Optimising paediatric tube weaning practices

By

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Thesis
Submitted to Flinders University
for the degree of

Doctor of Philosophy
College of Nursing and Health Science
30 August 2023

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ABSTRACT

Introduction

Infants born with complex medical conditions or children experiencing adverse diagnoses are surviving, partly due to tube feeding providing essential nutrition while they are unable to eat and drink orally (Miller, 2009). Although alleviating one challenge (i.e., lifesaving nutrition), perpetuating tube feeding, may lead to ongoing psychological, physical, and financial costs (Smith, Bryant & Hemsley, 2021; Stewart et al., 2022). Persistent tube feeding may result from the child's reduced opportunity for time-critical skill development, pain or medical trauma causing anxiety to eat and drink, or trauma impacting parental capacity to support their child's learning.

Improvements in child development, social inclusion and child and parent wellbeing have been reported once children transition from tube to oral intake (Cipolla, Reeves-Latour, Ramsay & Li, 2022; Lively, McAllister & Doeltgen., 2022). A range of approaches are utilised to (re)habilitate eating and drinking, with no consensus yet on best practices. Published weaning programs report varying strategies and outcome measures, making it challenging for parents and health professionals to understand best practice tube weaning.

Hence, the aims of this research program were threefold: first, to document the philosophies underpinning published tube weaning practices to guide parental decision-making; second, to explore the outcomes of a weaning program to determine whether physiological factors influence or predict weaning time and readiness; and third, to inform and improve clinical practice through understanding the parental tube-weaning experience.

Methods

This thesis comprises three research projects, specifically a (i) scoping literature review, (ii) quantitative retrospective case note analysis of variables thought to influence weaning and (iii) qualitative parent interview with thematic analysis of their tube weaning experiences.

Results

Research Project 1 identified three predominant weaning approaches: behavioural; biomedical and child- and family-centred. Numerous intervention variables were identified, with parent involvement and hunger provocation being key differences between approaches. Comparison of effectiveness across programs was limited due to the variation in outcomes measured, reinforcing the requirement for evidence-based clinical practice and research guidelines in this area.

Research Project 2 audited outcome data to determine if biological factors influence weaning time. Findings revealed which biological factors were predictive of time taken to tube wean and which were not, and therefore should not be used to determine weaning readiness. As the audited program relies on parental engagement, it was postulated that psychosocial variables may mitigate impacting biological variables.

Despite their vital role, limited published information exists on the parents' experience of tube-weaning, which subsequently informed Research Project 3. Seven overarching themes were identified relating to the barriers, facilitators, decision-making, learning and emotional journey of parents during weaning. This information could contribute to frameworks of healthcare and support.

Conclusion

This research contributes to understanding the philosophies underpinning, and the psychosocial factors which may influence tube-weaning, including the emotional and physical challenges parents may experience. Developing health professionals' understanding of how parents learn and how learning changes their behaviour will contribute to better understanding effective tube weaning. These findings informed the development of five key principles which may contribute to targeted and timely healthcare pathways for tube-fed children and their families.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed Emily Lively

Date 6 March 2023

ACKNOWLEDGEMENTS

I met with Professor Sue McAllister and Associate Professor Sebastian Doeltgen in 2014 as a therapist who was eager to share my clinical outcomes but with little understanding of how to successfully achieve this. Over the subsequent 9 years, Seb and Sue have guided me through to the completion of a PhD. I will be forever grateful for their patient feedback, explanations, probing thoughts, teamwork, flexibility, and bolstering encouragement and belief in both my clinical and research work. Together, Seb and Sue have challenged me beyond what I thought I could ever achieve and to both, I give my heartfelt thanks and gratitude.

The therapists and support services staff whom I have had the pleasure of working with over the last 13 years at Lively Eaters have contributed in some way, to this research, in particular Lynly Mader. The team has taught me so much about what it means to develop goals collaboratively, whilst considering the capacity and needs of others. Over the last 6 months my colleagues at Lively Eaters, in particular Sarah and Georgina, have taken on further responsibilities to allow me the time to focus on completing my thesis. I will forever be grateful to all of the wonderful Lively Eaters team.

Families Australia-wide and internationally have entrusted their health care to the Lively Eaters team and allowed us into their family and their homes. I am humbled by the vulnerability and openness they have shown and their willingness to consider and adopt change within their mealtime routines, behaviours, and the greater family context. I am thankful for the invaluable information and feedback parents have provided, within the context of the research presented in this thesis and within our clinical setting. Their input has contributed to the growth and enhancement of my clinical healthcare skills and my ability to support the Lively Eaters team to reflect upon their engagement with families.

The family whom I choose in addition to my own family (Ness, Steph, Jo, Shev, Kelly and Helen). Kilometers upon kilometers of pavements have been pounded with these incredible women who have kept me going when everything felt unachievable or when another roadblock stood in the way. They believed in me when I struggled to believe in myself. They are inspirational, thoughtful and generous and my life would not be as wholesome without them in it.

I remember my parents' doubt when I mentioned I was enrolling in higher degree research. Research was never my calling, however, I felt a moral responsibility to provide data in a clinical area within which Australian data was non-existent and to which I knew I had access. Mum and Dad have given their unwavering support to my family and me. Helping with school pick-ups, school holiday activities, making coffee and dinners to allow me additional study time. From a young age they taught me to strive to be the best version of myself and work hard to achieve whatever I set my heart and mind to. I wouldn't be the person I am today without their love, guidance and support.

In wine lingo, GSM is a melody of bright fruit, with a balanced tannin backbone, elegance and complexity. My ability to maintain energy, brightness and a reliable balance whilst managing complexities over the last 8 years would not have been possible with Gary, Sophie and Millie (my GSM).

For as long as my daughters can remember, 'mummy has been at uni'. From the first meetings where they brought their colouring books and snacks, to the day of submission when they reaffirmed 'we're so proud of you mummy, we knew you could do it', my girls have encouraged me until the end. For them growing up in a generation of instantaneous gratification, Sophie and Millie made me determined to model that hard work and struggle pay off and goals may take a long time to achieve.

Gary has stood by me during the last crazy eight years (and the nine before that!) and weathered my emotional storms with patience and an unwavering belief that I would complete this research project and make a valuable contribution to clinical practice. I could never have achieved what I have in work and research had Gary not been the constant, balanced backbone.

