Parental Perceptions of Forgoing Artificial Nutrition and Hydration During End-of-Life Care

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KEY WORDS artificial nutrition and hydration, death, end of life, palliative care

ABBREVIATIONS
ANH—artificial nutrition and hydration
EOL—end of life
FANH—forgo(ing) artificial nutrition and hydration
QoL—quality of life

Drs Rapoport and Steele conceptualized and designed the study, analyzed and interpreted the data, drafted the initial manuscript, and approved the final manuscript as submitted; Ms Shaheed acquired and interpreted the data, drafted the initial manuscript, and approved the final manuscript as submitted; and Dr Newman and Ms Rugg analyzed data, revised the manuscript critically for important intellectual information, and approved the final manuscript as submitted.


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WHAT’S KNOWN ON THIS SUBJECT: Forgoing artificial nutrition and hydration in children at the end of life is an acceptable practice under some circumstances. However, there is a paucity of pediatric evidence to guide health care providers’ and parents’ decision-making around this practice.

WHAT THIS STUDY ADDS: This study describes experiences of parents whose children died after forgoing artificial nutrition and hydration. All parents were satisfied with their decision and believed their child’s death was peaceful. This study adds to the limited evidence to guide clinical practice.

abstract

BACKGROUND AND OBJECTIVE: Forgoing artificial nutrition and hydration (FANH) in children at the end of life (EOL) is a medically, legally, and ethically acceptable practice under specific circumstances. However, most of the evidence on FANH involves dying adults. There is a paucity of pediatric evidence to guide health care providers’ and parents’ decision-making around this practice. Objectives were (1) to explore the experiences of bereaved parents when a decision had been made to FANH during EOL care for their child and (2) to describe the perceived quality of death in these children, as reported by their parents.

METHODS: This was a qualitative study using in-depth interviews with parents whose children died after a decision to FANH. Parental perceptions about the experience and their child’s quality of death were explored. Interviews were audiotaped and transcribed, then data were analyzed by using interpretive description methodology.

RESULTS: All parents were satisfied with their decision to FANH and believed that their child’s death was generally peaceful and comfortable. The child’s perceived poor quality of life was central to the decision to FANH, with feeding intolerance often contributing to this perception. Despite overall satisfaction, all parents had doubts and questions about the decision and benefited from ongoing assurances from the clinical team.

CONCLUSIONS: FANH in children at the EOL is an acceptable form of palliation for some parents and may contribute to a death that is perceived to be peaceful and comfortable. In situations in which FANH may be a reasonable possibility, physicians should be prepared to introduce the option. Pediatrics 2013;131:1–9
Artificial nutrition and hydration (ANH) is a life-sustaining treatment provided enterally (eg, nasogastric, gastric tubes) or parenterally that may be indicated when children cannot meet their dietary requirements or when it becomes unsafe to do so.\textsuperscript{1,2} Although ANH may support biological existence and increase weight, there is no evidence that it improves survival or quality of life (QoL) in dying children or adults.\textsuperscript{3–6} ANH carries significant risks and potential complications.\textsuperscript{7–11} Providing ANH at the end of life (EOL) is a medical intervention that may be withheld or withdrawn depending on the balance of risks and benefits.\textsuperscript{12–14} Forgoing ANH (FANH) may be considered in the presence of neurologic devastation, irreversible total intestinal failure, and proximate death from any pathologic cause.\textsuperscript{11,15} Although denying oral sustenance to children who want to eat or drink (and can do so safely) is ethically and legally wrong, when the potential or actual burdens are believed to outweigh the benefits, the option to FANH, either completely or by providing small amounts of “comfort feedings” insufficient to sustain life, may be a legitimate method of palliation.\textsuperscript{12–14,16–18}

