







VIEWPOINT

Paediatric tube-feeding: An agenda for care improvement and research

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This article presents an agenda to improve the care and wellbeing of children with paediatric feeding disorder who require tube feeding (PFD-T). PFD-T requires urgent attention in practice and research. Priorities include: routine collection of PFD-T data in health-care records; addressing the tube-feeding lifecycle; and reducing the severity and duration of disruption caused by PFD-T where possible. This work should be underpinned by principles of involving, respecting and connecting families.

Paediatric feeding disorder (PFD) can have wide-ranging and serious consequences for the health and wellbeing of the child and their family.¹ Feeding difficulties arise in 20–50% of children, and for 3–10%, those problems are severe or persistent.^{2–4} Tube-feeding at home (also known as home enteral nutrition) can help to maintain growth in many complex feeding cases,^{5,6} but can have side-effects for children and significant psychosocial impacts on carers and children.^{7–9} As a group of clinicians, parents and researchers, we propose an agenda that recognises PFD requiring tube-feeding (PFD-T) as a discrete research entity, offering priorities and principles to frame care improvement and research.

Paediatric Tube-Feeding

There are multiple, complex pathways to paediatric tube-feeding, as documented in ESPGHAN guidelines.¹⁰ Common indications include prematurity, congenital heart disease, cerebral palsy, cystic fibrosis, neurodevelopmental disabilities, metabolic disease and cleft palate.¹¹ Tube-feeding may also be required while children are critically unwell or after surgery.⁸ The Feeding Tube Awareness Foundation¹² identified over 350 conditions that can warrant tube-feeding, which is viewed as incomplete.

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Knowledge of paediatric tube-feeding care practices is fragmented, lacks a coherent agenda and is difficult to synthesise. Tube-feeding is managed in many different parts of the health system, confounded by weak and inconsistent prevalence data. Prevalence is often estimated to be around 1–4 per 100 000¹³ but can be as high as 83–92 per 100 000,⁵ although there are good reasons to think actual rates are higher.⁵ This is indicative of the fact that tube-feeding lacks visibility in the health system and clinical data collection: it is a category void.

In research, paediatric tube-feeding tends to be addressed with reference to particular conditions or diseases (e.g. References 14–19), but some studies have examined tube-feeding across more than one clinical domain.^{20,21} Children who tube-feed represent a heterogeneous group with multiple co-morbidities.²² Tube-feeding has been conceptualised differently by the many specialities working in the area.^{22–24} A recent consensus paper proposed a definition of a PFD that encompasses, although is not limited to, children who require tube feeding: impaired oral intake for more than 2 weeks that is not age-appropriate, and is associated with medical, nutritional, feeding skill and/or psychosocial dysfunction.²⁵ The US Centers for Disease Control and Prevention recently announced that PFD will be a stand-alone diagnostic code in the 2021 edition of the International Classification of Disease (see Reference 26).

The recognition of PFD as a discrete diagnosis is an essential foundation for paediatric tube-feeding research. Within PFD, tube-feeding is one approach to treatment (which itself incorporates variation, for example in the kinds of tube used). Some, but not all, children with PFDs will be tube-fed. Of children who meet the criteria for PFD however, our research has identified that those who require tube-feeding are a clinically distinct group who have unique health care and support needs over and above that associated with their PFD diagnosis.

We propose that PFD-T be defined as ‘children with PFD who require tube-feeding for more than two weeks’. This definition keeps PFD-T solely as a subgroup within PFD, with the 2-week duration differentiating children with PFD who may require short-term/acute tube-feeding (such as for a hospital admission with gastroenteritis). Keeping PFD-T within PFD means that a transition to oral feeding, while an important milestone, will not represent a ‘cure’ or the end of feeding difficulties for the child and family, and that PFD-T must be addressed using the same holistic approach to the child and family as outlined by the definition of PFD itself.

We propose PFD-T for use in research and care improvement purposes. This is not suggested as a diagnostic category, but as a means of identifying and collecting data about a discrete group that has a meaningful, shared basis to be considered as such (tube-feeding), despite different reasons for tube-feeding being needed (evident in the functional basis of the definition of PFD above).

