

Feeding Tubes in Children With Neurologic Impairment: An Opportunity for Shared Decision-making

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The use of feeding tubes is common in children with neurologic impairment. Benefits after tube placement include improvements in nutritional status, drooling, secretion management, constipation,¹ and ease of caregiver medication administration and feeding.² A systematic review of the literature in which family experience is described after gastrostomy tube placement revealed both positive and negative outcomes in a variety of domains, including the child's health and quality of life, parental stress, and family relationships.³ The effect of feeding tube placement on reflux-related outcomes, including aspiration and pneumonia (common issues in this population), remains unclear.

In this issue of *Pediatrics*, Nelson et al⁴ examine survival and acute health care use after feeding tube placement in a population-based cohort study of children with neurologic impairment. By using an impressively comprehensive and complete health administration data set from the province of Ontario between 1993 and 2015, the authors looked at health care use for an equal time period before and after feeding tube placement with a minimum time of 1 year, 4 weeks and a maximum time of 2 years, excluding the 4 weeks immediately preceding and after tube placement. The authors followed survival rates for up to 5 years after feeding tube placement.

The authors found no change in unplanned hospital days, reflux-related hospital days, emergency department visits, or outpatient visits after feeding tube placement. They did find a high mortality rate, 10.8% at 2 years and 22.9% at 5 years after tube placement. Given the stability of health care use before and after placement, the authors suggest that the high mortality rate is likely due to the severity of the neurologic impairment and underlying fragility rather than a result of feeding tube placement.

Although this study does not give us the prognostic information to tell us whether we ought to place a feeding tube for a given child, it does provide additional evidence of how we ought to approach the decision.

If we exclude, as this study does, children who have had their feeding tubes placed in the first year of life and might therefore be completely unable to obtain adequate nutrition orally, and if we accept the mixed outcomes reported in the literature to date, along with the findings of this comprehensive population-based study showing no significant impact on acute health care use rates or on reflux-related health care use, and high mortality rate likely due to underlying complexity and fragility, we are left with a decision that is more dependent on a family's values than on decisive medical evidence.

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The shared decision-making approach has been recommended for use in the context of feeding tube placement, both in an article by some of the authors of this study who identified these decisions as value sensitive⁵ as well as in the American Academy of Pediatrics 2014 clinical report “Nonoral Feeding for Children and Youth with Developmental or Acquired Disabilities.”⁶

As described by Nelson and Mahant,⁵ a shared decision-making model is one in which the clinician explores the family’s values relating to a decision, uses those values to frame the evidence about available options, and collaborates with the family to determine which option is the best fit for their child.

Despite the natural fit of the shared decision-making approach to this type of choice, widespread implementation of shared decision-making in pediatrics has been challenging.⁷ In particular, families of children with medical complexity are less often involved in shared decision-making than families of less medically complex children with special health care needs.⁸

One possible reason for this is timing. Data from the Nelson et al⁴ study revealed an increase in health care use in the weeks immediately preceding feeding tube placement for children who had tubes placed either during a hospital stay or those who

had the procedure done as an outpatient. This suggests that many feeding tubes may have been placed during times of crisis or acute deterioration, which is not the ideal time to engage in thoughtful decision-making. As highlighted in the American Academy of Pediatrics 2017 clinical report “Shared Decision-Making and Children with Disabilities: Pathways to Consensus,” the model is best implemented “well in advance of predictable (or unpredictable) crises.”⁹ In addition, the shared decision-making model often requires repeated conversations. In a setting of acute health challenges, this may not be feasible.

We can serve our most complex and fragile patients and their families best by approaching decisions such as feeding tube placement early and by regularly engaging in discussion about values and goals. This will facilitate shared decision-making when faced with a decision for which there is not yet one “right” answer.

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