The only study to examine the phenomenon of FANH in children revealed it to be a “justifiable and humane practice in the NICU.”\textsuperscript{19} Literature on adult patients suggests that prolonged fasting may effectively reduce symptoms commonly experienced at the EOL.\textsuperscript{20–23} Physicians of patients who voluntarily refused food and fluid describe a peaceful death\textsuperscript{24,25}; hospice nurses consistently portray the experience as free of pain and suffering, peaceful, and overall of good quality.\textsuperscript{26} Limited evidence supports that family members perceive the quality of death in relatives after FANH to be comfortable.\textsuperscript{21}

There is a paucity of pediatric evidence to guide health care providers’ and parents’ decision-making around FANH in children.\textsuperscript{27} Therefore, the objectives of this qualitative study were as follows: (1) to explore the experiences of bereaved parents when a decision had been made to FANH during EOL care for their child and (2) to describe the perceived quality of death in these children, as reported by their parents.

**METHODS**

The qualitative methodology of interpretive description\textsuperscript{28} was used to explore the research questions. In contrast to qualitative methods borrowed from the social sciences (eg, grounded theory, phenomenology), interpretive description is a form of inquiry specifically for applied health disciplines that aims to bridge the gap between practice and theory; it produces meaningful evidence to enhance clinical practice.\textsuperscript{29} Interpretive description is typically conducted on sample sizes between 5 and 30,\textsuperscript{28} which allows for the development of a deep, rich understanding of the phenomenon.\textsuperscript{30–32}

**Participant Eligibility Criteria**

Purposefully sampled bereaved parents whose child died after FANH were identified by members of the Hospital for Sick Children (SickKids) Paediatric Advanced Care Team. Recently bereaved parents (<6 months) were excluded as advocated elsewhere.\textsuperscript{33} The time since the child’s death was not restricted because the intense nature and uniqueness of the experience help maintain the accuracy of recall.\textsuperscript{34} Parents <18 years of age, who lived >125 miles from the hospital, or who were not fluent in English were excluded.

**Procedure**

An introductory letter signed by the child’s primary provider at SickKids and the principal investigator (A.R.) was mailed to identified parents. Those who wished to opt out of the study could return a supplied postcard or e-mail the research team. Two weeks after the anticipated receipt of the letter, parents who did not opt out were contacted by telephone. This procedure has been advocated by bereaved parents.\textsuperscript{29,35} The study protocol was approved by the SickKids institutional review board.

**Data Collection**

All but 1 interview took place in the family home. After written consent was received, demographic information was collected. A semistructured guide was used and modified during the study because data analysis informed the focus for subsequent interviews.\textsuperscript{26} Each interview lasted ~1 to 1.5 hours. Parents were interviewed separately to facilitate better understanding of the individual experience.\textsuperscript{36} At the end of the interview, questions were asked about study participation and contact information for local grief/bereavement agencies and a SickKids social worker was provided; no parents made use of the latter resource.

**Data Analysis**

Interviews were voice-recorded and later transcribed verbatim, checked for accuracy, and stripped of any identifying information. The qualitative data management software NVivo 9 (QSR International, Australia) was used to facilitate constant, comparative analysis. After immersion in the data by reading the first 3 transcripts on their own, investigators initially worked together to compare their observations and to design preliminary coding categories.\textsuperscript{28,37} Individual interviews were analyzed and codes were added and/or modified in an iterative process. The trustworthiness of the study was established through careful data collection and analysis procedures that ensured credibility and authenticity.\textsuperscript{28,38} The decision trail was recorded throughout the study to permit examination of
Parents were satisfied with their experience of FANH, even though the affective, cognitive, and practical impacts were substantial. They all believed that the final decision regarding FANH should rest with them, as parents, yet at the same time they desired the input and support of the health care team.

**Introduction of FANH to Parents**

The actual setting for discussing the option of FANH was unimportant to parents. What mattered most was the timing of the discussion, who introduced the option, and how it was presented. Parents not only had to be open to having this discussion, they needed to be ready; readiness was always predicated on viewing their child’s QoL as poor. At the time of introduction, all parents considered their child to have a poor QoL and most, but not all, recognized that their child was dying. Parents needed to be assured that FANH was medically and ethically legitimate, and they agreed that a physician was the ideal person to provide this assurance and to introduce FANH (Table 2).