Over the course of this PhD I have raised my two daughters, continued to run two businesses, and maintained my personal goals. However, it is the research presented in the following pages that has undoubtedly been the hardest thing I have undertaken to date.

Professional editing was used to review grammar, formatting, and style. No other alterations were made by the editors.

Financial support received during candidature:

- Flinders University Research Scholarship—Thesis Write-Up Stipend (1 year)
- Research Accelerator Grant, College of Nursing and Health Sciences, Flinders University (funded research assistant to complete the interviews for Research Project 3, which allowed for the maintenance of confidentiality and anonymity of participants). I would like to thank Jessica Thomas, Associate Lecturer and PhD Candidate for undertaking the parent interviews.
- The contribution of Australian Government Research Training Program Scholarship (RTP) support

PUBLICATIONS FROM THIS DOCTORATE

PUBLICATIONS:

1. Lively, E. J., McAllister, S., & Doeltgen, S. H. (2019). Variables impacting the time taken to wean children from enteral tube feeding to oral intake. *Journal of Pediatric Gastroenterology and Nutrition*, *68*, 880–886. https://doi.org/10.1097/MPG.0000000000002330

   The *Journal of Pediatric Gastroenterology and Nutrition* is a Q1 journal, H-index 138.

2. Lively, E. J., McAllister, S., & Doeltgen, S. H. (2021). Characterizing international approaches to weaning children from tube feeding: A scoping review. *Journal of Parenteral and Enteral Nutrition*, *45*(2), 239–250. https://doi.org/10.1002/jpen.1842

   The *Journal of Parenteral and Enteral Nutrition* is a Q2 journal, H-index 105.

3. Lively, E. J., McAllister, S., & Doeltgen, S. H. (2022). Parents' experiences of their child's transition from tube to oral feeding during an intensive intervention programme. *Child: Care, Health and Development*. https://doi.org/10.1111/cch.13088

   Child: Care, Health and Development is a Q1 journal, H-index 87.

CONFERENCE/WORKSHOP PRESENTATIONS—ORAL:

1. Research presentation—invited (30 minutes). Speaker for AusEE Tube Feeding Awareness Week online seminars, available nationally and internationally. February 2022.
2. Conference presentation—invited (45 minutes). 7th Nordic Conference on Feeding Difficulties in Childhood. Presentation titled 'Weaning children from enteral feeding tubes: International practices, factors influencing success and parents' experiences'. August 2021.
3. Conference expert panel—One of four invited professionals internationally to sit on this panel (60 minutes). 7th Nordic Conference on Feeding Difficulties in Childhood. August 2021.
4. International presentation (75 minutes)—Australian Paediatric Dysphagia Interest Group. Presentation titled 'Variables impacting the time taken to wean children from enteral tube feeding to oral intake'. This presentation presented the published outcomes of the quantitative research project. June 2019.

5. Three Minute Thesis (3MT) competition. ‘Tube feeding is hard to swallow’. Faculty of Nursing & Health Science Finalist, Flinders University, Adelaide. July 2019.
6. Conference presentation—nominated (20 minutes). Speech Pathology Australia conference. Presentation titled ‘Variables impacting the time taken to wean children from enteral tube feeding to oral intake’. This presentation showcased the research on this project to date, as well as the preliminary analysis. July 2017.

CONFERENCE PRESENTATIONS—POSTER:

1. Poster presentation: Retrospective case note audit of children who have accessed a multi-disciplinary intensive enteral tube weaning program. Australian Society for Medical Research conference, Adelaide. June 2016.

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GLOSSARY/ABBREVIATIONS

Glossary

Where possible, I have used the highlighted term to maintain consistency; however, please note that the following terms may be used throughout various sections of this thesis if the context privileged the use of one term over another.

Child/infant/children/baby

Parent/caregiver/significant person

Tube dependency

Feeding tube/tube/enteral tube

Mealtime skills—eating and drinking skills, behaviour, gross and fine motor, and regulation

Tube weaning/weaning

Tube feeding/enteral feeding/enteral tube feeding

Oral feeding/eating and drinking

Health professional/clinician/therapist/feeding therapist/health care professional

Abbreviations

AI	Artificial intelligence
ASI	Ayres Sensory Integration
BMI	Body mass index
BTF	Blenderised tube feed
CDC	Centers for Disease Control and Prevention
DSM 5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
EBP	Evidence-based practice
ED	Emergency department

FAF	Family as Faculty
GERD	Gastroeosophageal reflux disease
GT	Gastrostomy tube
HEN	Home enteral nutrition
IMH	Infant mental health (specialist)
IPFCC	International Parent and Family Centred Care
JBI	Joanna Briggs Institute
NICU	Neonatal intensive care unit
NEC	Necrotising enterocolitis
NG/NGT	Nasogastric/nasogastric tube
OGT	Orogastric tube
OT	Occupational therapist
PEG	Percutaneous endoscopic gastrostomy
PFD	Paediatric feeding disorder
PFD-T	Paediatric feeding disorder-tube
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analysis
PTSS	Post-traumatic stress symptoms
SCT	Social cognitive theory
SDT	Self-determination theory
SLP	Speech language pathologist
SPSS	Statistical Package for Social Sciences
VFSS	Videofluroscopic swallow study

INTRODUCTION

Enteral tube feeding became my 'bread and butter' when I was working in the United Kingdom in 2004. Prior to this, in my regional community speech pathologist role I had been drawn to working with children with feeding challenges. I will forever be indebted to Ms Jas Singh, one of the most passionate dietitians I have had the pleasure to work with. Jas, in the broadest and loudest of Scottish accents, introduced me to the world of tube-feeding babies while I was working with her at the Haringey Child Development Centre in London.

I was an early career speech pathologist hungry for learning opportunities, and Jas took me under her wing to teach me about tubes, syringes, lines, pumps, formulas, rates, volumes, growth charts, and child protection with enteral (tube) feeding. Jas showed me the power of working together in a multidisciplinary team to problem-solve challenges and agree to achievable goals from a nutrition, oral safety, and family functionality perspective.

Upon returning home to live and work in South Australia, I was fortunate to gain the role of senior paediatric speech pathologist at Flinders Medical Centre with the scope to develop and deliver infant and paediatric services in the areas of feeding (oral and enteral), cleft palate research, and complex child development assessments. I felt drawn to the families whose babies required ongoing tube feeding upon discharge from the hospital. The parents attended for outpatient reviews month after month and reported persisting challenges related to growth, tolerance of the type or volume of formula, and extensive hours of the day spent feeding their baby.

