Forgoing Artificial Nutrition and Hydration: What to Make of Parents’ Views

AUTHORS: Kimberly N. Canfield, MD, MPH, and Joel E. Frader, MD, MA

1Division of Academic General Pediatrics and Primary Care and 2Bridges Palliative Care Program, Ann & Robert H. Lurie Children’s Hospital, Chicago, Illinois, and 3Program in Medical Humanities and Bioethics, Feinberg School of Medicine, Northwestern University, Chicago, Illinois

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

ABBREVIATION FANH—forgoing artificial nutrition and hydration

Opinions expressed in these commentaries are those of the authors and not necessarily those of the American Academy of Pediatrics or its Committees.

doi:10.1542/peds.2013-0380

Accepted for publication Feb 8, 2013

Address correspondence to Joel Frader, MD, MA, A Todd Davis Professor of Academic General Pediatrics, Ann & Robert H. Lurie Children’s Hospital of Chicago, 225 E Chicago Ave, Box 16, Chicago, IL 60611-2605. E-mail: jefrader@luriechildrens.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275)

Copyright © 2013 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

AGING: No external funding.

COMPANION PAPER: A companion to this article can be found on page 861, and online at www.pediatrics.org/cgi/doi/10.1542/ peds.2012-1816.

In this issue of Pediatrics, Rapoport et al report qualitative findings of a study of parents whose children died after forgoing artificial nutrition and hydration (FANH). The authors explored the experiences of bereaved parents who chose FANH and describe the parents’ perceived quality of death in these children.

Rapoport et al conclude the parents were satisfied with their experiences and believed the deaths of their children were peaceful. The authors emphasize the parents’ readiness to discuss FANH when they perceived their child’s quality of life as poor. Patients’ difficulties with feeding played a key role in parental views of quality of life as intolerable. Further, while they relied on input from the health care team, the parents felt they must take personal responsibility for deciding if FANH was the right approach for their dying child. Finally, the study participants experienced persistent fears of being judged negatively for their decisions to FANH and those worries required sustained support from the health care team after initiating the FANH.

Given the complex medical, ethical, religious, political, and social currents surrounding FANH, especially with children, and the paucity of data about how patients and loved ones experience the process, the authors deserve commendation for their choice of topic and research design. Qualitative research methods allow exploration of poorly understood phenomena without imposing the assumptions inherent in quantitative, hypothesis-driven approaches. The “interpretive description” method permitted the parents to identify and elaborate on factors important to them as their children’s health declined. As the authors note, interpretive description builds on clinical expertise and aims to identify themes and patterns in the social world under study to inform clinical practice. Interpretive description and related social science methods have enjoyed increasing respect in medicine, and the National Institutes of Health requests for proposals now frequently solicit studies that employ qualitative approaches for the depth of insight they can provide in psychosocially complex situations.

The number of participants in the Toronto report may pose the greatest limitation on the study’s findings. The authors interviewed only 11 bereaved parents in 6 families from a fairly restricted geographical area, a small sample even by interpretive description standards. The authors could not provide further information about families not electing to participate in the study. The included parents were all married, over age 30, and all but 2 (who indicated no affiliation) self-reported as Judeo-Christian. We cannot know if the participants adequately represent the eligible pool of parents. In addition, feeding difficulties were practically and emotionally important in Rapoport et al’s study; gastrointestinal problems such as bloating or vomiting may not play
such a prominent role for all candidates for FANH. Thus, parental relief associated with reduced symptoms from decreasing or eliminating feedings may not occur in other populations. Rapoport et al. provides us with reassurance that the experience of parents who accepted the option to FANH for their child can meet palliative care expectations for comfort and support for the patients and their families. The study reminds us that families may not know about and do appreciate learning that FANH is a medically, ethically, and legally available option. However, US clinicians should know that some jurisdictions have legal restrictions on FAHN, and some hospitals, especially those with religious affiliations, may have institutional prohibitions on the practice. We also note parents in this study found it difficult when professionals caring for their children expressed conflicting opinions about FANH. The dissenting opinions left parents feeling negatively judged. Rapoport et al. conclude and recommend that health care teams should present “one voice” and thus shield families from such distress. However, efforts to “protect” families in this way may mirror typically unsuccessful attempts parents employ to keep “bad news” from their gravely ill children. Some parents will discern substantive differences among caregivers, recognize reluctance to discuss the matter openly, no matter how well intentioned, and the silence may undermine trust by preventing fully open communication. Stifling dissent among professionals may backfire, leaving some families deprived of participation in attempts to balance difficult ethical, medical, and emotional factors that affect decisions about FAHN. Finally, Rapoport et al.’s recommendations regarding reassurances to parents that FANH will not increase suffering rely heavily on information in adult medicine; we urge caution in extrapolating those data to situations involving young children. Frader has previously recommended candor, acknowledging uncertainty about the child’s experience, and promising to respond quickly to signs of distress. We understand the urge to assure parents their child will have a peaceful death. However, circumstances do not always play out as we would like. It makes more sense to promise efforts to pay compassionate attention to the child’s (and parents’) needs than guarantee particular medical outcomes. Rapoport et al. have provided data reassuring us that for some families the process of FANH proves not just acceptable, but therapeutic for the children and parents.

REFERENCES
2. Thorne SE. Interpretive Description. Walnut Creek, CA: Left Coast Press; 2008
Forgoing Artificial Nutrition and Hydration: What to Make of Parents' Views
Kimberly N. Canfield and Joel E. Frader

Pediatrics 2013;131:993; originally published online April 8, 2013;
DOI: 10.1542/peds.2013-0380

Updated Information & Services
including high resolution figures, can be found at:
/content/131/5/993.full.html

References
This article cites 4 articles, 1 of which can be accessed free at:
/content/131/5/993.full.html#ref-list-1

Subspecialty Collections
This article, along with others on similar topics, appears in the following collection(s):
Ethics/Bioethics
/cgi/collection/ethics:bioethics_sub
Hospice/Palliative Medicine
/cgi/collection/hospice:palliative_medicine_sub

Permissions & Licensing
Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
/site/misc/Permissions.xhtml

Reprints
Information about ordering reprints can be found online:
/site/misc/reprints.xhtml