**Decision-making Process**

All parents reported that being “on the same page” with their spouse was crucial during decision-making. Although some acknowledged the personal challenges they would face if lifesustaining treatments were continued, all parents were more concerned with the consequences for their spouse, other children (where present), and the family as a whole. Parents ultimately concluded that FANH represented the best of all options for their child; in some instances, it was viewed as “the only thing that made any sense” (Jake). This conclusion resulted in paradoxical feelings because no parent had wanted their child to die (Table 3).

**TABLE 1 Characteristics of Study Sample**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental role</td>
<td>Mothers = 6</td>
</tr>
<tr>
<td></td>
<td>Fathers = 5</td>
</tr>
<tr>
<td>Parents’ educational level</td>
<td>High school = 2</td>
</tr>
<tr>
<td></td>
<td>Apprenticeship program = 1</td>
</tr>
<tr>
<td></td>
<td>College = 2</td>
</tr>
<tr>
<td></td>
<td>University = 6</td>
</tr>
<tr>
<td>Parents’ religious affiliation</td>
<td>Catholic = 6</td>
</tr>
<tr>
<td></td>
<td>Jewish = 1</td>
</tr>
<tr>
<td></td>
<td>Converting to Judaism = 1</td>
</tr>
<tr>
<td></td>
<td>No affiliation = 2</td>
</tr>
<tr>
<td>Parents’ age, median (range)</td>
<td>Mothers = 35 (31–51) years</td>
</tr>
<tr>
<td></td>
<td>Fathers = 40 (33–55) years</td>
</tr>
<tr>
<td>Number of healthy siblings at time of FANH</td>
<td>Siblings = 0 in 1 family; 1 in each of 5 families</td>
</tr>
<tr>
<td>Child’s diagnosis</td>
<td>7 with genetic or suspected genetic conditions</td>
</tr>
<tr>
<td>Child’s age at diagnosis</td>
<td>In utero = 1</td>
</tr>
<tr>
<td></td>
<td>Before fourth week of life = 3b</td>
</tr>
<tr>
<td></td>
<td>Between 1 and 4 years = 3</td>
</tr>
<tr>
<td>Static versus progressive underlying condition</td>
<td>Static = 4</td>
</tr>
<tr>
<td></td>
<td>Progressive = 3 (2 from same family)</td>
</tr>
<tr>
<td>Form of ANH in place at the time of decision-making</td>
<td>None = 1</td>
</tr>
<tr>
<td></td>
<td>NG tube = 3</td>
</tr>
<tr>
<td></td>
<td>G-tube = 3</td>
</tr>
<tr>
<td></td>
<td>TPN = 1</td>
</tr>
<tr>
<td>Child’s age at death</td>
<td>1–3 months = 2</td>
</tr>
<tr>
<td></td>
<td>4–6 months = 2</td>
</tr>
<tr>
<td></td>
<td>14–15 years = 3</td>
</tr>
<tr>
<td>Length of time between FANH and death</td>
<td>≤2 weeks = 5</td>
</tr>
<tr>
<td></td>
<td>&gt;2 weeks = 2c</td>
</tr>
<tr>
<td>Length of time between child’s death and interview</td>
<td>Range = 1.5 to 5 y</td>
</tr>
<tr>
<td>Location of child’s death</td>
<td>Home = 6 (2 from same family)</td>
</tr>
<tr>
<td></td>
<td>Hospital = 1</td>
</tr>
</tbody>
</table>

n = 11 parents from 6 families; 7 children. G tube, gastrostomy; NG, nasogastric; TPN, total parenteral nutrition.

a Specific information not provided to maintain anonymity.
b No firm diagnosis for 1 child; underlying genetic condition suspected immediately at birth.
c Static conditions were accompanied by progressive comorbidities (eg, seizures, feeding intolerance).
d Some children had >1 form of ANH in place at the time of decision-making.
e Both of these children were from the same family; second child never received any form of ANH.
realization that their child was not going to improve. They also considered their child's ability to interact meaningfully with their environment, in both the short- and long-term. Parents of chronically ill children noted their child's decreasing ability to enjoy things that had previously given them pleasure. They not only considered their child's past and present situation, all parents incorporated their child's anticipated QoL into their decision-making as well.