There was limited scope for change within public health; however, I was motivated to improve the support for parents to make tube feeding functional and manageable within the demands of everyday life. In addition, as a therapist, I sought to teach children to eat and drink in a safe, enjoyable, and autonomous manner. To address the shortfalls of support and service provision that I had experienced as a therapist in public health, I commenced my private practice focusing solely on feeding disorders and the challenges they can present to children and families.

As a clinical speech pathologist working with families and children over the last 22 years, I have had the privilege to be with families at mealtimes—in their homes, in public spaces (e.g., cafes and playgrounds), in the school setting—and experience firsthand their challenges with tube feeding. Despite regular clinic-based interventions, I observed babies and children frequently reaching a plateau with oral acceptance. In addition, parents reported frustration and dwindling hope that their child would ever learn to eat and drink.

My desire to support these families to help their children achieve the best possible outcomes led to the development of the Lively Eaters intensive feeding therapy programs. These programs provide physical and emotional support to parents as they are coached to teach their child to eat in the context of family mealtimes. Over the last 12 years, the opportunity to facilitate this for families has afforded me valuable learning experiences. I have been drawn to understanding the development of infant feeding from the child's and the parents' perspective and how this may be altered when having to use a tube for feeding. In doing so, the physiological and psychological impacts of tube feeding and weaning have been brought to the forefront of my attention. In addition, I have sought to understand the factors within both the child and the parents that facilitate successful mealtimes. Seeking clarity on these clinical questions (and others) led me to undertake this PhD. Completing the research projects presented in the following chapters has deepened my understanding of these and other factors that contribute to a tube-fed child learning to eat and drink. I am motivated to share my learnings with other families and health professionals alike to improve tube-feeding and tube-weaning services both in Australia and internationally.

While tube feeding is lifesaving in the first instance, many parents come to 'hate' the tube that saved their baby's life and dream of the day it can be removed (sentiments expressed by research participants [P1, P3, P9, P10]; Lively et al., 2022). Some parents view the tube as a 'lifeline' for when their child is unwell and requires medications or additional calories to support growth (Brotherton, Abbott & Aggett, 2007; Martinez-Costa, Calderon Garrido, Borraz, Gomez-Lopez & Pedron-Giner, 2013). For others, tube feeding frequently evokes strong emotion because it consumes a considerable amount of time each day for families as they navigate many hospital appointments, unexpected complications and social isolation, the negative effect on the maternal emotional state, and time spent syringing fluid through a tube or cleaning up regurgitated feed (Brotherton et al., 2007; Dadich, et al., 2021; Page, Hinton, Harrop & Vincent, 2020; Pahsini, Marinschek, Khan, Dunitz-Scheer & Scheer, 2016; Wilken, 2012). However, the reality of tube weaning and subsequent tube removal also often comes at a high emotional cost for parents because, anecdotally, some become as dependent on the tube as their child.

Health professionals are becoming increasingly cognisant of the need for a tube exit plan; however, all too frequently when a tube is placed, no clear pathway is provided for teaching that child to eat and drink orally (Gardiner, Fuller & Vuillermin, 2014; Syrmis, Frederiksen & Reilly, 2020). Parents, too, are becoming increasingly proactive in seeking answers for how and when their child will learn to eat (Lively et al., 2022). The answers remain variable and largely depend on the family's local healthcare team's knowledge and opportunity to provide tube-weaning support or refer on for more specialised services if required. As yet, there is not an internationally agreed-upon set of best practice principles for tube weaning, and this further contributes to variability between tube-weaning programs and the experiences between families.

The research that I undertook during my PhD and that is presented in this thesis provides information to parents and professionals regarding the different philosophies underpinning the published tube-weaning approaches. In doing so, parents may be empowered to make informed decisions in the best interests of their child and family. The findings from this research may also assist healthcare professionals in their reflection on their tube-weaning practices and the information they share with families regarding the theoretical underpinnings of their approach.

In addition, I explored one therapeutic tube-weaning program in detail to investigate whether physiological factors influence the time it takes a tube-fed child to learn to eat and drink orally. This knowledge can contribute to decisions regarding tube-weaning suitability and provide professionals with research-based data to support clinical discussions and decisions.

Lastly, there are limited published data on how parents experience tube weaning. As a clinician–researcher, I feel strongly that the child is only one part of the equation, and that the family unit contributes significantly to how a child learns to eat and drink. Expanding our understanding of parents' experiences during tube weaning will inform how health professionals view and include parents as key team members while also providing targeted and meaningful support to them.

It is my hope that the research presented in this thesis will contribute to best practice tube weaning by providing research-based information on the challenges of learning to eat and drink from the child and parents' perspective. Increasing our understanding of how people learn and how new learning changes their behaviour may support the design of effective and timely tube-weaning processes and programs.

THESIS STRUCTURE

To orientate the reader, this thesis is presented in three parts, which reflects the thesis narrative rather than the order in which the research was undertaken (see Figure 1). Section 1 outlines the background relating to the many aspects that require consideration when teaching tube-fed children to eat and drink. These include the mechanics of swallowing, practical considerations regarding enteral feeding tube use and theories of how people learn to set the scene for how children wean from tube to oral feeding. This section also presents the research aims and objectives.

Section 2 presents three published research studies (Chapters 4, 7, and 9) along with supporting discussions (Chapters 5, 6, and 8) regarding the research findings. The published studies present (i) a scoping literature review, which led to further investigation of one of the approaches to tube weaning, (ii) a quantitative retrospective case note audit that, together with the scoping review, informed (iii) a qualitative parent reflection with subsequent thematic analysis.

Section 3 offers a summary of the research findings and an integrated discussion regarding the challenges of tube weaning (Chapter 10). The section culminates in outlining a set of five principles for tube weaning with associated clinical and research-based recommendations (Chapter 11). Chapter 12 and the epilogue summarise the key findings, with personal reflections on how the research outcomes have influenced my clinical tube-weaning practice.

