life for the Family**

Quality of life for the family of the newborn is another major factor that can lead to one's decision to withhold treatment for their newborn. If a newborn survives but has disabilities and/or further health complications, parents' lives are affected as they will most likely end up being the primary caregivers. Also, this may have a great impact on every member of the family, not just the primary

caregiver. Caring for a child with poor health and/or disabilities can be extremely difficult as it can be time consuming, physically challenging, and emotionally difficult. All of those challenges can also lead to marriage problems, career issues, difficulty caring for other children, and even “caregiver strain” (Delaney et al., 2022). Caregiver strain is “the process by which the demands and responsibilities associated with caring for one’s child exceed their resources to cope with those demands, thereby resulting in the caregiver often feeling overwhelmed and unable to perform their role to the best of their ability” (Urizar Jr et al., 2022). Additionally, a study regarding the mental and physical effects of caregiving on caregivers of persons with disabilities found that 32% of caregivers experienced higher levels of anxiety and stress, and 71% exhibited multiple symptoms of depression. Also, in regards to physical issues, 48% of the caregivers in the study expressed having trouble sleeping, 44% expressed having headaches, and 49% reported muscle pain (Urizar Jr et al., 2022). I’ll admit that being Claire’s sister and one of her caregivers is very difficult at times mentally and physically because of her multiple needs each day. Also, since she can only say a few words, it is difficult for us to communicate our feelings to her. Claire is a wonderful addition to our family, but it truly is strenuous at times. Moreover, every child with disabilities is different, and there are people with even more severe needs than my sister. Ultimately, a child with disabilities and/or health issues can alter family dynamics.

### **Family Resources**

Parents also have to consider whether they have the finances to care for a child who could have disabilities or further health complications. Tools such as assistive aids, transfer equipment, diapers, medications, doctor’s appointments, hospital visits, surgeries, occupational therapy, physical therapy, speech therapy, recreational therapy, and more could be necessary for a child with serious health conditions and/or disabilities. All of those costs can add up very quickly and not every family can afford them. One article even expressed that “financial debt resultant from neonatal care can push families into acute nutritional crises and contribute to the death of other family members” which is unbelievable (Schnall et al., 2019).



### **Hospital Resources**

In addition to families needing resources for their child, the hospital that their newborn receives treatment at might not have the necessary resources to implement lifesaving interventions. There are four NICU levels and some people live in an area that is extremely far away from a level IV NICU which could provide the highest level of care and interventions. Moreover, some surgeries are extremely complicated and only a handful of surgeons at the best hospitals in the world can perform them.

### **Religious and Spiritual Beliefs**

Even though there are reasons for followers of the Catholic, Protestant, Jewish, and Islamic faiths to continue life-sustaining treatment, there are circumstances in which withholding life-sustaining treatments can be justified under the Catholic, Protestant, and Islamic faith. First, part of the Catholic perspective is that treatment can be withheld if there are no further indications medically to preserve life. Secondly, part of the Protestant perspective is that “The child’s right to live and to protect his health does not prohibit limitations of medical therapy,” and the indication for limitation is based upon whether parents feel their child could have a future and whether the newborn has the ability to become healthier (Oehmke et al., 2019). Finally, part of the Islamic perspective is that “Termination of therapy is a legitimate option even though preserving life is a central Islamic concept,” but it is vital that “an Islamic spiritual caregiver shall help the parents to deal with their fears and to take away or reduce the religious worries” (Oehmke et al., 2019).

## **IV. CONCLUSION**

In conclusion, the decision whether or not to withhold life sustaining treatments for a critically ill newborn is one that should be guided by “the child’s best interest as a balance between the expected

benefits and burdens of life-sustaining treatment” (Richards et al., 2018). The decision should also be guided by the “principles of beneficence, nonmaleficence, parental autonomy, correct medical facts and justice” (Pant, 2021). Additionally, this decision is impacted by how life is defined as there are multiple ways that it can be defined. One’s background, beliefs, values, and more affect how they define life. Some define life as a heartbeat whereas others define life as more than that and so on. Researching this topic ultimately taught me the importance of educating patients and their families especially when consent is needed, viewing patients holistically, providing patients with multiple options, prioritizing the opinions of patients and their families, and the importance of remaining unbiased when ethical dilemmas occur in the hospital.

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