
Decreasing Disabilities by Letting Babies Die

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ABSTRACT: A Catholic hospital is decreasing the prevalence of disabilities in its Neonatal Intensive Care Unit [NICU] survivors. The hospital developed guidelines that encourage parents to allow their premature baby to die. Using extremely negative message framing, a physician guides the prospective parents to choose to forego an examination of their baby when it is born. Making this choice before birth ensures that no intervention or health care will be provided. The goal is to decrease the probability that the family will leave the hospital with a baby who will be disabled. The outcome is the death of a baby who may or may not have been disabled. **Key Words:** Disability; Justice; Message framing; Palliative; Periviability; Unethical.

A woman may give birth prematurely due to pregnancy complications such as preterm labor, preterm rupture of membranes, restricted fetal growth or toxemia. Such a woman is usually hospitalized for several days or weeks prior to delivery, or she may appear “just in time” in advanced labor with an imminent delivery. At certain gestational ages, premature babies have a significant chance of being disabled if they survive. Surviving babies born at less than 26 weeks gestation may have a persistent neurologic

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disability known as Neurodevelopmental Impairment [NDI]. NDI is graded as moderate to severe or profound. A child is classified as having moderate NDI if moderate cerebral palsy, bilateral blindness, or bilateral hearing loss requiring amplification is present. A score of less than 70 on either the Psychomotor Developmental Index or the Mental Developmental Index of the Bayley Scales of Infant Development is classified as moderate NDI while a score of 50 is severe NDI. If adult assistance is required for the child to move, profound NDI is present. (Tyson 2008, 1673).

There are no physical findings at birth that can predict whether a baby born at less than 26 weeks gestation will live, let alone whether it will suffer a disability. Describing dramatically different possible outcomes, health care providers may give conflicting advice in these situations. A neonatologist might tell a family that their baby born at 24 weeks gestation will have a 91% chance of dying or surviving with a serious handicap and therefore treatment would be futile and not recommended. Yet another neonatologist could tell the same family that if their baby survives it would have a 37% chance of being neurologically normal and therefore treatment is recommended. To resolve potential conflict, the hospital developed guidelines that gave parents a consistent professional prognosis for their baby who was about to be born before 26 weeks gestation. The premise was that parents should have the right to decide what is in their best interests. A subsection of the medical staff at the hospital voted and the results tallied to demonstrate a consensus that enabled this Catholic hospital to institute mandatory guidelines requiring adherence by doctors and nurses when counseling families. These "Perivability Guidelines" were published in 2006 and they allow physicians to counsel parents to deny life-sustaining medical care for their babies born before 26 weeks gestation (Kaempf 2006, 26). These are babies that are born about 3.5 months early and weigh less than 800 grams, or 1-pound 12-ounces. The result of implementing these guidelines is the death of many babies who would have survived if treated.

Background

The ethical foundation of modern medicine has moved from an ethic based on the sanctity and dignity of every human life to an ethical framework constructed around the principles of autonomy, beneficence, non-maleficence and justice. None of these principles defend the intrinsic value of all human life (Pierucci 2014, 435); in application, these principles assume that some human lives are more valuable than others. Many modern ethicists proclaim that being a human does not make one a person. The human non-person is not due the same healthcare considerations as a person.

Autonomy

Labeled as human but a non-person, a premie at the borderline of viability is treated more like a fetus than a child. At the hospital, parental rights are similar to the rights of a pregnant woman to abort a fetus. These premies are not eligible to be treated according to the ethical principles we apply elsewhere. With adults, other people make treatment decisions only in exceptional cases. This is not the case in the

nursery: the premature baby's interests are subordinate to the parents' interests. Once the decision to deny treatment is made, the neonatologist will not be present at the baby's birth (Marmion 2018, *Linacre Q*, 9). This would not be acceptable for adults: the family makes the decision to withhold treatment only after having an examination and getting an official prognosis.

