Ethics Consult Report

Withdrawal of Artificial Nutrition and Hydration

A 6-month-old CICU/Palliative care patient with diffuse neurological injury, cardiac disease and severe ischemia

Stowe Locke Teti

A medical team considers withdrawal of artificial nutrition and hydration supporting a 6-month-old girl with complex cardiac disease, devastating neurological injury, and ongoing, unmanageable pain. Diffuse neurological injury and severe ischemia in all four limbs offers a bleak prognosis. Drawing on the bioethics literature on the subject, the following case presentation and analysis one way a medical team and family can approach such a situation.

Situation

Reason for Consult

The Palliative Care and Heart and Kidney (HKU) teams are considering withdrawal of the artificial nutrition and hydration (WANH) being used to maintain a 6-month-old female patient with complex cardiac disease, devastating neurological injury, and ongoing pain. Some members of the medical team are uncomfortable with the idea, and an ethics consult has been requested to clarify the issues involved. Specifically, it has been asked whether artificial nutrition and hydration (ANH) should, or should not, be treated any differently that withdrawal of other life support interventions, such as ventilators. A second request was in regard to what sort of decision-making framework is appropriate to use in such cases.

The clinical ethicist has been informed that the Allow Natural Death (AND) policy has been explained and offered to ML's mother for her child via withdrawal of the artificial nutrition and hydration (WANH), but the issue has not been pursued beyond that.

Patient Condition Summary

ML is a 6-month-old female with:

- Diffuse neurological injury (8/10 severity) due to oxygen deprivation.
- Severe ischemia in all 4 limbs that has resulted in loss of hands and feet .
- Facing probable 4-limb debridement/ amputation.
- Ongoing pain from transition zones/wounds and wound care.

> "Her devestating neurological and physical injuries are the result of the limitations of current medical technologies to rescue her intact from the conditions of her birth."

Extracorporeal Membrane Oxygenation (ECMO) can be a bridge to curative therapies, but comes with its own risks. While overall mortality remains high, morbidity can also pose distinct challenges for medical teams and families. In this case, the patient's

Background

Diagnosis

ML has a history of complex cardiac disease and is s/p two heart repairs. Two significant iatrogenic factors contribute to the current bleak picture. The first is severe neurologic injury secondary to ECMO decannulation/ cardiac arrest. There was extensive brain damage, sparing the brainstem. This resulted in blindness and lack of intentional motor control. Her ability to suck and swallow is doubted by her physicians, but unknown. The second is severe ischemia to all of her limbs following prolonged ECMO (related to inability to remove from bypass following surgery). Her hands and feet are reportedly not salvageable, but remain attached to advancing necrotized live tissue, forming transition zones on all four limbs.

Prognosis

Since the neurological damage is a result of oxygen deprivation, no recovery of function can be expected, as might be the case with trauma. The MRIs presented during the ethics consult displayed extensive brain tissue loss throughout prefrontal and midbrain areas, leaving only the brainstem intact. The patient requires medication to prevent seizures, is blind, will likely be unable to exhibit motor control. Functions such as sitting are unlikely, and she has a high chance of being non-verbal. She may be able to hear.

She is facing, minimally, self-amputation of hands and feet. Currently the transition zones are being monitored, but daily wound care causes significant pain even with the use of strong analgesics. Debridement of necrotized tissue on all four limbs will eventually be needed if efforts are made to preserve limb length. Wound care reports undetermined lengths of healthy tissue exist towards the centers of each limb.

Psychosocial

This family has a complex social situation. The father was present via phone for part of the ethics consult, but is reportedly not involved. The consult was attended by the mother's mother and mother's grandmother. The mother may have been high during the consult, and reportedly uses marijuana to cope. Social Work feels there is a strong likelihood this child would end up in foster care, reporting this mother does not have the means to care for a child with profound disabilities. However, both grandmother and great-grandmother stated support for whatever the mother decides.

Ethical Assessment

Kopelman has argued the Best Interests Standard is most appropriate in these circumstances; assessing the patient's immediate and long-term interests and setting as one's prima facie duty that option which maximizes the person's overall or long-term benefits and minimizes burdens. [1] Carter and Leuthner (2003) proposed a framework specifically for analyzing the

decision to withdraw ANH in infants. [2] It includes two sets of questions that will be addressed here. The first set has to do with medical facts. The questions are:

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

As reported by Neurology, ML will never be able to develop the capacity for thought, or move intentionally, and is likely to be both nonverbal and unable to maintain her body positioning. The type of neurologic insult involved, oxygen deprivation, precludes the kind of significant recovery sometimes possible with head trauma, and the diffuse nature of the damage likewise precludes one brain area taking over the function of another.

