

Withholding and withdrawing artificial nutrition and hydration

E Tsai; Canadian Paediatric Society, Bioethics Committee



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Although the practice of withholding and withdrawing artificial nutrition and hydration (ANH) has become more common, it remains controversial, particularly in the paediatric setting. Decisions regarding ANH, along with other medical interventions, should be considered in the individual context of the child's overall plan of care. The purpose of the present practice point is to provide guidance for Canadian paediatric health care practitioners regarding when withholding or withdrawing ANH may be an ethically permissible option as part of a palliative care plan and to briefly address some pragmatic considerations.

Key Words: *Artificial nutrition and hydration; Ethics; Paediatric end-of-life care; Palliative care*

STATEMENT OF THE PROBLEM

The practice of withholding and withdrawing artificial nutrition and hydration (ANH), although still at times controversial, occurs widely in a variety of health care settings. Cases in the public media, such as that of Terri Schiavo (1), raise awareness in parents as well as health care practitioners about this practice. The purpose of the present practice point is to provide formal guidance for Canadian paediatric health care practitioners regarding when it may be ethically permissible to consider withholding or withdrawing ANH as part of a palliative care plan.

BACKGROUND

The term ANH refers to nutrition and hydration provided through artificial means such as feeding tubes (eg, nasogastric and gastric tubes) and intravenous routes (eg, total or partial parenteral nutrition). Current legal and ethics experts find no distinction between withholding (ie, not initiating) versus withdrawing ANH or other life-sustaining therapies. Nevertheless, many lay people and health care professionals perceive them to be different. Those who hold reservations to forgoing ANH may view it to be 'natural' or 'ordinary' treatment compared with medical interventions such as ventilation and dialysis, which conversely, are perceived to be 'unnatural' or 'extraordinary' treatments. From the perspective of those who equate ANH to 'food and drink', it is not a medical intervention but rather "the sort of care that all human beings owe each other. All living beings need food and water in order to live, but such nourishment does not itself heal or cure disease. When we stop feeding the permanently unconscious patient, we are not withdrawing from the battle against any illness or disease; we are withholding the nourishment that sustains all life" (2). Food and drink, being central to celebrations of life in most cultures, are often strongly associated with nurturing and positive emotions. Therefore, ANH may symbolize care and compassion more than other medical interventions. If ANH is viewed through any of these lenses, its provision is not only a professional obligation but also an ethical one.

L'abstention et la suppression de l'alimentation et de l'hydratation artificielles

Même si la pratique de ne pas administrer ou de supprimer l'alimentation et l'hydratation artificielles (AHA) est devenue plus courante, elle demeure controversée, notamment en milieu pédiatrique. Il faut évaluer les décisions au sujet de l'AHA, tout comme celles portant sur les autres interventions médicales, compte tenu du plan de soins global de l'enfant. Le présent point de pratique vise à orienter les dispensateurs de soins pédiatriques du Canada quant aux circonstances dans lesquelles l'abstention ou la suppression de l'AHA peut être une solution recevable sur le plan éthique dans le cadre d'un plan de soins palliatifs et à aborder brièvement quelques considérations pragmatiques.

ANH, however, does not refer to nutrition and hydration provided through normal means of eating and drinking. Children who are able and wish to eat and drink should be offered food and fluids by mouth. Other terms used in the literature include 'medically assisted' or 'medically provided' nutrition and hydration; these terms emphasize how ANH does not fundamentally differ from other treatments. If one accepts this assertion, then the principles and procedures involved in weighing the option to forgo ANH in end-of-life decision-making are the same as for any other medical intervention such as ventilatory support. For the subset population of preterm infants who cannot suck or swallow due to immaturity, whose requirement for ANH is usually only temporary, decisions to forgo ANH should be based on clinical context beyond prematurity.

Indications for initiating ANH include neurological impairment leading to an inability to feed orally and/or risk of aspiration; malnutrition due to inadequate intake or increased caloric requirements; malabsorption due to intestinal disease or short gut syndrome; and support of chronic diseases such as cancer or congenital heart disease. The provision of ANH is beneficial and desirable for many patients when it will enhance their health and overall quality of life. However, it is not without risks because initiation involves technical procedures that may be unpleasant for the patient and can lead to significant complications. Long-term ANH may be a significant financial burden for families depending on support available from government programs or private health plans.