Beneficence

The hospital guidelines recommend beneficial neglect; that is, neglecting the baby will in some way benefit the family and/or society. Equating disability and death, proponents argue that it is not fair to siblings when parental resources of time and money are re-directed to an extremely premature baby (Camosy 2010, 50). They deny treatment for newly born premature babies in whom, despite a high survival rate, the rate of disability is high. For adults, a disability is never a reason to withhold treatment (Bellieni 2011). The Union of European Neonatal and Perinatal Societies' "Ethical Charter of Newborn Rights" states that a future disability is not a sufficient reason to withhold NICU care from a newborn (Guimaraes 2011, 857). The hospital guidelines are based on the premise that a disabled child's quality of life adversely affects the family and society.

Non-maleficence

The hospital limits this discussion to "quality of life." Potential complications of neonatal intensive care include mental retardation, cerebral palsy, blindness and deafness. Although advances in medical care had increased the number of survivors at earlier gestational ages, the percentage of survivors between 23 and 26 weeks with NDI remained about the same when the hospital published its guidelines in 2006 (Meadow 2012, 947). This was the reason that the hospital made the decision at that time to encourage parents to deny treatment for babies born at less than 26 weeks gestation. But an article published in 2015 showed that the rate of major morbidity in survivors was decreasing for babies born at 25 and 26 weeks gestation due to changes in maternal and infant care practices. Among extremely premature babies born at academic centers from 1993 to 2012, survival without major morbidity increased approximately 2% per year for babies born at 25 to 28 weeks gestation (Stoll 2015, 1039). This may be the reason the hospital revised its guidelines in 2016 (Kaempf 2016). A recent review reported that NDI has decreased for the cohort of surviving babies born at 23 weeks gestation (Younge 2017).

Projecting impairments that could develop in the NICU leads the parents to fear that their baby will have some degree of persistent disability. This expectation is amplified as they are counseled to expect the difficulties that will follow when the baby goes home and matures to school age. However, the ability of a baby or child to progressively adapt to a disability is not discussed with the family. Studies have shown that subjective quality of life is similar in very low birth weight survivors when compared to normal birth weight peers (Payot 2011, 99). Most parents who have raised an extremely low

gestational age survivor continue to support aggressive resuscitation for these babies (Cummings 2015, 590).

Justice

Not providing life-sustaining interventions to babies who have a reasonable chance of intact survival is contrary to most theories of justice (Hendriks 2018, 2). The hospital limits its discussion to “the just appropriation of resources,” but NICU care for premature babies is cost-effective when compared with other medical interventions. Quality-adjusted life-year [QALY] metrics are used in assessing and comparing the costs of medical interventions. QALY is a measure of the value of health outcomes, including both the quality and the quantity of life lived. It is estimated that NICU care costs between \$5,000 and \$10,000 per QALY (Meadow 2012, 944). Comparing NICU costs with costs of other medical or public health interventions reveals that NICU care is not so financially burdensome after all. For example, vaccinating 12-year-old girls for HPV costs \$43,600 per QALY and adult intensive care unit costs are greater than \$100,000 per QALY. This may not be a valid model for just allocation because the QALY analysis is limited to what was spent in the NICU. Future costs of subsequent physician visits, occupational therapy, physical therapy and special education are not considered (Camosy 2010, 191). But this criticism is common to all QALY analyses, so NICU care could still be considered a bargain in comparison.

Methods

A subgroup of the medical staff at the hospital voted upon whether it would be appropriate to withhold or provide NICU interventions at each gestational age between 22 weeks and 27 weeks. The vote tally’s resultant consensus was used to create the hospital “Periviability Guidelines” which are shown in Table 1 (Kaempf 2006, 26). When counseling parents, the provider must refer to the consensus statement described in this Table: the “majority of medical staff do...” or the “majority of medical staff do not...” recommend NICU care. The result of implementing these guidelines is the death of many babies who would have survived if treated.

Survival data is accessible through the website of the National Institute of Child Health and Human Development (NICHD), an agency of the National Institute of Health. The information on this website is intended to better inform health care providers and families about possible outcomes based on specific characteristics. Table 2 shows the data extracted from the NICHD website calculator for a girl born at 23 weeks gestation and weighing 475 grams. Referring to the guidelines in Table 1, a neonatologist consulting the family could say:

The data predicts that one out of three girls born at this gestational age will survive if treated. Of those that survive, 35% will have no significant neurodevelopmental problems.

