
The Ethics of Withholding/Withdrawing Nutrition in the Newborn

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The provision of nutrition and hydration to newborn infants is considered fundamental care. For premature and critically ill newborns, similar considerations generally hold true. Nutrition may be provided for these infants using assisted measures such as parenteral nutrition or tube feedings. However, for some newborn infants the provision of medically assisted nutrition may be a more complicated issue. In particular, the goals of nutrition need to be clearly elaborated for newborns with lethal conditions or for whom appropriately administered intensive care is unsuccessful in sustaining life. These infants may benefit from palliative measures of care and a limitation or withdrawal of burdensome or nonbeneficial interventions. This article explores issues pertinent to deciding and communicating the appropriate withdrawal of medically assisted nutrition and implementing palliative comfort measures.

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Throughout the neonatal period, the use of early and aggressive parenteral nutrition has become normative.¹ Indeed, fluid and nutrition provisions are fundamental components of what may be seen as basic newborn care in both the well and the sick, or premature, newborn. As with other interventions, the provision of nutrition should be directed toward accomplishing some goal for the newborn patient. Reasonable considerations include:

1. Obtaining an approximation of in utero fetal growth in premature infants in order to facilitate normal development
2. Providing sufficient energy substrate for basic metabolic demands, as well as any increased needs in the sick newborn
3. Ensuring that there is a proper nutrient balance to support the infant's immune function

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and ensure, in the surgical patient, wound healing

An evidence-based approach toward nutritional therapies is recommended, and a wealth of nutritional data is available for managing the premature or sick newborn. Additionally, the nutrition plan should fit with the overall goals of care for the patient, and both patient benefit and safety must be addressed in providing the composition and means of administering parenteral or other medically provided nutrition.

Ethical Considerations of Withdrawing Artificially Administered Nutrition and Hydration in Adults

Ethical considerations around the provision or withholding of nutrition gained attention in medical practice in the late 1970s and early 1980s. An "emerging stream" of thought that fluids and nutrition could be withheld became apparent, argued around 2 propositions:

1. The medical administration of nutrition is a medical intervention, and
2. A benefits/burdens calculation was the critical element of judgment about withholding/withdrawing medical interventions (the rule of proportionality).

In an early article, Seigler and Weisbard² argued against this emerging stream. They stated that while these 2 propositions were true, it was "troublesome" that physicians or families might conclude that the "burdens" of withdrawal

could outweigh the “benefits” of treatment (eg, sustaining life by providing nutrition).

We would argue that such thinking may be flawed, as it appears to be against the normative approach that clinicians commonly take for resolving such weighty decisions. For example, when clinicians are deciding to continue or withdraw a ventilator, they don’t balance the benefits of assisted ventilation against the burdens of withdrawing the ventilator. Instead, they consider the benefits and burdens of the treatment (eg, tracheal intubation and assisted ventilation) itself. They may ask, “Should I start the ventilator? Continue it? Or, withdraw it?” realizing the importance of understanding the consequences of *not* providing the treatment (ventilation/oxygenation), which also has its separate benefits and burdens. They do not, however, report the treatment as beneficial and the withholding or withdrawal as burdensome. To do so would demonstrate a value bias. Such a biased analysis is not a rational weighing of proportionality.

In the early 1980s, Yarborough³ proposed that the symbolism often attached to feeding (even artificially administered nutrition) may mislead physicians as they try to make right and good decisions for and with their patients - even those who are terminally ill. Many physicians voiced the perception that these measures were essential - even when other medical interventions were being withdrawn. Generally, clinicians argued that the withdrawal of artificially administered nutrition would be the equivalent to “starving a patient to death.” Attempting to elaborate on a deeper level, Yarborough asked clinicians to consider the provision of medically administered nutrition as “force feeding” rather than a presumed essential good. He proposed that:

1. Those who insist on tube feeding should present the burden of proof of demonstrating benefit rather than those who would forego it having to explain [potential] harms,
2. Unbiased, more reasoned and less emotional, ethical decisions regarding artificially administered nutrition requires more facts about the attendant risks and benefits of such measures (especially in the terminally ill patient), and
3. The potential that forced artificial nutrition might even be considered a form of torture (rather than a means of providing comfort

for a supposed state of suffering) should be studied.