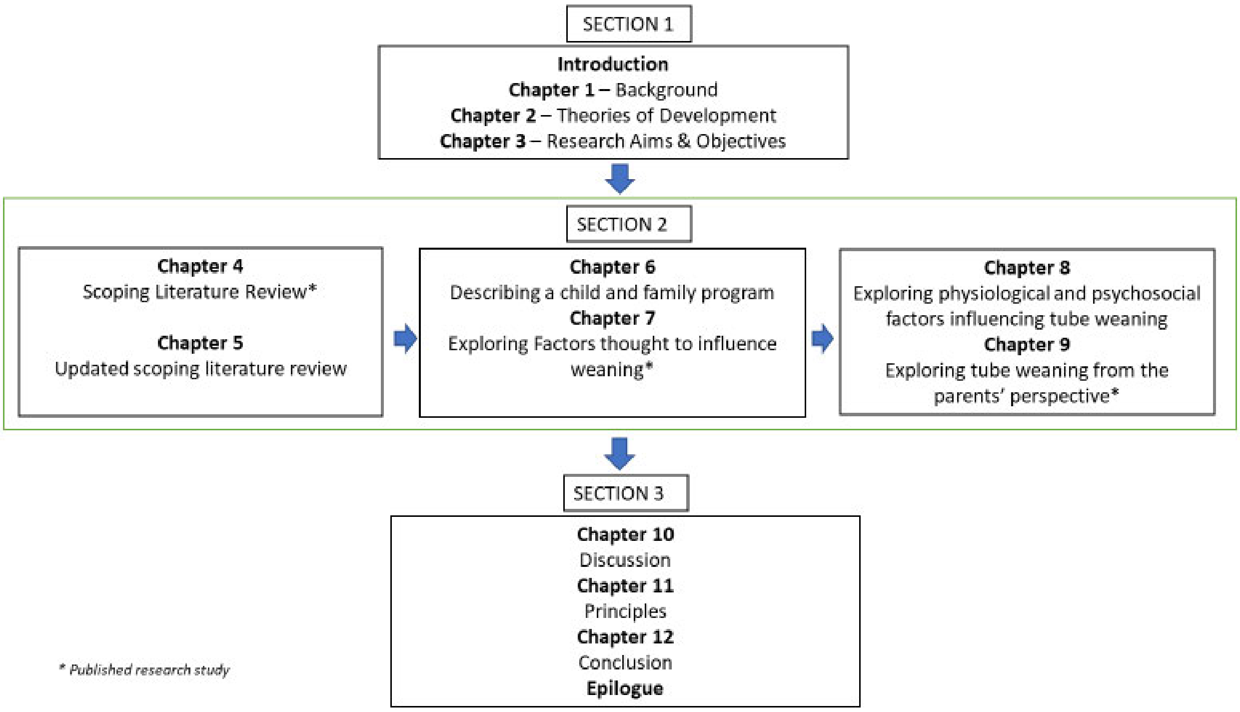

Figure 1: Thesis structure overview

CHAPTER 1: BACKGROUND

Food and drink preferences and dislikes are very personal decisions. Food choices are grounded in our experiences with meals, and these experiences can vary greatly across individuals, cultures, and contexts. Because children are nurtured with unique influences and experiences, each child’s journey of learning to eat and drink is different. Some children do not have an opportunity to develop food and drink preferences because they are fed via an enteral feeding tube directly into the gastrointestinal system. This thesis will explore some of the many challenges experienced by tube-fed children as they embark on learning to eat, drink, and be active participants at mealtimes. This thesis aims to extend our understanding of these challenges, along with those faced by children’s caregivers. To give some perspective to the enormity of the challenge in transitioning from non-oral to oral feeding, Figure 2 outlines an activity that I often undertake with new clients or audiences at workshops. The reader is invited to reflect on this activity in their own time, if they wish.

How often have you thought about what you would eat if you could choose anything? Imagine your favourite meal. How would you present it on the plate? Breathe in deeply and imagine the smell of it, your taste buds bursting as you anticipate the flavour of your first mouthful. Do you devour it because it is delicious, or do you savour each bite and make it last for as long as possible? Your favourite food now may be something you never imagined enjoying when you were a child. Over time and with new experiences, your palate and taste buds may have developed and changed, and you may now eat foods unpalatable to your younger self. You are acutely aware of what you enjoy eating and drinking.

Now imagine if you have never eaten. The world of food and drinks is foreign. Your perception of taste is heightened as your taste buds were not exposed to various foods during typical oral sensory development. Every new bite requires concentration. You are unsure if you will have to spit it out, so you take a nibble to test it. The food breaks up all over your tongue, and you panic at the sensation of the foreign grainy texture. The grains make you cough as little pieces stick to the back of your throat, and you have not yet mastered swallowing anything other than your saliva. Someone suggests a drink to 'wash it down'. This exacerbates your cough as you must simultaneously coordinate grainy food pieces and a liquid in your mouth. Perhaps it is not worth all the effort to 'take a bite'. Perhaps it is less scary to wait until someone gives you a tube feed …

Figure 2: Scene setting for the personal role that food and drinks play in a person's life

This chapter provides the background for the multiple components that influence the development of feeding and mealtime skills, swallowing and mealtime assessment, and tube feeding and tube dependency. Understanding these components is vital for appreciating the journey of a tube-fed child learning to eat and drink.

Overview of Chapter 1

The foundations of eating and drinking begin in infancy from soon after birth (Delaney & Arvedson, 2008). Because early feeding experiences guide the way for later mealtime competence, the required critical swallowing and mealtime skills are discussed in **Part 1** of this chapter. Learning to eat and drink successfully depends on a person's ability to swallow safely and tolerate the sensory sights, smells, and flavours of food. It incorporates a person's mental representation of what that food experience means to them—for example, whether it induces pleasure or pain. Mealtimes frequently occur in an environment that requires social engagement and behaviour regulation (Morris & Klein, 2000). What happens when any or many of these skills—swallowing, sensory processing, psychological, behavioural, or the feeding/mealtime experience—break down?

Tube feeding is the alternative to eating and drinking when it is either unsafe or not functional to do so orally. The possible impact of challenging feeding on a child's health, comfort, and enjoyment is illustrated in the reflective exercise in Figure 2: '*perhaps it is not worth all the effort to have the tiny bite. Perhaps it is less scary to wait until someone gives you a tube feed*'.