A different outcome may occur if the neonatologist framed the message this way:

Table 1
Hospital Medical Staff Guidelines for the Care of Extremely Early Gestation Pregnancies and Extremely Premature Infants - 2006

Weeks-Days at Birth	Obstetric Care	Neonatal Care
<23	Tocolysis as indicated. No steroids. No cesarean delivery for fetal indications.	NICU care not offered. Comfort care provided.
23-0 to 23-6	Tocolysis as indicated. Steroids not recommended. Cesarean delivery for fetal indications not recommended.	NICU care not recommended because of high mortality and neurologic disability rates. Comfort care provided.
24-0 to 24-6	Tocolysis as indicated. Steroid use if mother/family choosing NICU care at <26 wk. Cesarean delivery may be declined or chosen after review of clinical outcomes. Majority of medical staff do not recommend cesarean delivery for fetal indications.	NICU care may be declined and comfort care provided or NICU care may be chosen by the mother/family after review with the medical staff of the probable and potential clinical outcomes. Majority of medical staff do not recommend NICU care.
25-0 to 25-6	Tocolysis as indicated. Steroid use if mother/family choosing NICU care at <26 wk. Cesarean delivery may be declined or chosen after review of clinical outcomes Majority of medical staff do recommend cesarean delivery for fetal indications.	NICU care may be declined and comfort care provided or NICU care may be chosen by the mother/family after review of probable and potential clinical outcomes with medical staff members. Majority of medical staff do recommend NICU care.
26-0 to 26-6	Tocolysis as indicated. Steroids as indicated. Cesarean delivery for fetal indications recommended strongly .	NICU care provided in the majority of cases.

Kaempf J, Medical Staff Guidelines for Periviability Pregnancy Counseling and Medical Treatment of Extremely Premature Infants. *Pediatrics* 117(1); January 1, 2006, p 26.

Table 2
NICHD Neonatal Research Network: Extremely Preterm Birth Outcome Data

Gestational Age (*Best Obstetric Estimate in Completed Weeks*): 23 weeks Birth Weight:

475 grams

Sex: Female

Singleton Birth: Yes

Antenatal Corticosteroids: Yes

Estimated outcomes for infants in the Neonatal Research Network sample are as follows:

Outcomes	Outcomes for All Infants	Outcomes for Mechanically Ventilated Infants
Survival	25%	35%
Death	75%	65%
Survival Without Profound Neurodevelopmental Impairment	16%	23%
Death or Profound Neurodevelopmental Impairment	84%	77%
Survival Without Moderate to Severe Neurodevelopmental Impairment	9%	13%
Death or Moderate to Severe Neurodevelopmental Impairment	91%	87%

www.nichd.nih.gov/about/org/der/branches/ppb/programs/epbo/Pages/epbo_case.aspx

The data predicts that the statistical risk of death is 65% for females born at 23 weeks gestation and weighing 475 grams if they receive NICU care, and the risk of survival with profound NDI another 12%, and moderate to severe NDI another 10%. Taken another way, there is only a 13% statistical chance of survival without at least moderate to severe NDI. All my colleagues agree that there should be no medical intervention in this case.

Using only statistical outcome data, the neonatologist frames the message to the expectant parents in such a way that they choose to deny treatment before the baby is even born. The neonatologist has not made a definitive diagnosis because he cannot examine the baby yet. In fact, the neonatologist will not even attend the birth. This is framing bias, and it compromises efforts to approach prenatal counseling in a non-directive manner (Haward 2008, 109). But the guidelines mandate a “party line” that pushes a negative narrative that will ensure an outcome that agrees with the consensus statement: “NICU intervention not recommended.”