Presently, many clinical and ethical professional societies see no difference in artificially administered nutrition and other medical interventions that might become inappropriate in a given patient’s condition and, thereby, should be considered for withdrawal.^{4,6}

Recently, the potential benefits and burdens of nutritional support were reviewed by Winter.⁷ His report addresses the provision of such interventions compared with withholding/withdrawing (WH/WD) them in regards to survival, response to therapy, and comfort or correction of metabolic abnormalities in adults.⁷ He concludes that clinical benefits of nutritional support fail to be demonstrated in study after study of patients at or near the end-of-life. Importantly, he cites a general complication rate of at least 15% (infection, thrombosis) attendant to providing parenteral nutrition. And even in artificially administered enteral feedings, often thought to be less invasive, he found a 76% complication rate.

In Winter’s review of the benefits and burdens of *not* providing these interventions, it was evident that there was a reduction in the metabolic rate, urea load, respiratory secretions, coughing, nausea, vomiting, diarrhea, and urine output in adults at the end of life for whom nutrition was withheld.⁷ Fasting in adults was also reported to lead to some psychological or behavioral changes. These included a release of endogenous endorphins, which could provide an analgesia effect and rising pain threshold, or even euphoria, accompanied by the preservation of mental function. A reduction in hunger also accompanies the production of ketones seen in fasting adults. In the end, WH/WD of nutrition and hydration in the terminal adult had some benefits and did not hasten death.

Pediatric Withdrawal of Artificially Administered Nutrition

The support found in the adult literature that withholding artificially administered nutrition near the end-of-life does not prolong life, may not be true in pediatrics. Certainly, there are pediatric patient populations for whom gastrostomy tube feedings or parenteral nutrition will prolong the life of the child. This may be so,

even if the child will ultimately die from their underlying condition. A ready example would be the premature infant with an extremely short gut - perhaps following necrotizing enterocolitis (NEC), or an infant with severe hypoxic-ischemic encephalopathy (HIE). This fact, that lives *can* be prolonged with artificially administered nutrition, ought to lead clinicians to engage the family in dialogue concerning what constitutes a valued life - or alternatively, what may be considered as prolonging death. Families generally require information, an opportunity to have time for reflection, and the allowance to contribute to this most difficult decision. Providing nutrition, therefore, which might at first be considered as essential care for every infant, may need to be reconsidered in light of the infant's underlying diagnosis, prognosis, and limits of what medicine has to offer. As noted by Dr. Ronald Cranford, "anyone who believes that eating and drinking in normal children are remotely similar to providing a feeding tube for severely brain damaged children has never been present at the bedside of these patients and has no good sense of the medical reality."⁸

Decision-Making

To proceed with the decision-making process for the WH/WD of artificially administered nutrition, many issues must be examined. The focus needs to remain on the infant and his/her perceived best interests. All pertinent decision-makers need to be identified. All explicit medical, as well as human value, facts need to be obtained and contemplated. And, finally, external concerns such as legal precedents must be weighed.

Decision-makers. Parents, as principal decision-makers for their children, hold a well-established prerogative. But parenting can be most difficult in the neonatal intensive care unit (NICU).⁹⁻¹¹ Myths concerning the capabilities of parents need to be dismissed. Barring evidence of their being mentally incapacitated (eg, mother postoperatively managed under sedation/analgesia), acting with obvious harmful intent toward the infant, or simply being absent or uninvolved, all parents should be enjoined in mutually deriving the best interests of their infants and share in decision making.¹²

Myths that may require attention include:

1. Parents are unable to hear and understand the facts
 2. Parents cannot help but be overwhelmed by emotions
 3. Parents cannot speak out of concern for the infant's interests rather than their own self-interest.
- These myths call for enhanced communication, psycho-social and practical supports, and a sharing of ideas addressing infant interests now, and in the future, as well as quality of life considerations and attention to perceptions of infant pain and suffering.
- Neonatal and pediatric health care professionals retain an interest in the well-being and long-term outcome of their young patients. In the NICU, outcomes may be uncertain. Yet, the inclination to treat or intervene on behalf of the premature and critically ill newborn seems rational when growth, development, healing, and some measure of health can be attained. Nonetheless, tragic situations do exist wherein cure-oriented care needs to give way to comfort measures in view of a terminal prognosis. This may also be true when situations exist in which the benefits of continued interventions are, at best, uncertain and the burdens to the child associated with their provision may not be acceptable to the family.
- The state may also hold some interest in preserving an infant's life if it is clear that the life will be meaningful in a human relational sense. Similarly, if it is perceived that an infant is suffering, and that such suffering can be reduced but the parent(s) do not allow it, the state's interests may prevail and parental rights be limited or terminated through court actions.
- Factual considerations.** The facts that need to be considered in making decisions to WH/WD artificially administered nutrition fall into two categories. First are the medical facts:
1. Underlying diagnosis
 2. Response to previously given treatments
 3. Likely response to appropriate treatments or interventions not yet offered
 4. Ultimate prognosis for the infant's condition
- These all need to be determined and discussed.
- Example.** Is there:
1. an underlying lethal condition (eg, Trisomy 18)?
 2. a refractory chronic and debilitating condi-

- tion (eg, severe respiratory failure on assisted ventilation at > 3 months of age?)
3. multiple organ-system failure (eg, overwhelming sepsis)?
 4. an irreparable loss of vital tissue or organ function (eg, severe brain injury, loss of bowel)?

Or is the condition one that can be treated over time and met with some improvement; or for which there exists nutritional, medical, or surgical options (even organ transplantation) given time, relative health and access to such measures at home or in the hospital? Special consideration must be given on an individualized basis for complicated patients when the long-term therapeutic option is considered experimental at best, such as those with a severely shortened bowel in whom bowel transplant may be but a remote possibility. For some such patients intervening liver failure, recurrent infections, or poor growth may preclude operative repairs or transplantation and the hard choice of withholding further parenteral nutrition may be most prudent.

The second category of factual considerations is human value in nature.

1. What do the parents anticipate, expect or desire for this infant?
2. What values, principles, or other constructs motivate their likelihood to consider risk, weigh options and proceed with decision-making?
3. And also, what values are upheld or pursued by the involved health care team?

These facts aren't often explicitly discussed on rounds. It may require a family care conference, ethics consult, or other deliberately planned session to uncover them. Yet, these values are important in shaping choices. The pursuit of these facts is essential in order to pursue an informed, shared decision-making process as advocated by the American Academy of Pediatrics.¹³⁻¹⁵ The benefits of a negotiated best interest standard, as described by Leuthner, may lead to accomplishing mutually recognized goods for the infant by parents and health care professionals alike.¹⁶

Legal issues. External considerations that may shape decisions for WH/WD of artificially administered hydration and nutrition require examination as well. Real people within society and

institutions make choices that may lead to precedents for others. Eight judicial decisions regarding the withdrawal of technologically provided nutrition (and hydration) exist: 4 addressed patients in a persistent vegetative state (PVS) and 4 addressed never competent persons.¹⁷ Many appellate court decisions regarding nasogastric or gastrostomy tube feedings, as well as parenteral nutrition, hold these measures to be equivalent to life-sustaining technologies such as mechanical ventilation.

In a recent issue of the *Journal of the American Medical Association*, 7 legal barriers to end-of-life care were addressed as myths, realities or having grains of truth.¹⁸ One myth that the authors describe is that of the WH/WD of artificial fluids and nutrition from terminally ill or permanently unconscious patients being illegal. In reality, they state, much like any other medical treatment, it can be withheld/withdrawn if the competent patient refuses or, in the case of an incapacitated (including never competent – eg, newborn) patient, the appropriate surrogate may decide. The role of surrogates, however, differs among the different states. In states like Wisconsin, the option to WH/WD artificially administered nutrition at the request of a surrogate decision-maker is not allowed unless the patient is terminal, in a persistent vegetative state, or there is some explicit refusal of this treatment prior to the respective patient losing decision-making capacity. We contend, however, that the value of human dignity extends to both competent and incompetent individuals. Cognitive or developmental incompetency should not result in a denial of the right of being free from medical interventions.