Part 2 of this chapter explores two fundamental aspects. First, many functional considerations of feeding tubes, including tube options, who may require one, and the choice of nutrition provided, are unpacked. Decisions regarding these aspects can contribute to later oral enjoyment when learning to eat and drink. Second, the psychological effects that tube feeding may have on the child and their family, as well as the significant effects on the health system, are highlighted. Increasing awareness to families and health professionals of the potential psychological imprints of tube feeding highlights the need for more timely tube exit planning.

Many parents strive to teach their tube-fed child to eat and drink. They seek a sense of normality and greater ease to participate in daily activities and family experiences (Hopwood, Elliot, Moraby & Dadich, 2020). They may be physically and emotionally exhausted by the ongoing complications and frustrations that tube feeding can contribute to daily life. These aspects are discussed in **Part 3** of this chapter, including what is involved in teaching tube-dependent children to trust in eating and drinking, and the different options for undertaking this. Factors that may influence child and parent readiness to transition from tube feeding to oral eating and drinking (i.e., tube weaning) are also explored.

I begin by describing how swallowing and feeding develop and what happens when this does not follow the typical developmental path.

Part 1: Skills Required to Eat and Drink

Learning to Eat

Eating and drinking are considered one of the most nourishing and pleasurable aspects of life. Mealtimes serve many social, cultural, and personal purposes, including giving and receiving love (e.g., early feeding experiences in caregivers' arms, cooking someone their favourite food), celebrations (e.g., weddings, birthdays), providing a sense of family and culture, physical growth and health, sensory exploration and development, relaxation, and physical, mental, emotional, and spiritual nourishment (Adams, Dadabhay & Neille, 2020).

Learning to eat is a complex process that involves the development of oral motor skills, gross and fine motor capacity, sensory-processing abilities, emotional and social regulation, and cognitive skills. The development of these skills is grounded in trust, which is influenced by the environment surrounding a baby and the interactions between the significant caregivers and the infant (Dunn Klein, 2019). As such, learning to eat does not occur in isolation, and successful feeding initially develops from the careful interpretation of the baby's cues by caregivers. Any disruption to the child's motor, sensory, emotional, or cognitive development or the environment within which the baby exists can interfere with learning to eat (Delaney & Arvedson, 2008). This is particularly pertinent in the early stages of feeding development; however, a disruption at any age or stage of development may result in challenges to oral acceptance of food or fluids.

One of the critical skills required for successful feeding and mealtimes is the ability to swallow food and drinks safely. In utero, babies develop the skill to swallow amniotic fluid at around 22–24 weeks' gestation (Miller, Sonies & Macedonia, 2003); however, following birth, they must learn to apply this skill to other foods and consistencies. This section explains the intricacies of learning to swallow safely, which is a prerequisite for growth and nutrition.

Development of Swallowing

Safe swallowing is a complex developmental skill involving the precise coordination of 26 muscle pairs and six cranial nerves (Malone & Arya, 2011). Successful swallowing is also influenced by the body's sensory system and the individual's environment, family, and past experiences. Although the biomechanical mechanism of swallowing is not the purpose of this research, an understanding of the complexity of these processes and the various time points and ways in which they may be affected is relevant for consideration during tube weaning.

Throughout this thesis, the term 'feeding' refers to the sucking and swallowing of liquid facilitated through interactions with a parent (Morris & Klein, 2000). This differs from 'eating', which develops through immersion in mealtimes and encompasses taking solid food into the mouth, chewing it, and swallowing it (Morris & Klein, 2000).

Development of Swallowing Prenatally

Early swallowing begins in utero with embryonic (first eight weeks' gestation) and then foetal (nine weeks to birth) changes occurring to facilitate the function of swallowing. The embryonic stage leads to the development of most external and internal structures, including those critical for swallowing, namely the oral cavity, pharynx, larynx, and oesophagus (Moore & Persaud, 2003). Because embryonic images of these structures are often unclear, an image of these structures in an infant is provided in Figure 3. Any interference with this stage of development may have a lasting effect on later swallowing functions—for example, frequent choking, food becoming lodged, or aspiration (food or fluid entering the lungs) (Delaney & Arvedson, 2008).

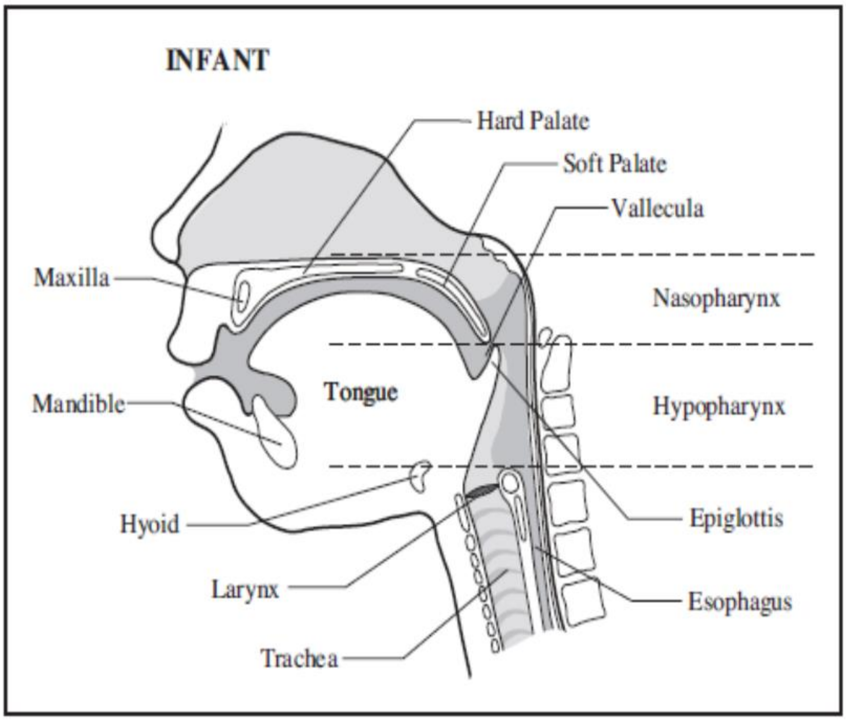

Figure 3: Internal anatomical structures of an infant that are important for swallowing (Arvedson, Brodsky & Lefton-Greif, 2020, p. 12). Reproduced with permission

Throughout the foetal stage of development and following birth, the coordination between oral, sensorimotor, and respiratory function emerges and refines (Carroll, 2003; Miller, 1999). Foetal swallowing begins with pharyngeal swallowing around 10–14 weeks' gestation, non-nutritive sucking around 15 weeks, and by 22–24 weeks, the foetus can swallow amniotic fluid (Delaney & Arvedson, 2008; Miller et al., 2003). It is not until approximately 26–29 weeks' gestation that the lungs mature enough to breathe air (Miller, 1999). Because successful feeding postpartum requires the coordination of sucking, swallowing, and *breathing*, it is not safe to attempt oral feeding of babies born younger than 26–29 weeks (Delaney & Arvedson, 2008).