Results

Neonatologists and ethicists have criticized the guidelines since they were published in 2006. An editorial in the Vatican newspaper specifically criticized these guidelines (Bellieni 2011). The European Union of Neonatal and Perinatal Societies published the “Ethical Charter of Newborn Rights” (Guimaraes 2011, 856), and these guidelines were not compliant with its recommendations. In 2014 the NICHD, the Society for Maternal-Fetal Medicine, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists jointly published an article [NICHD Consensus Paper] and their recommendations are summarized in Table 3. The consensus was that NICU care was to be recommended at 23 weeks gestation (Raju 2014, 1089). Comparing Table 1 and Table 3, it is clear that the hospital was not in compliance with the new consensus recommendations. Soon after the NICHD Consensus Paper was published, the hospital re-pollled its medical staff to gauge continued support for its own guidelines. The results are shown in Table 4. Despite the fact that there were no significant differences in the outcomes of the polling done in 2006 and repeated in 2014, the hospital revised its “Perivability Guidelines” anyway (Kaempf 2016, 192). This revision exposes the fallacy of the process in which the hospital developed these guidelines in the first place. The guidelines were never consensus-based; they were developed in a noninclusive autocratic manner (Marmion 2018, 209). From the beginning, the hospital has exhibited intra-institutional moral complicity (Hampshire 2000, 45) and it continues to mount a focused solidarity to defend against outside criticism (Kaempf 7/2017).

The new guidelines are summarized in Table 5 (Kaempf 2016, 193). Now “the medical staff will support either palliative comfort care or NICU care” at 24 weeks gestation whereas previously the majority did “not recommend NICU care.” Recommendations for the obstetrician assisting at a premature baby’s delivery were also changed: Cesarean delivery for fetal indications is now recommended at 25 weeks gestation whereas previously the majority did “not recommend Cesarean delivery.” Cesarean section would now be an option even at 23 and 24 weeks gestation. While these are encouraging changes, the guidelines remain noncompliant with the NICHD Consensus Paper that recommends NICU care at 23 weeks gestation.

Discussion

Our patient-centered ethic designates the physician as the agent of the patient. The physician determines together with the patient that course of treatment that will best promote the patient’s wellbeing, setting aside effects on others, including effects on the physician, the patient’s family, or society. NICU parents lack the expertise needed to judge whether a particular health intervention is necessary or would be beneficial and whether it is being rendered in an appropriate way. They are especially vulnerable due to anxiety that leads to loss of self-confidence, making it difficult to engage in self-protective bargaining. Due to this dependent relationship, it is important to the success of their partnership in the service of their baby’s well-being that the family believes

Table 3
General Guidance Regarding Obstetric Interventions for Threatened and Imminent
Perivable Birth, According to Whether the Fetus is Considered Potentially Viable
and the Parent Wishes for Aggressive Intervention

Weeks-Days at Birth	Obstetric Care	Neonatal Care
<22	Antenatal corticosteroids not recommended. Tocolysis not recommended. Cesarean delivery for fetal indications not recommended.	NICU care not recommended. Comfort care only.
22-0 to 22-6	Consider antenatal steroids if anticipate delivery at or later than 23-0/7 weeks. Tocolytics not recommended unless given concurrent with antenatal steroids. Cesarean delivery for fetal indications not recommended.	NICU care not recommended unless considered potentially viable based on individual circumstances.
23-0 to 23-6	Antenatal corticosteroids recommended. Tocolytics to be considered. Cesarean delivery for fetal indication recommended.	NICU care recommended unless considered nonviable based on individual circumstances.

Raju et al, Perivable Birth: Management and counselling, AJOG 123(5), May 2014

that the neonatologist will be guided in his recommendations solely by the baby's best interests (Brock 1986).

Neonatologists have a limited ability to predict how an individual premature baby will respond to treatment at birth (Pierucci 2014, 432). Extremely low-birth-weight babies who are resuscitated and survive have "health related quality of life" as young adults similar to that experienced by those born at normal weight (Saigal 2006, 1146). But NICU care is withheld even for babies with a significant chance for survival because the hospital bases its guidelines upon equating disability and death. While promoting the guidelines as "shared decision making," it never included families in the collaboration that created and/or modified the guidelines (Kaempf 2018, 206). In fact, families are harangued by medical tyrants into making a decision for palliative care.

