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

Abstract

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 healthcare 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.

Keywords

Gastroenterology; education; nutrition; paediatric feeding disorder; enteral feeding; tube-feeding; health services research; nutrition

Introduction

Paediatric Feeding Disorder can have wide-ranging and serious consequences for the health and wellbeing of the child and their family (Hopwood et al 2020). Feeding difficulties arise in 20-50% of children, and for 3-10%, those problems are severe or persistent (Estrem et al 2018; Horton et al 2018; Puntis 2012). Tube-feeding at home (also known as home enteral nutrition) can help to maintain growth in many complex feeding cases (Krom et al 2019; Wilken et al 2018), but can have side-effects for children and significant psychosocial impacts on carers and children (Enrione et al 2005; Morton et al 2019; Nelson et al 2015). As a group of clinicians, parents and researchers we propose an agenda that recognises Paediatric Feeding Disorder 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 (Braegger et al 2010). Common indications include prematurity, congenital heart disease, cerebral palsy, cystic fibrosis, neurodevelopmental disabilities, metabolic disease and cleft palate (Fleet & Duggan 2020). Tube-feeding may also be required while children are critically unwell or after surgery (Morton et al 2019). The Feeding Tube Awareness Foundation (2016) identified over 350 conditions that can warrant tube-feeding, which it viewed as incomplete.

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 100,000 (Edwards et al 2016) but can be as high as 83-92 per 100,000 (Krom et al 2019), though there are good reasons to think actual rates are higher (Krom et al 2019). 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 (eg. Banhara et al 2020; Craig & Scambler 2006; Bicakli et al 2019; Pedersen et al 2004; Sleigh 2005; Sleigh & Brocklehurst 2004), but some studies have examined tube-feeding across more than one clinical domain (Guerriere et al 2003; Spalding & Keever 1998). Children who tube-feed represent a heterogeneous group with multiple co-morbidities (Sharp et al 2010). Tube-feeding has been conceptualised differently by the many specialities working in the area (Bryant-Waugh 2013; Lukens & Silverman 2014; Sharp et al 2010). A recent consensus paper proposed a definition of a paediatric feeding disorder (PFD) that encompasses, though is not limited to, children who require tube feeding: impaired oral intake for more than two weeks that is not age- appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction (Goday et al 2019). 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 Pederson 2020).

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 healthcare 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 two-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 (Puntis 2012). 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 a statements from [Author5] and [Author6], 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. [Author5]
>
> 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. [Author6]

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 healthcare 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 (Edwards et al 2016; Hopwood et al 2020; Krom et al 2019; Wilken et al 2018; Wright et al 2011). 'Tube weaning should be addressed from the beginning of tube-feeding in all children who are expected to restore oral feeding' (Trabi et al 2010, p 664). At tube initiation, a plan covering the timing, method and team for weaning is recommended (Dunitz-Scheer et al 2009). 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 (Syrmis et al 2020; Gardiner et al 2017). Relatedly, the timing of transition from an nasogastric tube to a gastrostomy is variable, as is guidance on when is optimal to do so (Syrmis et al 2020). 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 (Sharp et al 2017, 2020).

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	- 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	- 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	- 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 nasogastic tube insertion and gastrostomy insertion (Craig et al 2006)	- Safely reducing tube-feeding prevalence - Routine screening and investing risk and protective factors for parent stress and anxiety (Sleigh 2005) - Pathways to second and third phases, including a documented tube exit plan when appropriate
Phase 2		
Thriving while tube-feeding	- Enhancing education and support for families, incorporating healthcare and psychosocial domains with a focus on optimising physiological progress, enabling joy during mealtimes as	- Identifying and avoiding unintended complications (Pahsini et al 2016) - Joint decision-making with families around transition from nasogastric tubes to gastrostomy, as appropriate (Syrmis et al 2020)

	quickly as possible, enabling children and their families to participate in preferred activities and psychological support for parents (Banhara et al 2020; Craig et al 2003; Liley & Manthorpe 2003; Sharp et al 2020) - Enabling social support and connection for children who are tube-fed and their siblings, parents and others delivering care, particularly by addressing stigmatization (Banhara et al 2020; Craig et al 2003; Liley & Manthorpe 2003; Sharp et al 2020)	- Pathways to the third phase, with clear progression towards tube weaning or meaningful goals when tube-feeding is life-long (Syrmis et al 2020; Wright et al 2011)
Phase 3		
Tube-weaning	- Supporting tube weaning to happen as soon, quickly and safely as possible (Dovey et al 2017; Dunitz-Scheer et al 2009; Pediatric Society New Zealand 2013; Sleigh 2005; Syrmis et al 2020; Trabi et al 2010; Wilken et al 2018) - Ensuring families feel safe and confident in the timing of and approach to tube-weaning	- Supporting tube weaning to happen as soon, quickly and safely as possible (Dovey et al 2017; Dunitz-Scheer et al 2009; Pediatric Society New Zealand 2013; Sleigh 2005; Syrmis et al 2020; Trabi et al 2010; Wilken et al 2018) - Better understanding tube-dependency and tube-weaning pathways including psychologically-informed approaches (Gardiner et al 2017; Lively et al 2019; Taylor et al 2019)
Transitioning to long-term tube-feeding	- Supporting children and their immediate families to thrive when tube-feeding is long-term - Identifying and progressing towards meaningful endpoints or goals (eg. participation in education, employment, transition out of paediatric care), including through research, community advocacy, and workplace innovation.	- Attuning interactions between clinicians / care providers and families to a long-term tube-feeding experience when tube removal is not possible

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 (Estrem et al 2018), 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 2018, p 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 (Wilken 2012, p 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 (Bryant-Waugh 2019). Families can be involved in setting agendas as co-producers of care and changes in the way care is delivered (Hopwood et al 2020; Wilken 2012). 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 (Tong et al 2010). Nonetheless, the involvement of families can help to define and accomplish the best possible care (Fulop et al 2018).

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 (Hopwood & Edwards 2017).

The principle of respect can be enacted by considering what matters to families in a joint process to imagine and create new possibilities (Hopwood & Edwards 2017). 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 (Sleigh 2005), meaning professional biomedical concerns regarding weight gain may not obviously align with parents' concern that their child feels loved (Morrow et al. 2008). 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 (Craig et al 2003; Liley & Manthorpe 2003). 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 your tube, you're out of hospital now, carry on." There's no real support. (Duff 2013)

Some parents report negative experiences associated with a focus on growth charts that fails to acknowledge the child in their entirety (Pahsini 2018), a sentiment echoed by Author6:

> 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 (Puntis 2012).

What matters to families may be surprising or counterintuitive. Although caring for a child who tube-feeds is time-consuming and exhausting (Brotherton et al 2007; Krom et al 2019), 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 (Hurt et al 2015). A sense of normalcy is important to many parents of children who tube-feed (Brotherton et al 2007). 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 (Banhara et al 2020; Hopwood et al 2020). Such connections are found by some families through social media groups (Banhara et al 2020), 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 (Hopwood et al 2020; Wilken 2012). 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 (eg. tube exit plans) and new ways of working with families (eg. around parent mental health). It may also involve advocacy in the healthcare 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.

Figure 1 A PFD-T care improvement and research agenda

[INSERT FIGURE 1 HERE]

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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