Development of Swallowing in Infancy

Typically developing babies learn the precise coordination required to suck and swallow liquids immediately after birth; however, for the first month, suckling is mostly reflexive (Morris & Klein, 2000). With time and practice, parents learn to interpret and respond to their baby's subtle cues relating to hunger, satiation, contentedness, social engagement, and alertness (Morris & Klein, 2000). Infants improve their coordination, speed, and efficiency of feeding to receive the energy they require within a 20–30-minute timeframe every 2–3 hours (Delaney & Arvedson, 2008).

In infancy, a safe swallow involves the precise coordination of sucking, swallowing, and breathing to ensure the fluid does not enter the airway. To achieve this, a baby must maintain regulated cardiorespiratory and behaviour states (e.g., calm and alert) and a rhythmic suck–swallow–breathe pattern (Delaney & Arvedson, 2008). As coordination of suck–swallow–breathe improves, the pace and length of sucking patterns and volume increases from one suck per swallow to 2–3 sucks per swallow (Qureshi, Vice, Taciak, Bosma & Gewolb, 2002).

Anatomical proportions in infancy facilitate suckling, which is the forward and backward movement of the tongue to extract liquid (see Figure 2, infant).

[redacted]

Figure 4: Lateral views of the internal structures necessary for swallowing at different maturation stages (Arvedson & Lefton-Greif, 1998). Figure 4 has been removed due to copyright restrictions

Specifically, a proportionately larger tongue fills the oral cavity and limits the direction of movement of the tongue. Fat pads in the cheeks provide additional lateral support, and the posterior one-third of the tongue remains within the oral cavity. Compared with an older child and adult, there is minimal distance between the larynx (see Figure 2, infant, green) and the oral cavity (see Figure 2, infant, red and yellow). This provides additional airway protection because the larynx sits high under the base of the tongue (Bosma, 1986). As the suckle matures, the tongue movement changes to an up-and-down pattern, creating a more efficient negative pressure between the oral cavity and the nipple teat to extract liquid (Morris & Klein, 2000). The lips form a tight seal around the nipple to reduce the loss of liquid from the mouth (Delaney & Arvedson, 2008).

Development of Oral Skills from Six Months

From about six months of age, the oral cavity and larynx lengthen and grow, allowing for additional movement of the oral structures required for bolus manipulation of food from a liquid to a semi-solid (Delaney & Arvedson, 2008) (see Figure 4, toddler). The development of chewing is aided by changes within the neuronal development that occur at this time, including diminishing tongue propulsion (~6 months of age) and increased sensory responsiveness to texture in the mouth (Dodrill & Gosa, 2015). It is through cortical maturation and myelinisation that cognitive and behavioural functioning develop (Deoni, Dean, Remer, Dirks & O'Muircheartaigh, 2015). In turn, cortical maturation contributes to the development of more refined motor control of the jaw, tongue, and lip movements required for biting, chewing, and swallowing. This is a critical part of oral motor development that occurs in parallel with cortical development in other (non-oral) motor systems and facilitates exploration in the environment (e.g., mouthing toys, balance, imitation) (Adolph & Franchak, 2017). It is not only the maturation of the cortical system that contributes to ongoing development; the opportunity and experience to practice each new oral motor milestone is equally important (Eicher, 2002).

Oral motor skills mature with expanding cortical development and the presentation of more textured foods. Foods of increasing texture allow for increased tongue movement, including lateral motion, to move food pieces to the teeth for chewing before returning them centrally to the tongue in preparation for swallowing (Illingworth & Lister, 1964; Kennedy & Kent, 1985). With experience, masticated food is moved by the tongue across the molar surfaces laterally until pieces are small and safe enough to swallow. Until this point, these functions are associated with the *oral* phase of swallowing, which is mostly under volitional control (Delaney & Arvedson, 2008).

From this point, the swallow is triggered as part of the *pharyngeal* phase of swallowing (Morris & Klein, 2000). This is an involuntary (but volitionally modifiable) and complex motor response driven by pattern generators located in the brainstem. Muscle contraction resulting from precisely coordinated sequences of action potentials deflects the epiglottis to direct the food or fluid towards the pharynx and upper oesophageal sphincter located at the top of the oesophagus and away from the larynx (Dodrill & Gosa, 2015). Airway protection occurs simultaneously by the larynx in three ways to avoid food or fluids entering the lungs (Jafari, Prince, Kim & Paydarfar, 2003; Panara, Ahangar & Padalia, 2022). First, the true vocal cords adduct (i.e., close), second, the false vocal cords adduct, and third, the arytenoids close against the deflecting epiglottis (Logemann et al., 1992). In addition, the larynx elevates to sit under the base of the tongue and, in doing so, facilitates the opening of the upper oesophageal sphincter for bolus transit (Jafari et al., 2003). Breathing temporarily ceases as these protective sequences occur, further contributing to airway protection (Jafari et al., 2003; Logemann et al., 1992).

The final phase of swallowing is referred to as the *oesophageal* phase, where food or fluid is propelled downward through the oesophagus to the stomach (Panara et al., 2022). An interruption to any part of the above sequence may affect the safety and efficiency of the swallow (Dodrill & Gosa, 2015). Reduced opportunities for oral motor exploration and skill development may affect this part of cortical development and have ongoing implications for learning to eat and drink. The next section explores reasons for interruptions to the precise coordination of the muscles and nerves associated with safe swallowing.

Swallowing Impairment in Infancy and Childhood

Swallowing impairment (dysphagia) can be invisible to the untrained and even at times the trained eye, and the disability associated with impaired swallowing is largely hidden from view (McHutchion, Pringle, Tran, Ostevik & Constantinescu, 2021). However, it can have severe health and psychosocial implications if left untreated (Hewetson & Singh, 2009; Smith et al., 2021). It is therefore important to understand how swallowing may be affected and impairment detected, as well as the available options for treatment to alleviate symptoms and improve swallowing function.