Pain and suffering contributed significantly to perceptions that a child's QoL was (or would be) poor and weighed heavily on decision-making. Parents identified pain and suffering at the time of decision-making in all but 1 child; the parents of that girl anticipated these symptoms because of their experience with her older brother. The severity and relentless nature of the pain and suffering permitted parents to consider an option, FANH, that would mean accepting their child's death.

Parents described various factors contributing to their child's suffering, such as seizures, breathing difficulties, and skin breakdown. However, the primacy of feeding difficulties was noted by all. Challenges included pain with feedings, bloating, leakage around tube sites, nausea, and vomiting. All parents perceived that continuing feedings was no longer a viable option: "by feeding him, we were, from what we could see, decreasing his quality of life" (Elizabeth).

Even before discussing the option of FANH with the health care team, 1 mother had already felt compelled to withhold ANH for short periods: "I kind of even started to not feed him . . . I was sick with watching him. He was just so clearly uncomfortable" (Marilyn).

Parents found it helpful when professionals shared their past experiences with FANH as well as the evidence from the adult medical literature. Anticipatory guidance about what life might look like if ANH were continued (or initiated) helped them envision the impact of this life-sustaining treatment on their child and family. Parents were reassured to learn that death after FANH is indeed comfortable and that their child would not "starve to death." Once the decision was made, parents continued to need reassurance and guidance from health care professionals as death approached.
Parents found it difficult when professionals expressed divergent opinions about FANH or vacillated about the best way to proceed. Dissenting opinions led to parents feeling negatively judged; sometimes, however, negative judgment was more overt. A nurse caring for a child at home was surprised to learn that ANH would not be provided: “You can’t just let her die” (Jake).

Not all parents felt judged by professionals, but all anticipated judgment from some family and friends stemming from religious or societal beliefs. Parents preempted being judged by not sharing the decision to FANH with these individuals. Even family and friends who were informed were not involved in the decision-making process; parents believed the decision was theirs alone to make.

**Perceptions About Quality of Death and Overall Experience**

Although most children died at home, the actual location of death was not of prime importance; what mattered most to parents was being able to spend the EOL period in the setting of their choice. Parents believed that their child’s quality of death was good, especially when the dying process mirrored the earlier description provided by the palliative care team. However, some parents had worried about how death might unfold, and some were disturbed by their child’s changes in appearance as death approached: “we just saw him starting to waste away and that was the hard part” (Jack). A few felt guilty about their decision, and most found it emotionally difficult to watch their child die. Yet, despite some mixed feelings, parents expressed no regrets about opting for FANH and all reported being satisfied with their decision (Table 4).
Parents reported that death after FANH was not associated with added suffering. Nonetheless, every parent chose to give their child some form of “comfort feeding.” Although some were unsure how FANH affected their child’s comfort, others noted obvious improvements and believed death was peaceful. Some parents shared that their child’s increased comfort after FANH led them to reflect on their decision to initiate ANH: “if we’d have known prior what we know now” (Jake). Indeed, based on their experience with their son, Jake and his wife chose not to start ANH in their younger daughter, who died of the same progressive condition.

**Study Participation Experience**

All parents were happy that they participated in this study, despite the fact that, at times, it was emotionally difficult to talk about the issue (Table 5).