Babies destined for palliative care receive "comfort care" which is a euphemism for "no care at all." Parents of 84 babies born less than 26 weeks gestation choose palliative care at the hospital, a Catholic hospital in Portland, Oregon (Kaempf 2016, 194). According to the NICHD outcomes calculator, 43 of these babies could have survived if given appropriate care, and 24 of them would have had no evidence of NDI. Studies

Table 4
NICU Resuscitation Survey: 2006^a compared with 2015^b

Recommendation*	1	2	3	4	5
Gestation, weeks					
26w0d to 26w6d	2006 0%	0%	3%	19%	79%
	2015 0%	0%	0%	10%	90%
25w0d to 25w6d	2006 0%	4%	16%	45%	36%
	2015 0%	5%	15%	58%	23%
24w0d to 24w6d	2006 3%	34%	35%	24%	5%
	2015 5%	38%	35%	23%	0%
23w0d to 23w6d	2006 53%	36%	7%	3%	0%
	2015 48%	48%	3%	3%	0%
22w0d to 22w6d	2006 89%	7%	5%	0%	0%
	2015 92%	8%	0%	0%	0%

*Recommendation

1. Strongly discourage resuscitation
2. No resuscitation but OK if parent request to resuscitate
3. Neutral
4. Resuscitation but OK if parent refuses
5. Strongly encourage resuscitation

^a Kaempf, et al, Pediatrics 117(1), January 2006, p 25. [107 survey participants]

^b Kaempf J, Periviability Counseling and Shared Decision Making for Extremely Premature Infants: an 18 year review, 2015 Swanman Perinatal Conference, Portland, Oregon, May 7, 2015. [40 survey participants]

at the hospital showed that none lived longer than 171 minutes (Kaempf 2009, 1512). The Catholic hospital's outcome data showed this paradox: the survival rate for 23-week babies given appropriate care was 21%, much lower than the 38% survival expected for other centers in the United States (Marmion 2017, 858). If the parents go against the recommendation of the neonatologist and demand resuscitation, will their baby

Table 5
PSVMC Medical Staff Guidelines for the Care of Extremely Early Gestation Pregnancies and Extremely Premature Infants - 2015

Weeks-Days at Birth	Obstetric Care	Neonatal Care
<23	Tocolysis as indicated. Steroids are not recommended unless NICU care chosen. No cesarean delivery for fetal indications.	NICU care not offered. Comfort care provided.
23-0 to 23-6	Tocolysis as indicated. Steroids not recommended unless NICU care chosen. Cesarean delivery for fetal indications only if NICU care chosen. Intermediate obstetric care options are available.*	NICU care not recommended due to high mortality and high neurologic disability rate. Comfort care provided. NICU care can be provided if the family chooses.
24-0 to 24-6	Tocolysis as indicated. Steroid use if mother/family choosing NICU care. Cesarean delivery may be declined or chosen after review of clinical outcomes. Cesarean delivery should be discussed only if NICU care chosen. Intermediate obstetric care options are available.*	NICU care may be declined and comfort care provided, or NICU care may be chosen by the mother/family after review with the medical staff of the probable and potential clinical outcomes. The medical staff will support either palliative comfort care or NICU care.
25-0 to 25-6	Tocolysis as indicated. Steroids are recommended. Cesarean delivery is recommended after consultation with medical staff.	Resuscitation and NICU care are recommended. Palliative comfort care can be provided. A request will prompt an ethics consultation to promote full understanding of the clinical and ethical issues.
26-0 to 26-6	Tocolysis as indicated. Steroids are recommended. Cesarean delivery for fetal indications recommended.	NICU care provided in virtually all cases unless certain conditions are present such as major congenital anomalies that are generally incompatible with life.
* Intermediate obstetric management would not necessarily mean cesarean section but may include fetal monitoring with the use of maternal fluids, oxygen, and position changes as needed. If the fetal heart rate worsens and a non-reassuring fetal status is thought to be significant despite these intermediate measures, then palliative comfort care would be recommended.		

Kaempf J, Periviability Counselling and Shared Decision Making for Extremely Premature Infants: an 18 year review, 2015 Swanman Perinatal Conference, Portland, Oregon, May 7, 2015.

get the care it needs by a begrudging neonatologist? Is the outcome worse for babies resuscitated against the neonatologist's recommendation?