Dysphagia is the term given to difficulty swallowing food or liquids that results from an interruption to any of the phases of swallowing (Panara et al., 2022). The causes of childhood dysphagia can be prenatal or postnatal. Prenatally, infants who have experienced interruptions to specific stages of embryonic development (e.g., as seen in Down syndrome, foetal alcohol syndrome, cleft palate, oesophageal stricture; Morris & Klein, 2000) may not master the coordination required for sucking, swallowing, and breathing, and may present with dysphagia at birth.

Postnatally, dysphagia may result from a range of conditions, including neurological (e.g., cerebral palsy, acquired brain injury; Field, Garland & Williams, 2003; Panara et al., 2022), anatomical (e.g., laryngo-tracheo-bronchomalacia; Field et al., 2003), or physiological (e.g., cardiac or respiratory disease; Slater et al., 2021, oesophageal motility challenges; Field et al., 2003; Panara et al., 2022).

Other experiences may inadvertently influence swallowing as a result of their unpleasant nature and subsequent alteration of the sensations or function of swallowing. These include gastrointestinal disorders (e.g., eosinophilic oesophagitis or gastro-oesophageal reflux disorder), ingestinal injuries (e.g., cleaning agents, battery), and iatrogenic complications (e.g., medications, tracheostomy) (Dodrill & Gosa, 2015).

An early sign of dysphagia in babies is the refusal of breast or bottle feeds or excessive drowsiness because they learn to avoid situations that cause pain. In turn, babies may lack energy as a result of inefficient feeding and overexertion, which may manifest as slow weight gain in addition to drowsiness. For those who continue to feed and eat, observable signs of dysphagia include coughing when swallowing, regurgitation of food or fluid out of the nose, and choking on food as it enters the airway (larynx) rather than being directed to the stomach (via the oesophagus) (see Figure 5). Longer-term health implications of dysphagia include recurrent upper respiratory or chest infections and poor weight gain, nutrient deficiency, and dehydration (Dodrill & Gosa, 2015; Panara et al., 2022).

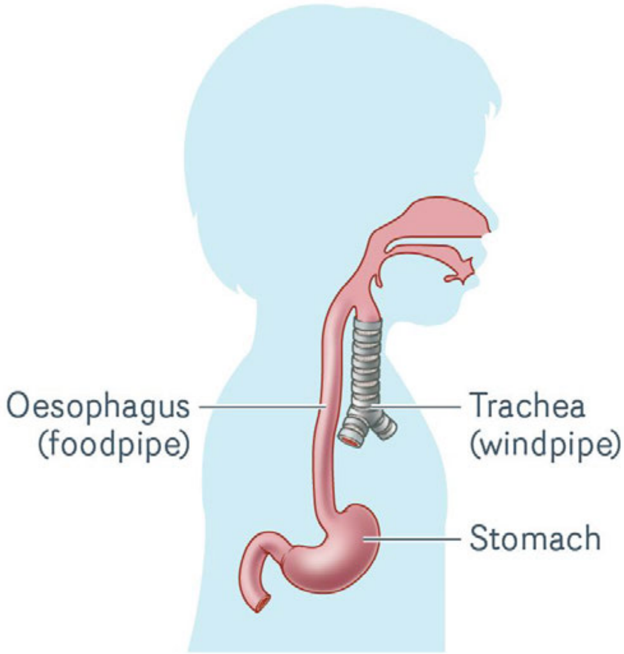

Figure 5: Typical anatomy of the oesophagus (food to the stomach) and trachea (air to/from the lungs) (https://www.rch.org.au/transition/brochures/Oesophageal_atresia_and_Tracheo-oesophageal_Fistula/).

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Beyond these consequences, dysphagia may affect a child's quality of life, with children reporting higher anxiety, lower self-esteem, and psychosocial implications (Hemsley et al., 2019; Smith et al., 2021). In addition, parents have described their fear and anxiety of feeding their dysphagic child, with some experiences of choking or food becoming 'stuck' resulting in traumatic responses (Stewart et al., 2022). This can affect their confidence in parenting and their enjoyment of mealtimes (Stewart et al., 2022). Dysphagia also affects society more broadly, with increased healthcare expenditure across the adult dysphagic population required to provide ongoing therapy and medical review (Attrill, White, Murray, Hammond & Doeltgen, 2018). It stands to reason that these costs also relate to the paediatric dysphagia population.

The myriad of anatomical and neurophysiological factors contributing to swallowing dysfunction means that a range of swallowing-related biomechanics may be impaired; therefore, the characteristics of the presenting dysphagia are usually unique to the individual. Assessment and subsequent management of the presenting swallow and functional feeding capacity are crucial to determine the cause of the swallowing difficulty. Understanding where the breakdown in function occurs can provide direction for therapy to improve the swallowing function. Best practice swallowing assessments in paediatrics should incorporate instrumental assessment and clinical observations to determine the swallowing dysfunction (Dodrill & Gosa, 2015).

There are several ways to assess the structures and function of swallowing in children. Assessments can be carried out by speech pathologists, otorhinolaryngologists (ear, nose, and throat specialists), radiologists, and gastroenterologists. A brief overview of the swallowing assessment is presented below to provide a clinical context to this thesis, but it is not central to this research program.

Instrumental Swallow Assessment

Instrumental assessments include videofluoroscopic swallowing study (VFSS), fibreoptic endoscopic evaluation of swallowing (FEES), and pharyngo-oesophageal manometry. These assessments use equipment to visually observe the oral and pharyngeal swallowing function, which a trained health professional interprets regarding the anatomy and physiology of a child's swallow. The three assessments differ in their view of the swallow (anatomical position and dimension) and thus in the information they provide.

A VFSS uses X-rays to visualise the swallow in real time from the oral cavity and through the pharynx. Pulsed fluoroscopy is used to track the path of barium-infused food or fluid of varying textures and consistencies as it is swallowed by the child (Arvedson, 2008). The food or fluid is referred to as the bolus. This assessment allows for a *two-dimensional* observation of the structures and function of swallowing food or liquid passes through the *oral cavity to the pharynx and the oesophagus posteriorly and vocal cords anteriorly* (Fabricio, Pacheco-Castilho, Pontes-Neto & Dantas, 2020) (see Figure 6). At times, this swallowing assessment is inconclusive due to challenges such as positioning the child appropriately for the length of the study or refusal of the food or fluid by the child (Chih-Hsiu, Tzu-Yu, Jiann-Chyuan, Yeun-Chung & Shiann-Yann, 1997; Weir et al., 2007) (see Figure 7).