PFD-T requires urgent attention from the linked perspectives of care improvement and research, recognising and understanding outside the silos of conditions that lead to it.⁴ Better understanding of, and care in relation to, PFD-T could make a positive difference across many child health domains including chronic disease and disability.

To contextualise this agenda, we offer statements from [Author4] and [Author5], both parents of children who have tube-fed.

Having two children with complex feeding difficulties was a struggle each day, balancing feeds and fasting times with children who would often vomit but needed the formula to manage their metabolic disorder. We weren't able to go out much and missed many 'normal' experiences that families around us had. One thing we learned quickly from our feeding specialists was to make food fun. This was one actually of the hardest things to do as a parent because I so desperately wanted them to eat. Today, even though the kids aren't able to eat much, they love to taste food, sit with us for meals, making food, baking, and talking about flavours. Formula is their main diet, but food is a big part of their lives. [Author4]

No-one ever mentioned to us when tube-feeding was initiated the side effects of tube-feeding or that our daughter could become tube-feeding dependent. There was no exit plan. The lack of recognition of all aspects of tube-feeding and the impact on the child and family is a failure of the healthcare system. Unless we systematically acknowledge these issues, we can't begin to systematically address them. [Author5]

Priorities

PFD-T care improvement and research should address five priorities, summarised in Table 1. Routine and standardised collection of data regarding PFD-T in health-care records and data collection is crucial. The absence of this currently compromises opportunities to: gauge prevalence, monitor progress, measure outcomes and correlate these with other health, social and demographic variables. Care improvement, health service resourcing and

economic modelling all depend on robust data. Routine documentation in clinical records will also better enable data linkage, randomised trials and meta-analyses addressing PFD-T.

PFD-T, in general, can be conceived in terms of three phases: initiation of tube-feeding, thriving while tube-feeding, and either tube weaning or transition to long-term tube-feeding (weaning is not possible for all). These are distinct but not isolated from one another. Failure to support and plan for thriving while tube-feeding and eventual tube-weaning can cause significant anxiety for families, tube-feeding dependency and unnecessary delays weaning.^{1,5,6,13,33} ‘Tube weaning should be addressed from the beginning of tube-feeding in all children who are expected to restore oral feeding’ (Trabi *et al.* 34: 664). At tube initiation, a plan covering the timing, method and team for weaning is recommended.³⁵ Poor awareness of tube weaning may negatively impact the quality of care for children who are tube fed, included infrequent use of tube exit plans.^{32,38} Relatedly, the timing of transition from an nasogastric tube to a gastrostomy is variable, as is guidance on when is optimal to do so.³² Evidence of what constitutes high-quality care across the tube-feeding lifecycle is urgently needed, recognising the importance of multidisciplinary and interdisciplinary approaches that actively include parents and caregivers as experts in the lived experience of caring for children who tube feed.^{28,41}

Principles: Involving, Respecting and Connecting Families

This agenda does not favour particular clinical practices or research methods. We suggest that three principles should underpin the priorities listed above. Heeding calls in recent research,² these fall under a family-centred guiding ethos of *involvement, respect and connection*.

Involvement

*Family has an essential influence on feeding; however, studies to date neglect to address the family context of feeding difficulty (Estrem *et al.*²: 340).*

The ambition to improve the care and wellbeing of children cannot be attained by focusing exclusively on the child. Securing better outcomes requires understanding what happens in families, making decisions with families, supporting them to act on those decisions and monitoring and managing unintended consequences:

To improve outcomes for tube-fed children, we must learn more about the impact of tube-feeding on their parents, for it is upon them that these children depend (Wilken⁴²: 254).

