

Complex Decision-Making for Gastroesophageal Reflux in Children With Neurologic Impairment

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Gastroesophageal reflux disease (GERD) diagnosis and treatment options for children with neurologic impairment (NI) have been debated for >3 decades. GERD has an undoubted impact on children with NI; however, it is difficult to differentiate GERD from other common gastrointestinal diseases in this population, and there is no robust evidence distinguishing the various management options. In response to these challenges, the 2017 European Society for Pediatric Gastroenterology, Hepatology, and Nutrition guidelines formalized recommendations surrounding common diagnostic considerations and treatments for GERD in children with NI. Recommendations include initial treatment with a proton pump inhibitor, the consideration of formula and feeding changes, and pursuing diagnostic testing to gain objective data and rule out other causes of persistent symptoms.¹ Gastrojejunal tube (GJT) feeding is suggested when GERD is causing aspiration, in addition to when there is recurrent vomiting or gastroparesis.¹ Fundoplication and total esophago-gastric disconnection are to be reserved for severe refractory GERD per these guidelines given the surgical risks and lack of clear benefit.¹

In this issue of *Hospital Pediatrics*, Dewan et al evaluate Canadian physician perspectives and practice decisions regarding GERD and 2 anti-reflux procedures (ARPs), including post-pyloric feeding with GJT and fundoplication.² By using a cross sectional electronic survey questionnaire, hypothetical practice behaviors surrounding GERD management, including ARP, were examined in 4 different clinical vignettes. Vignette scenarios consisted of a young child with NI and a gastrojejunostomy tube who was on a proton pump inhibitor with each case then further illustrating varying complications of GERD, including failure to thrive, pain, severe aspiration, and moderate aspiration.

Pediatricians were, overall, likely to consider ARP for the failure to thrive (78%, 49% GJT vs 5% fundoplication vs 19% both), pain (57%, 35% GJT vs 8% fundoplication vs 19% both), and severe aspiration (56%, 48% GJT vs 8% fundoplication vs 19% both) scenarios, but not for the moderate aspiration scenario (19%, 22% GJT vs 4% fundoplication vs 7% both). Among options for treatments and interventions before ARP, ≥60% of respondents indicated they would consider adjusting feeds, changing formulas, and prokinetic medications. Contrary to the authors' hypothesis, there was no association between any of the physician characteristics (sex, age, number of ARP per year, year in practice, specialty, or Canadian province) and likelihood to consider ARP.

There are substantial limitations in this study to consider. The simplification of complex clinical decision-making into binary survey responses is challenging. In particular, survey questions lacked an explanation of time in the

www.hospitalpediatrics.org

DOI: <https://doi.org/10.1542/hpeds.2024-007791>

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HOSPITAL PEDIATRICS (ISSN Numbers: Print, 2154-1663; Online, 2154-1671).

Drs Warniment and Thomson drafted, reviewed, and revised the commentary for critically important intellectual content.

FUNDING: No external funding.

CONFLICT OF INTEREST DISCLOSURES: The authors have indicated they have no potential conflicts of interest relevant to this article to disclose.

COMPANION PAPER: A companion to this article can be found online at www.hosppeds.org/cgi/doi/10.1542/hpeds.2023-007643.

decision-making process such that one physician could respond that they are considering ARP, although they would not plan to until trying several additional interventions, whereas another physician could respond in the negative because they want to complete several additional interventions. In addition, despite the authors' attempts to identify a favored ARP, examining GJT and fundoplication together also brings challenges to interpreting results. As noted by the authors, GJT and fundoplication have different indications, associated risks, long-term implications for families, and future health care utilization concerns. Possible differences in the interpretation of the question or responses by clinicians could vastly change the results of this study.

The authors suggest variability in ARP considerations within and between scenarios because of a lack of overall evidence and adherence to the guidelines for GERD management. However, it is also possible that the variable rates of ARP consideration across the scenarios are reflective of the incredibly complicated process of diagnosing and managing gastrointestinal diseases in children with NI, thus exhibiting effects from the respondents' different assignments of probabilities that the child in the vignette had GERD or other diagnoses that could benefit from ARP. For example, challenges abound in the management of both vomiting and pain given the well-described overlap in GERD symptoms with other common diagnoses in children with NI (eg, constipation, visceral hyperalgesia, gallbladder disease, gastrointestinal dysmotility, infectious or neurologic causes of vomiting).^{3,4} Consequently, a single treatment may not improve or resolve symptoms. In addition, in the case of a child experiencing aspiration pneumonia, comorbid challenges of secretion burden and dysphagia will remain present in the face of adequate GERD treatment.^{4–7} Published guidelines can certainly help clinicians navigating these diagnostic and management challenges particularly in avoiding harmful and or nonbeneficial management strategies. However, recognizing the complexity of decision-making, these guidelines do not provide a linear algorithm. Thus, the variation in clinical decision noted from the aspiration and pain scenarios is understandable and perhaps appropriate within the context of current best evidence. In contrast, the failure to thrive scenario more clearly described a child with “refractory GERD” who already had treatment of comorbidities and exclusion of other pathology; this difference may explain the higher rates of ARP consideration.

This study included mostly tertiary care pediatricians, hospitalists, and complex care pediatricians, with a smaller number of pediatric gastroenterologists and surgeons. Many children with NI have primary care clinicians, including advanced practice providers, who are not associated with tertiary care centers while in the early stages of GERD treatment and work up. Additionally, although GERD is commonly managed by general pediatricians, subspecialists are frequently involved because initial treatments fail, other diseases are being ruled out, and ARPs are being considered. For example, in the case of a young child with NI admitted for recurrent aspiration pneumonia, pulmonologists, otolaryngologists, and gastroenterologists may be consulted for respiratory

support, secretion management, and decisions for next steps in gastrointestinal evaluation for persistent vomiting and aspiration. Largely excluding both community primary care clinicians and subspecialists from this study diminishes the complexity and multidisciplinary nature of decision-making for children with NI.

Although it is not a limitation, the lack of family and caregiver representation in decisions surrounding ARP should not be overlooked. In their discussion, the authors promote intentional shared decision-making as one approach to choosing between treatment options when there are uncertainties in the benefit of ARP.⁸ Family priorities, input on treatment options, and acknowledgment of home-life situations that complicate “real-life” decision-making for these children is critical. For example, if a family anticipates more challenges with a GJT that impact their quality of life (eg, frequent, lengthy trips to hospitals for replacement or difficulties with continuous feeds), they may see fundoplication as the best option, whereas another family may favor GJT given goals to avoid surgical procedures. Few studies exist on family quality of life and satisfaction after ARP, but it is important to examine outcomes such as these that are meaningful to families.^{9,10} Given the more subjective symptoms involved in GERD (ie, pain), serious implications to home routines and lifestyle, and potential risks of ARPs, families must be partners in navigating a stepwise approach to this complex problem.

It is incredibly difficult to interpret concordance to guidelines on the basis of these survey results alone; however, in most cases in this study, physicians aligned with guidelines considering evidence-based interventions before the consideration of ARP and limiting ARP usage to refractory GERD. Clinical decision-making surrounding GERD in children with NI is difficult to understand given the complexity of the problem and the importance of family input. The authors of future studies should seek to examine the process of shared decision-making across the continuum of care and to understand outcomes that are important to patients and families. Such studies could illuminate the critical context for decisions and their associated outcomes while keeping families and patients at the center of the decision-making process.

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