So, where does this leave the newborn? The incompetent newborn/child has a right to refuse medical treatment, which can properly be exercised by involved and informed parents. To presume that life-sustaining treatment should continue until death is imminent, if the patient has not previously indicated otherwise, would make the newborn infant or child a passive object of medical technology.¹⁷ The burden of proof should rest with the medical staff to demonstrate that a parent/guardian is not acting in the best interests of the infant before usurping this authority from them.

But what if the newborn/infant/child is not in a terminal or irreversible state? Do the interests of the State prevail in a weightier fashion

then? The so-called Baby Doe rules (Child Abuse Amendments) could arguably pertain. Should physicians, parents, or others question the consideration of artificially administered hydration and nutrition as “medically indicated” treatment or construe it as clinically “appropriate” in all cases?

In the Federal 1984 Child Abuse Prevention and Treatment Act it is stated, “The term “withholding of medically indicated treatment” does not include the failure to provide treatment (other than *appropriate* nutrition, hydration, or medication) to an infant when, in the treating physician’s . . . reasonable medical judgment:

1. the infant is chronically and irreversibly comatose,
2. the provision of such treatment would
 - a) merely prolong dying,
 - b) not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or
 - c) 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.”¹⁹ [19, *italics added*].

Varied interpretations of this language exist:

1. every infant should *always* be provided with medical means of nutrition
2. every infant should receive nutrition *appropriate* for his/her medical situation.

While in reality this law does not apply directly to physicians, nurses, or parents, it does get the attention of many. And while it does not create a federally mandated standard of care, or authorize any civil or criminal penalties, it is often misinterpreted as doing so.²⁰ What the amendment addresses is the receipt of federal dollars for patient care - and the potential that such money may be curtailed if an institution is reported, investigated, and found to be in breach of the Child Abuse and Neglect Amendments by withholding care against the standards stated above. Given the broad interpretation of “*appropriate* nutrition, hydration, or medication” and in the purview of clinical judgment, the present authors do not believe that there should be any restrictive interpretation of these rules to prohibit the withdrawal of nutrition.

Emotional Considerations

Strong psychological forces exist that lead parents and professionals alike to think of nutrition and hydration as different than medical treatments. Pediatric professionals demonstrate this when they make a distinction between artificial breathing and feeding through their practice patterns of treatment withdrawal. The Pediatric Section of the Society for Critical Care Medicine found that 98% of physicians were apt to withhold cardiopulmonary resuscitation (CPR), 86% withdraw ventilators, and only 42% withdraw tube feedings.²¹ A pediatric house-staff survey (3rd year residents) demonstrated that 100% would withhold CPR and vasoactive drugs, 97% would withdraw ventilator support, but only 45% would withdraw fluids and nutrition.²² A 1992 Child Neurology Society survey revealed that 75% of pediatric neurologists *never* withheld nutrition and hydration even in cases of persistent vegetative state in children.²³ And in a recent inpatient review of the care provided to terminally ill infants and children, while CPR or assisted ventilation were withheld or withdrawn in 55% and 64%, respectively, only 23% of dying infants and children had their nutritional support removed prior to their death.²⁴

Those who argue against withdrawing artificially administered nutrition generally hold that there is something fundamental about eating, or being fed. This intuitive desire to help provide food to infants seems to have even more symbolic importance to parents than other family members who might be asked to consider it in an adult relative because of the nature of parenting and the very biologic and social role that parents fulfill. Parents nurture their infants by doing many things - including feed them. Yet, while it would indeed be wrong to withhold hydration and nutrition from otherwise healthy infants, some infants *are not* - or may never be - healthy at all.²⁵ Hence, the moral or ethical confusion of an obligatory provision of nutrition to all infants should be avoided.¹⁷

Johnson and Mitchell have recently written about the issue of WH/WD artificial means of nutrition.²⁶ They agree that no moral distinction exists between an endotracheal breathing tube (ETT) and a feeding tube of any sort - plastic tubes that enter a body orifice for the purpose of providing necessary elements for survival, be this sugar, protein, fat or oxygen, have no moral

distinction. Additionally, they and others, address a few of the psychological issues pertinent to this issue^{17,26}:

1. Societal beliefs that children are not supposed to die
2. Medicine may have a “cure” for any given condition “just around the corner”
3. Clinicians should not “give up” on any infant.