Therefore, we advocate working as partners *with* families rather than simply caring for or doing research about them. This is consistent with calls for family-centred models of paediatric feeding care.⁴³ Families can be involved in setting agendas as co-producers of care and changes in the way care is delivered.^{1,42} In doing this, it is important not to medicalise parents, whose already navigate complex additional responsibilities that may overwhelm their sense of connection with their child.⁴⁴

Table 1 Priorities for care improvement and research in paediatric feeding disorder requiring tube-feeding (PFD-T)

Area	Priorities	
	Carer perspective	Clinical care perspective
Recognition and data collection	<ul style="list-style-type: none"> Approaching care and communicating in a way that recognises the importance of PFD-T as a distinct experience within PFD, especially its connections with other aspects of the child and family's health 	<ul style="list-style-type: none"> Ensuring PFD-T data are collected routinely in healthcare records, identifying standardised data points in the tube-feeding lifecycle Using these data to measure and understand variability, equity and change in healthcare practices, resources and outcomes, within and across services
Phase 1 Tube initiation	<ul style="list-style-type: none"> Ensuring families engage with tube-feeding, as indicated, to ensure safe, adequate growth and nutrition for their child Reducing distress for children and families regarding nasogastric tube insertion and gastrostomy insertion²⁷ 	<ul style="list-style-type: none"> Safely reducing tube-feeding prevalence Routine screening and investing risk and protective factors for parent stress and anxiety¹⁸ Pathways to second and third phases, including a documented tube exit plan when appropriate
Phase 2 Thriving while tube-feeding	<ul style="list-style-type: none"> Enhancing education and support for families, incorporating healthcare and psychosocial domains with a focus on optimising physiological progress, enabling joy during mealtimes as quickly as possible, enabling children and their families to participate in preferred activities and psychological support for parents^{14,28–30} Enabling social support and connection for children who are tube-fed and their siblings, parents and others delivering care, particularly by addressing stigmatisation^{14,28–30} 	<ul style="list-style-type: none"> Identifying and avoiding unintended complications³¹ Joint decision-making with families around transition from nasogastric tubes to gastrostomy, as appropriate³² Pathways to the third phase, with clear progression towards tube weaning or meaningful goals when tube-feeding is life-long^{32,33}
Phase 3 Tube-weaning	<ul style="list-style-type: none"> Supporting tube weaning to happen as soon, quickly and safely as possible^{6,18,32,34–37} Ensuring families feel safe and confident in the timing of and approach to tube-weaning 	<ul style="list-style-type: none"> Supporting tube weaning to happen as soon, quickly and safely as possible^{6,18,32,34–37} Better understanding tube-dependency and tube-weaning pathways including psychologically-informed approaches^{38–40}
Transitioning to long-term tube-feeding	<ul style="list-style-type: none"> Supporting children and their immediate families to thrive when tube-feeding is long-term Identifying and progressing towards meaningful endpoints or goals (e.g. participation in education, employment, transition out of paediatric care), including through research, community advocacy, and workplace innovation 	<ul style="list-style-type: none"> Attuning interactions between clinicians/care providers and families to a long-term tube-feeding experience when tube removal is not possible

Nonetheless, the involvement of families can help to define and accomplish the best possible care.⁴⁵

Respect

Parents develop significant knowledge, skills and expertise in the course of caring for children who tube feed. Harnessing this in care improvement and research will require clinicians and researchers to take a humble stance in relation to knowledge gained through families' experiences within and beyond the health system, without displacing their clinical expertise. This requires relational expertise – a capacity to elicit and hear what matters to others, be explicit about what matters to oneself as a professional, and draw on others' understandings when needed.⁴⁶

The principle of respect can be enacted by considering what matters to families in a joint process to imagine and create new possibilities.⁴⁶ What might be significant from a clinical perspective might not map directly onto what matters to families. The psychological and emotional significance of feeding may transcend the nutritional aspect for many parents,¹⁸ meaning professional biomedical concerns regarding weight gain may not obviously align with parents' concern that their child feels loved.⁴⁷ This is particularly significant when families transition from hospital to home. Education for parents focusing on feeding procedures and tube maintenance may neglect what matters to parents.^{29,30} Neonatal Trust Chief Executive Michael Meads commented:

There's a huge emotional toll on the family... this just seems to be being brushed under the carpet. Hospitals just say "Here's