Were it not already forgone due to this neurological devastation, her blindness and loss of limbs would impose significant developmental limitations; without hands or feet, tactile potential is reduced, severely limiting her ability to learn from and interact with her environment. However, ML is capable of feeling pain, and the transition zones between live and necrotic tissue on all four limbs cause her significant pain and suffering.

Moreover, ML's current condition is in part a result of iatrogenesis. Her devastating neurological and physical injuries are the result of the limitations of current medical technology to rescue her intact from the conditions of her birth. We must therefore ask if pursuing this course of action is truly in her interests, being especially sensitive to any further iatrogenic harm she may be exposed to.

> "Far from relieving suffering, artificial feeding might in itself be a form of torture."
>
> —Howard Brody

The question at hand is whether the continued use of ANH is ethical given the above conditions. In this case, ANH is not being used as a bridge to a curative therapeutic intervention, as a result of feeding issues in a patient who has some quality of life, or to maintain a patient in a persistent vegetative state. The Carter and Leuthner framework concludes with a set of value considerations:

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. What values are upheld or pursued by the involved health care team?

ML's mother has stated she does not want her daughter to suffer, and has not advocated for a "do everything" approach. Patients, or their duly appointed surrogates, may accept or refuse ANH on the basis of the same considerations that guide all other medical decision-making: potential benefit versus risks, harm and discomfort, and cultural or religious beliefs. [3] In other words, *net benefit* is the standard by which the decision to administer, continue, or withdraw ANH should be made. The discontinuation of ANH is not, and should not, be held to a higher standard than other medical care decisions. [3,4,5]

Clinicians and families sometimes are concerned that withdrawal of ANH is tantamount to "starving" the patient, evoking images of a patient being "starved to death," or "dying of thirst." Human interactions involving food and eating are embedded and value-laden in most cultures; the idea of denying that to vulnerable patients elicits a strong response in many. In the late 1980s, Yarborough asked how we might respond if those images were replaced by that of forced feeding, pointing out that these emotive images diverge from what, in fact, occurs. [6] Direct observation of those who undergo withdrawal of food and fluids indicate that hunger is not an issue. In 2000, Brody went so far as to suggest that, "far from relieving suffering, artificial feeding might in itself be a form of torture," [7] pointing out a number of meta-analyses confirm no substantial benefit has ever been shown for ANH at the end of life. [8] Dehydration can help avoid the agonal stertors (gasping respiration) which afflicts patients during this time. [9]

It must be emphasized that there is no substantive difference between ANH and artificial ventilation; both are medical interventions used to sustain patients who would otherwise not survive. If we would recommend removal of a vent in this patient, we should be no less hesitant to recommend removal of ANH. [10] In this case, removal of ventilation was already recommended and carried out with the expectation that she would pass; unexpectedly she was able to breathe on her own.

As a result, withholding/withdrawal of nutrition and/or fluids can be ethically justified under the principles of non-maleficence and compassion.

There is still some reticence to apply this reasoning [11] to WANH in general. In this case, ANH is making possible the continued experience of pain by a patient who, to the best of our knowledge, is capable of only of sentience, not cognition. Even if a greater degree of neurological function were to exist, the patient's very limited means to perceive and respond to her environment precludes meaningful development. Thus, any minor indeterminacy in neurological prognosis is rendered moot by these other factors. ML's future includes further loss of bodily integrity due to the four-limb amputation, and with that, potential for great suffering. The health care team has expressed significant reservations with continuation of care under these circumstances.

Regarding ongoing care, the significant suffering that would be incurred in the debridement of dead tissue, amputation, formation of terminal limb ends, and attendant recovery [12], must be considered against the benefits gained. [1] There is no way to know whether the pain from these injuries will ever abate [13] and as there is no means of communicating with this patient, the possibility for continuous, unrelieved, undiagnosed pain is clear and present; as one author reports, "There are a plethora of pain assessment tools to use in this age range because none is ideal." [14]

ML's quality of life is limited to immediate sense perception via the working components of her sensory apparatus. The net benefit calculus includes ongoing pain, but no observable positive sensation. Given the information provided, withholding/withdrawal of ANH is ethically permissible, justified by the principles of non-maleficence and beneficence.

Recommendation

- In light of the patient's diagnosis and prognosis, and her ongoing suffering, withdrawal of ANH is recommended, justified by the principles of beneficence and non-maleficence.

- Space procedures that induce pain (such as dressing changes) as much as possible, with maximum attention to pain control and sedation.

Follow-up

ML passed away one month after the ethics consult. ANH had not been removed.

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Endnotes

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