**DISCUSSION**

To the best of our knowledge, this is the first study to explore parental perceptions of FANH in children at the EOL by using in-person interviews. Parents were satisfied with their decision to FANH and generally believed that their child’s death was peaceful and comfortable. These findings are largely consistent with the adult medical literature\(^1\) and what is implicit in a recent quantitative study involving infants in the NICU.\(^2\)

Many of the parents in this study believed that their child’s comfort increased after FANH, largely as a result of noticeable improvements in bloating, vomiting, or other signs of feeding intolerance. Yet, comfort may be associated with FANH even in the absence of overt symptom resolution. Analgesia and feelings of euphoria may accompany prolonged fasting, the result of increased circulation of endogenous opioids and ketones released in the catabolic state.\(^6,20\) Moreover, there is evidence that the metabolic abnormalities one might anticipate after the cessation of nourishment, which could conceivably result in discomfort, do not in fact occur.\(^23\) Although feeding intolerance is not an absolute requirement for FANH, parents in our study recognized that the provision of ANH to their child near the EOL, not in fact its discontinuation, was what resulted in increased suffering.

Although not all parents were confident that their child’s comfort increased after FANH, nothing that parents said indicated that the child suffered more as a result of this decision. Parental doubts about quality of death may reflect their own suffering from watching their child die, rather than the child’s actual discomfort as a result of FANH. The notion that discontinuing feedings (generally equated with the unpleasant experience of “starvation”) might improve comfort is counterintuitive, perhaps even more so among parents whose instinct is to feed a child.\(^59\) This cognitive dissonance may explain why all parents in this study felt compelled to provide small volumes of feedings after the decision.

A number of recommendations for clinical practice arise from this study. Parents who are open to FANH believe that their child is suffering but may not realize that FANH is an option. Therefore, physicians should take responsibility for introducing FANH upon ascertaining that the family perceives the child’s QoL as poor. Rather than emphasizing decreased nourishment with the term “forgoing artificial nutrition and hydration,” focus should be on the goal of “feeding for comfort,” an approach that is endorsed by others.\(^40\) Physicians also need to assure parents that under certain EOL circumstances, FANH is medically, legally, and ethically acceptable and is not a form of euthanasia. Health care providers should share their knowledge and experience with parents, because that information helps with decision-making while allowing them time and space to weigh the option. It should be assumed that parents will worry about the possibility of hunger,

<table>
<thead>
<tr>
<th>Theme</th>
<th>Illustrative Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I don’t have second thoughts as far as I don’t regret the decision, but again it’s a decision that we often think, ‘Was it OK to make that decision?’ But it was the right decision, we don’t have second thoughts about that; it had to be the right decision.” (Sarah)</td>
<td></td>
</tr>
<tr>
<td>Persistent doubts and questions</td>
<td></td>
</tr>
<tr>
<td>&quot;I feel comfortable with [FANH], it was the best thing for him, and for my wife and myself . . . everyone involved. Like that part, I don’t question it one bit. I don’t sit there ever and say: ‘Oh I wish we did this differently’ . . . I know for a fact, we did everything we could. Whether it be going to the hospital as many hours as we could or spending as much time with him, and bringing him home and caring for him the best way we could.” (Coaster)</td>
<td></td>
</tr>
<tr>
<td>Satisfied with decision, no regrets</td>
<td></td>
</tr>
<tr>
<td>&quot;He became more comfortable. . . he wasn’t bloated. . . when he was being fed, like his belly would just sort of bloat. And he wasn’t breaking down the food that he was receiving, so it was very uncomfortable for him. So once we stopped [ANH] [it] just sort of allowed him to go peacefully.” (Coaster)</td>
<td></td>
</tr>
<tr>
<td>Increased comfort after FANH</td>
<td></td>
</tr>
</tbody>
</table>

Pseudonyms are used.

**TABLE 4 Perceptions About Quality of Death and Overall Experience**
starvation, and dehydration after FANH. \(^4^1\) Clinicians must emphasize that in these situations, feelings of hunger and starvation do not usually occur. \(^2^2\) as death approaches, many voluntarily refuse to eat and drink due to loss of appetite. Symptoms associated with dehydration, apart from thirst, have not been typically reported; good oral hygiene will avoid drying of the mucous membranes.