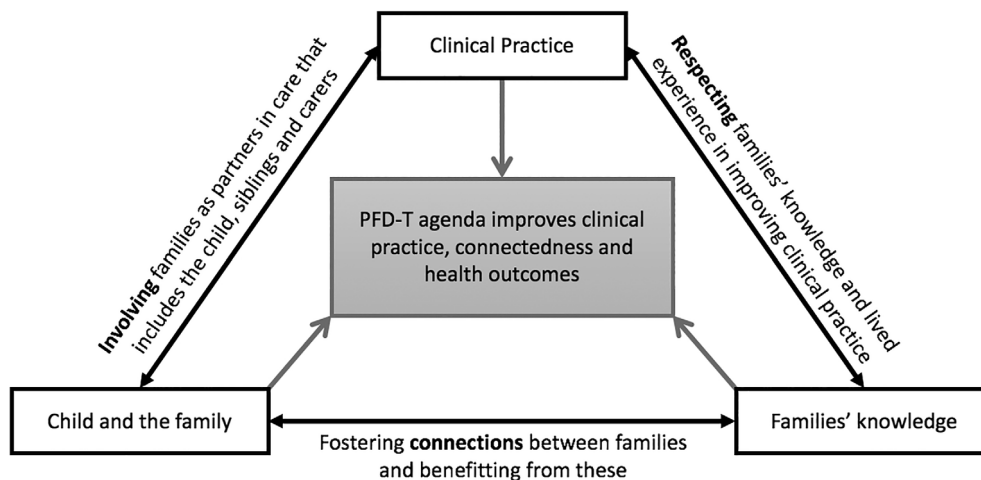


Fig 1 A paediatric feeding disorder requiring tube-feeding (PFD-T) care improvement and research agenda.

*your tube, you're out of hospital now, carry on." There's no real support.*⁴⁸

Some parents report negative experiences associated with a focus on growth charts that fails to acknowledge the child in their entirety,⁴⁹ a sentiment echoed by Author5:

Our daughter was achieving 'perfect' biomedical nutrition via the feeding tube, but at what cost? For our family, mobility without tube-feeding equipment and other negative side effects of tube feeding including vomiting and a strong oral version.

Long-term outcome measures should extend beyond physical growth to including functional status, general health and quality of life.⁴

What matters to families may be surprising or counterintuitive. Although caring for a child who tube-feeds is time-consuming and exhausting,^{5,50} studies show that some parents spend extra time preparing home-made meals rather than using commercial formulas because what matters is creating a feeling that tube-feeding is still a 'meal-time' that involves an emotional connection.⁵¹ A sense of normalcy is important to many parents of children who tube-feed.⁵⁰ Respecting what matters to families can strengthen outcomes and reduce the risk of disengagement from services due to poor experiences.

Connection

Many families of children who tube-feed say what matters to them is being connected with other families with children who tube feed.^{1,14} Such connections are found by some families through social media groups,¹⁴ but many remain disconnected from others sharing similar experiences. Child and family outcomes can be improved by connecting families with each other, and clinicians can play a significant role in linking families to tube-feeding-focused groups: Education is not a uni-directional process from clinician to parent. Given how important

participating in 'normal' activities in the community is to families, assistance in connecting families to their communities is also needed.^{1,42} Connecting with each other can help to reduce unwarranted variation in clinical care and to propagate brilliant practices in health services. We therefore advocate care improvement and research that happens through and produces new connections between clinicians, families and each other.

Conclusion

These five priorities and three principles, summarised in Figure 1, constitute an agenda for care improvement and research in PFD-T, a serious issue that urgently warrants attention. Addressing this agenda may require new elements of practice (e.g. tube exit plans) and new ways of working with families (e.g. around parent mental health). It may also involve advocacy in the health-care system to deliver change along lines that matter to families and address the child's health holistically. The principles outlined above can provide a basis for doing so.

Children who tube feed deserve the best possible care to reduce the severity, frequency, and duration of tube feeding as well as any adverse effects. This agenda aims to ensure children who tube feed thrive, and enjoy mealtimes plus all the benefits of interacting with siblings and friends as members of families whose wellbeing is intact. The agenda is a call for specific priorities in research and care improvement, grounded in the principles of involvement, respect and connectedness.

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