Perhaps the most pertinent real concern, both factually and emotionally, is the potential uncertainty of outcomes for a given condition in a young infant. This may be true for neurologic and metabolic diagnoses, and even some other chronic conditions.

Many of the psychological stumbling blocks may revolve around the concept of “starving” and the issue of “time.” If a clinician withdraws a ventilator from an infant, the infant typically does some breathing on his/her own. It may be only one agonal breath in a critically-ill infant, but continued respiratory function may follow for some time in others - even for days. Typically, if an infant does some intermittent breathing, allowing it to live for a few hours or days, it is not argued that clinicians should reinstate the ETT because the infant is taking in only half the oxygen she or he needs. Instead the standard of care is to apply palliative care through giving oxygen and medication for comfort.

Yet this is the conclusion that many arrive at in cases concerning artificially administered feedings. It has been argued that if an infant takes in only one half of the feeding required to survive, there is justification in providing the other one half through artificial means.²⁶ The course of reasoning for this is that without feeding, the infant’s dying (and alleged suffering) will be protracted – therefore, a slow “starving” of the infant should be avoided. This rationale may well be the first of a few psychological traps into which any caregiver may fall. The exploration of what is meant when people say the word “starving” requires further attention.

Typically when the word “starving” is used, there are two parts to the word that come to mind. The first of these is the lack of nutrition (including the lack of calories, protein, fats, and sugars). It may well be true that taking in only one half of the necessary feedings necessary to sustain life, accomplish growth, or heal disease may lead to a slow death through lack of nutrition. But the question must be asked, “Is this

really any different than the infant who takes intermittent breaths of oxygen – not enough to survive, but enough to prolong things a little?” Why would the response to these two scenarios be different?

The second part to be considered when using the word “starving” is that there is a connotation of suffering which accompanies the lack of nutrition. Suffering is to be avoided - the goals of medicine include the reduction or elimination of suffering. And it is this meaning of the word that people rely upon for an emotional response to the avoidance of “starving.” Such a consideration does have moral weight, but the moral weight is no different than that of the infant for whom the ventilator is withdrawn. In this latter case it is argued to give morphine to take away the suffering attributed to air hunger. Is this any different than providing morphine to take away food hunger? If the infant will be suffering, clinicians do not want to cause a long-suffering death. Again, Dr. Ronald Cranford states, “patients do not show any of the terrible signs of starvation described by pro-life supporters.”⁸

In reality, the difference that may exist between the withdrawals of these 2 interventions is likely to be in the length of time from withdrawal of the intervention until death. Is there any moral significance in the “time” from WH/WD of any intervention to death? To assign too much significance to this consideration of time may present a second psychological stumbling block for caregivers. If time is the issue, it probably underscores why most clinicians have so easily come to grips with stopping ventilation - the infant usually dies rather quickly. Without much time on their hands to fret over this being the “right” decision, it may be more readily accepted. Comfort care is provided for a relatively short time and it is generally considered that the right thing was done. On the other hand, when all nutrition is discontinued, it can take up to two to three weeks for an infant to die. This gives clinicians and parents plenty of “time” to question the moral credibility of their actions. If the infant takes in one half the necessary volume of feedings orally, this time may be even more prolonged - in the range of months. Time and the notion of suffering, then, engender a discussion, or questioning, of right action. Does it really matter if it only was a few hours or days? And even if the infant doesn’t suffer, what about others?