As described in the Canadian Paediatric Society position statements on treatment decisions (3) and advance care planning (4), decisions for children are based on one of two standards: known wishes in the case of a child or youth with decision-making capacity to consent; or best interests as determined by a substitute decision maker. As long as ANH is desired by the patient or deemed to be in his/her best interests, it is appropriate to initiate or continue this treatment. However, a time may come when the perceived benefits of ANH are outweighed by significant burdens, such as when it will

Correspondence: Canadian Paediatric Society, 2305 St Laurent Boulevard, Ottawa, Ontario K1G 4J8. Telephone 613-526-9397, fax 613-526-3332, websites www.cps.ca, www.caringforkids.cps.ca

TABLE 1
Summary of general principles from the American Academy of Pediatrics clinical report on forgoing medically provided nutrition and hydration in children

1. Children capable of safely eating and drinking who show signs of wanting to eat or drink should be provided food and fluids.
2. Medically provided fluids and nutrition constitute a medical intervention that may be withheld or withdrawn for the same types of reasons that justify the medical withholding or withdrawing of other medical treatments.
3. Decisions about whether medical interventions should be provided to a child, including medically provided fluids and nutrition, should be based on whether the intervention provides net benefit to the child.
4. The primary focus in decision-making should be the interests of the child.
5. Although withholding or withdrawing medically provided fluids and nutrition may be morally permissible, it is not morally required.
6. Medically provided fluids and nutrition may be withdrawn from a child who permanently lacks awareness and the ability to interact with the environment. Examples of such children include children in a persistent vegetative state or children with anencephaly. The diagnosis and prognosis should be confirmed by a qualified neurologist or other specialist with expertise in the evaluation of children with these conditions.
7. Medically provided fluids and nutrition can be withdrawn from children when such measures only prolong and add morbidity to the process of dying. In these situations, continued fluids and nutrition often provide very limited, if any, benefit and may cause substantial discomfort. Some examples of children in this group include those with terminal illnesses in the final stages of dying, infants born with heart defects that are ultimately incompatible with survival beyond a few months and for which transplant is the only therapeutic option, infants with renal agenesis, or infants with a severe gastrointestinal malformation or a disease that is destructive to a large portion of the gastrointestinal tract, leading to total intestinal failure, and whose parents have opted for palliative care rather than intestinal transplant.
8. Parents or guardians should be fully involved in shared decision-making with the physician and health care team and should support the decision to withhold or withdraw medically provided fluids and nutrition. Parents should be reassured that their child will be kept comfortable and should be informed about the likely course of events, including broad estimates of when the child's death is anticipated. Comprehensive palliative care measures for the child, including appropriate sedation and oral hygiene, should be provided in this situation.
9. Ethics consultation is strongly recommended when particularly difficult or controversial decisions are being considered.

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only prolong survival without supporting quality of life, or when it is initiated as a bridge to improvement but the expectation cannot be fulfilled. At this point, decisions regarding life-sustaining interventions including ANH should be re-evaluated in the individual context of that child's ongoing goals of care.

NEW INFORMATION

The American Academy of Pediatrics recently published a comprehensive clinical report titled "Forgoing medically provided nutrition and hydration in children" (5). The report provides examples of situations in which the burdens of treatment may outweigh the benefits and, therefore, the provision of ANH may be considered as

BIOETHICS COMMITTEE

Members: Drs Susan Albersheim, British Columbia Children's Hospital, Vancouver, British Columbia; Kevin Coughlin, St Joseph's Hospital, London, Ontario; Pascale Gervais, Laval University Hospital Centre, Sainte-Foy, Quebec (Board Representative); Robert Hilliard, The Hospital for Sick Children, Toronto, Ontario; Thérèse St-Laurent-Gagnon, Centre de réadaptation Marie-Enfant, Montreal, Quebec; Ellen Tsai, Kingston General Hospital, Kingston, Ontario (Chair)

Principal author: Dr Ellen Tsai, Kingston, Ontario

morally optional. It also emphasizes that other considerations may be relevant to parental decision-making. The general principles outlined in the conclusions of the report are summarized in Table 1. Withholding or withdrawing ANH should not be considered morally obligatory in any of these circumstances.

If a decision is made to forgo ANH, it is imperative that appropriate medical care continues to be provided to the child. Palliative care measures, such as oral swabs for dry mouth, should be instituted. Similarly, symptoms of pain or dyspnea may require initiation or adjustment of analgesia and/or sedation as for any other terminally ill patient. In the majority of cases, care for the child will take place in an institutional setting such as a hospital or hospice. In rarer circumstances, the family may choose to take the child home. Attention to psychosocial needs is imperative to ensure that parents do not feel abandoned, particularly because it may be weeks before the child dies.

Finally, it should be acknowledged that some members of any health care team may harbour personal or professional objections to forgoing ANH. It may be helpful to request external legal or ethics consultation, or arrange for team conferences to clarify misconceptions and openly discuss differences of opinion. If conflicts cannot be resolved, it may be necessary to allow individual providers to recuse themselves so that the plan of care can be followed in accordance with the child or family's wishes. Irrespective of whether the provider directly participates, measures such as debriefing may be advisable to attend to moral distress during and following the care of these patients.

CONCLUSION

Although individuals may hold personal or professional reservations, withholding or withdrawing ANH is both legally and ethically permissible. The present practice point and a recent American Academy of Pediatrics clinical report (5) provide guidance regarding situations in which it may be an option, emphasizing that decisions regarding ANH, along with other medical interventions, should be considered in the individual context of the child's overall plan of care.

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