Equating a potential disability with death is medical tyranny. It excludes the opportunity for parents to determine how they view the risks for survival and the risk of morbidity for a baby delivering at an extreme gestation. Then end result is predictable: death not only from failure to initiate life-sustaining interventions, but also from inexperience in caring for the most premature babies. Fatalism leads to fatal outcomes. The parents should have been told that the hospital does not believe in life-saving interventions for these babies but that other hospitals do provide such treatment.

Sequela

What happens to parents who choose beneficial neglect? The long-term emotional and psychological effects on parents who have passively accepted the potentially preventable death of their baby are unknown. How will they handle the emotional and psychological repercussions when they happen to meet a family with a NICU survivor in the marketplace, at work or at family activities? They will relive the agony of their misery. The parents are the long-term victims of the guidelines.

Discrimination Against Infants with Disabilities

Since 2005, the Department of Health and Human Services interpreted the provisions of both the Child Abuse Prevention and Treatment Act and the Born Alive Infant Protection Act to mandate the examination of all "born alive" babies. Withholding treatment from a premature baby could constitute a violation of the Emergency Medical Treatment and Labor Act that obligates physicians and hospitals to treat a person who presents for emergency medical care regardless of ability to pay. Violations can result in severe CMS sanctioned monetary penalties (Marmion 2018, *Linacre Q*,10).

Conscience Rights

Hospital health care providers and nurses must use the consensus statement—NICU care "not offered" or NICU care "not recommended"—when counseling parents. This is the third assault against the conscience rights of health care providers: abortion, euthanasia, and now infanticide. If a physician were to recommend treatment when the dictum is to state "the majority of the medical staff do not recommend NICU care," she will be at risk professionally (Marmion 2017, 859). An ominous situation for a health care provider is to be labeled "disruptive." This politically correct designation allows the hospital to take whatever disciplinary steps are necessary to correct the disruptive behavior, ultimately penalizing the recalcitrant doctor with loss of hospital admitting privileges and reporting the offender to the state medical board for additional disciplinary action against her medical license.

Catholic

By equating disability and death, powerful authority figures determine that a vulnerable life is not worthy to be lived. It is the intent of the denial of life-sustaining

interventions that demonstrates its unethical nature. If an extremely premature baby were to continue to live without receiving life-sustaining intervention, would the neonatologist be pleased with the outcome? No, the goal is a dead baby. It is infanticide. According to Catholic teaching, euthanasia is an act or an omission that is intended to cause death (Camosy 2017). *Catholic Health Care Services Ethical and Religious Directive #60* prohibits participating in euthanasia in any way (USCCB 2018, 27).

The *Catechism of the Catholic Church* #2268 condemns infanticide as an especially grave crime “by reason of the natural bond which it breaks,” and #2271 states that “life must be protected with the utmost care from the moment of conception: abortion and infanticide are abominable crimes” (*Libreria Editrice Vaticana* 1994, 546-7). *Evangelium Vitae* #14 summarily condemns the hospital’s guidelines: “The point has been reached where the most basic care, even nourishment, is denied to babies born with serious handicaps or illnesses. The contemporary scene, moreover, is becoming even more alarming by reason of the proposals, advanced here and there, to justify even infanticide, following the same arguments used to justify the right to abortion. In this way, we revert to a state of barbarism which one hoped had been left behind forever.” (John Paul II 1995, 14)

Conclusion

A Catholic hospital has developed guidelines denying care for some premature babies. Once selected for palliative care, a doctor will not be present at birth to evaluate the baby. These untreated babies all die. For older children, the family makes decisions to withhold treatment only after having an examination and getting an official prognosis, and the possibility of a “potential” disability is never a sufficient reason to withhold treatment.

This policy of systematically withholding medical evaluation and resuscitative care from a subset of premature babies with significant chances of survival is highly problematic from both medical and ethical points of view. It certainly results in death for babies who are denied life-sustaining intervention. For those choosing NICU intervention, the care could be substandard and result in poor outcomes. The long-term emotional consequences for the family are unknown.

The hospital’s guidelines, developed and promulgated by a Catholic institution with the imprimatur of its ethicist who happened to be a priest, have an aura of magisterial legitimacy that is scandalous.

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