In the end, infants with conditions that ultimately lead to their demise pose no real moral dilemma concerning “time” other than the importance that it be spent free of suffering, with optimal human contact, and in comfort. Such a consideration, then, can support the decision to remove all artificially administered hydration and nutrition and initiate active comfort measures.²⁷ It could even be argued to not provide artificial tubes but instead turn hopes toward making the best care and comfort for the baby in the remaining time that he/she has with family.

If an infant is to be provided some volume of their feedings as a first measure of comfort, it should be done orally. This will serve to satisfy his/her hunger, avoiding hunger “pains” as well as provide an opportunity for parental/child interaction. In these circumstances there is not likely to be any second component to the definition of starving - no suffering. The fact is, however, that artificial feedings can issue more discomfort than benefit for the dying child. Risks attendant to the administration of nutrition are noteworthy (catheter thromboses or infection, tube malposition, aspiration). And, as was previously noted regarding adults, the burden of proof that such measures are truly beneficial *to the infant* remains to be demonstrated beyond the simple fact of prolonging the infant’s biologic life - perhaps without any potential for perceiving benefit or interacting in a human relational sense.²⁸

Practical Strategies in the NICU

Given the occasional necessity to consider the WH/WD of artificially administered nutrition in the NICU, what guidance can be given?

First and foremost, the necessity of maintaining communication between the parents, extended family, and the health care staff must be underscored. All involved should be aware of the infant’s signs and symptoms that may develop with the withdrawal of artificial hydration and nutrition, the time frame over which these will likely appear following withdrawal, and a best estimate as to the time of death. Any staff member that is uncomfortable with a decision to WH/WD hydration and nutrition should be allowed to step down from the care of the infant.

With the withdrawing of ventilator support or vasoactive medications, and the expectation that death will occur in minutes to hours, intrave-

nous access may be important for comfort medications. It is reasonable to cap the intravenous line and remove it only after the infant’s death. While some caregivers feel more at ease removing these other modalities first, and only much later address the withdrawal of nutrition or hydration, this is an unnecessary step that may lead to more psychological distress than removing all therapies at once. It is also important to withdraw nutrition and hydration together because withdrawal of nutrition alone prolongs the death without the biological advantages of dehydration on relieving other symptoms.

If an infant has survived the withdrawal of other therapies, it is important to understand the potential time frame of death from the WD/WH of artificially administered hydration and nutrition. This may depend somewhat upon the disease process and the size of the infant. For example, the preterm infant who had NEC and has severe short gut syndrome will likely die within a week or so from stopping all hydration and nutrition. However, the full-term infant with gastroschisis and short gut from infarction of the intestine may survive up to three or four weeks. While it will be impossible to predict when a child might die at the outset, it is important that the staff and family are prepared by recognizing a reasonable range of time over which this may occur. If the infant acts hungry and can take in some oral feedings, they should be provided. In this setting, it is important to remain focused on the overall goals of comfort care, rather than the more typical “growth and development” aspects of nutrition, even if this infant might live weeks to months. Staff can learn to teach or redirect the focus of care and emotions from wondering and sadly wishing for an infant’s death to being quick to enjoy each extra day given as a gift. These actions will go a long way in helping families cope and avoid second guessing.

Pertinent symptom management for infants receiving palliative care is important for nurses and physicians to master. Generally, infants that die from the WD/WH of hydration and nutrition do so comfortably. While there will likely be significant electrolyte disturbances, seizures are extremely rare except in those infants who have an underlying seizure disorder or neurological condition. If a child is going home with a family, lorazepam is a good agent for signs of agitation - it can be given IV, IM, PO or subcutaneously for a seizure. Morphine should also be available for

any signs of discomfort, and familiarity with its use is commonplace among hospice staff. Both of these medicines can also be given sublingually or by dropper. Good skin and mucous membrane care is important in helping to prevent symptoms of thirst and discomfort. It is also an outward sign that the infant is well cared for by the family.

When the infant stops urinating, death can soon be anticipated. It usually will occur within a number of days from the point of anuria. Sleep periods will increase, and the infant eventually will not consciously awaken again. Parents usually describe death as happening comfortably in the infant's sleep.

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