Ongoing parental doubts and questions about FANH should be expected; clinicians should provide anticipatory guidance around the dying process, reassurances about the child’s comfort, and regular support. Some parents may appreciate speaking with other families whose child died after FANH; some might want written information about FANH. All parents should be offered opportunities to make memories and create legacies, such as photographs and hand molds.

Parents in our study emphasized the importance of the multidisciplinary team speaking in 1 voice. Regardless of the legitimacy of FANH under specific circumstances, personal beliefs may lead some professionals to be uncomfortable with this option or to reject it outright. The opinions of dissenting team members must be respected; their opinions, however, should not be shared with the family to avoid feelings of negative judgment. These staff members should be excused from direct involvement in the situation. In addition, to minimize the impact of moral distress, opportunities should be made available for staff to voice their objections without the family being present. \(^4^2\)

Although the changes associated with FANH open up the possibility of death at home, it is not uncommon for parents to be concerned about coping in this setting. \(^4^3\) The health care team may allay these fears by explaining what the child’s death at home after FANH will look like, mobilizing necessary community resources including nursing and hospice, and providing ongoing support and reassurance as death ensues.

This study has several potential limitations. The findings are limited to these 11 parents and represent retrospective perceptions of their FANH experience; they may not be generalizable. Caution must be used when applying these recommendations in other centers and with parents in the midst of having to consider this option. Most parents in this study had a higher than college-level education and nearly all had another healthy child at the time of decision-making. It is possible that these factors influenced their perceptions. All parents in this study withdrew ANH in their dying child (1 set of parents also withheld ANH); these findings may be less relevant when ANH has not yet been initiated. This study only examined the perceptions of parents who opted to FANH; future studies are needed to investigate the experience of parents who chose not to FANH.

**CONCLUSIONS**

Although FANH at the EOL is a legitimate form of palliation in children, clinicians have needed to rely on the adult medical literature or personal anecdotes to portray the experience to parents. This is the first study to use in-person interviews to describe the perceptions of parents whose children died after FANH. A number of recurrent themes emerged from this study: parents need to be ready to discuss FANH, which is largely determined by their perception of their child’s poor QoL and the detrimental effects of

### TABLE 5 Study Participation Experience

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there any questions that you think we should not ask parents?</td>
<td>• Parents felt that all questions asked were appropriate</td>
</tr>
<tr>
<td>Are there other questions that you think we should ask parents? On a scale of 0 to 10 where 0 is “not at all” and 10 is “the most difficult I can imagine,” how difficult was it for you to talk about this issue?</td>
<td>• No questions were off limits • Parents felt that all relevant questions about the experience were asked</td>
</tr>
<tr>
<td>Are you happy that you decided to participate?</td>
<td>• All parents were happy that they participated in this study</td>
</tr>
<tr>
<td>Did this interview help you in any way? If so, how?</td>
<td>• All parents noted positive aspects</td>
</tr>
<tr>
<td>Would you recommend participation in this study to other parents?</td>
<td>• All would recommend participation to other eligible parents</td>
</tr>
<tr>
<td>How did you feel about the opt-out approach to recruitment?(^a)</td>
<td>• All agreed that this approach worked for them</td>
</tr>
<tr>
<td></td>
<td>• One suggested this approach might increase accrual rates</td>
</tr>
<tr>
<td></td>
<td>• None felt it was coercive</td>
</tr>
</tbody>
</table>

\(^a\) This question was asked of only the last 3 parents to be recruited to the study.
feeding, parents must be the ones to decide if FANH is right for their dying child, but they value the input and reassurance of a unified medical team, particularly a trusted physician; and persistent doubts and fears of being judged are common in parents and necessitate regular and ongoing support from the medical team after FANH.

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