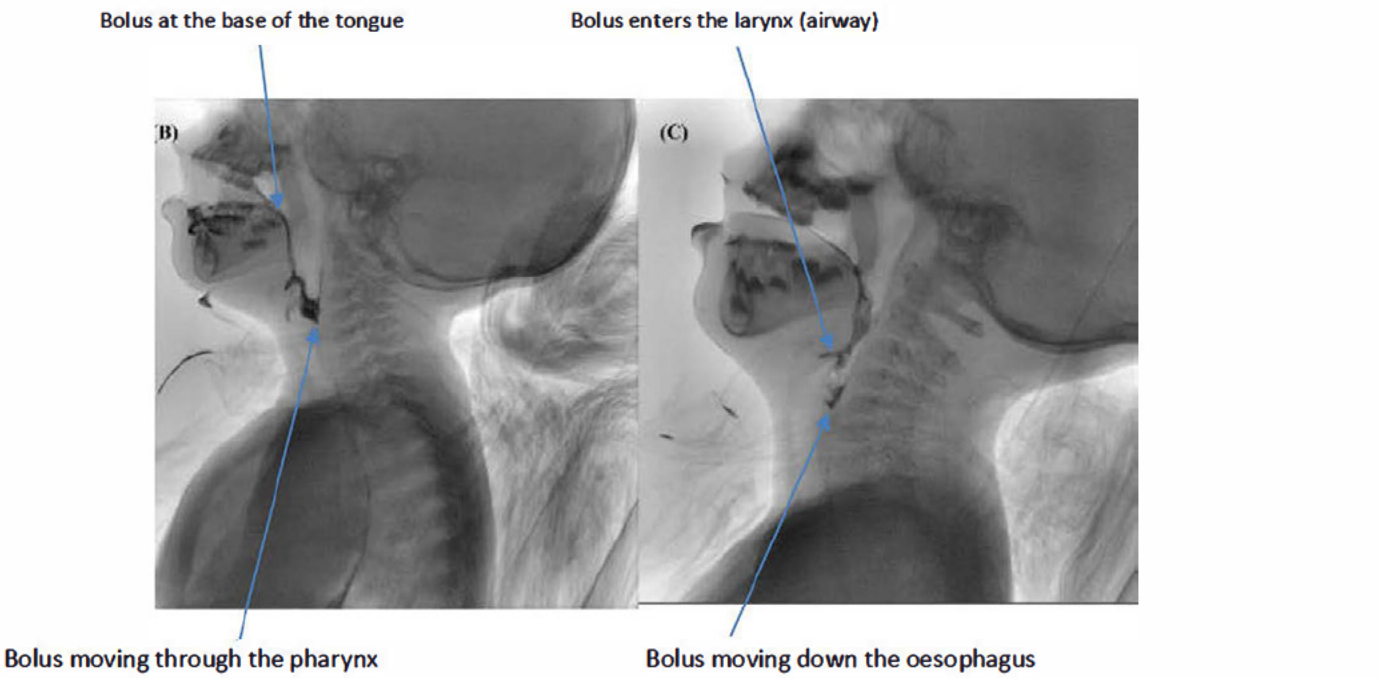


Figure 6: 2D image of the structure and function of the swallow as seen during VFSS (Yoo et al., 2022). Reproduced with permission


Figure 7: Child participating in a VFSS procedure (Batchelor et al., 2019). Reproduced with permission

FEES uses a flexible endoscope passed via the nose to the pharynx and larynx and provides a *three-dimensional* view to detect structural or functional swallowing deficits (Chih-Hsiu et al., 1997) (see Figure 8). FEES does not provide information about the oral and oesophageal phases of the swallow because of the placement of the endoscope. Information can be gained on the function of the *pharynx during or after swallowing but not as the swallow occurs* (Dodrill & Gosa, 2015) because light is reflected into the endoscope from the pharyngeal and laryngeal tissues, causing a moment of 'white out' (ASHA, n.d.-b). FEES can also be used to evaluate sensation within the laryngopharyngeal areas of children with dysphagia. Aspiration may be detected by adding a blue or green dye to liquids and tracking their pathway during swallowing. Evidence of coloured liquid on the subglottic shelf post-swallow suggests aspiration (Marvin, Gustafson & Thibeault, 2016). In the absence of using dye to detect aspiration, the health professional can interpret the findings to provide an aspiration risk score (Ulualp et al., 2013). For FEES to be successful, the child must tolerate a flexible nasal endoscope passing through their nostril before swallowing food or fluid (see Figures 9 and 10), which may be an inhibiting factor for some children with oral aversion, past medical trauma, or sensory-processing challenges.

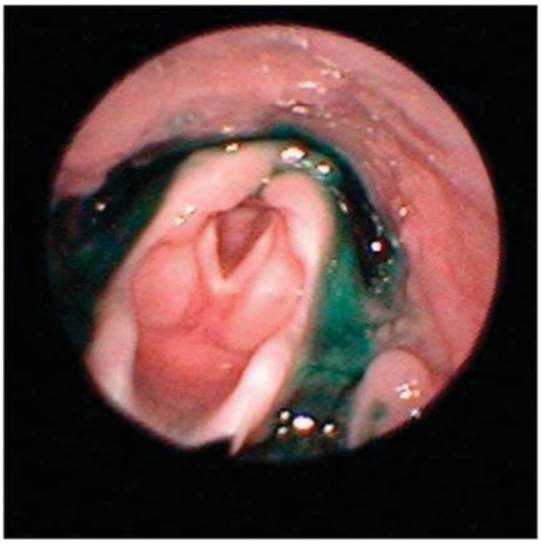


Figure 8: Superior view of pharyns and larynx during FEES; the green liquid is fluid pooling in the valleculae and pyriform sinuses (Miller et al., 2019). Reproduced with permission.

Figure 9: Position of the endoscope during feeding (black lead being held) (ASHA, n.d.-b). Reproduced with permission

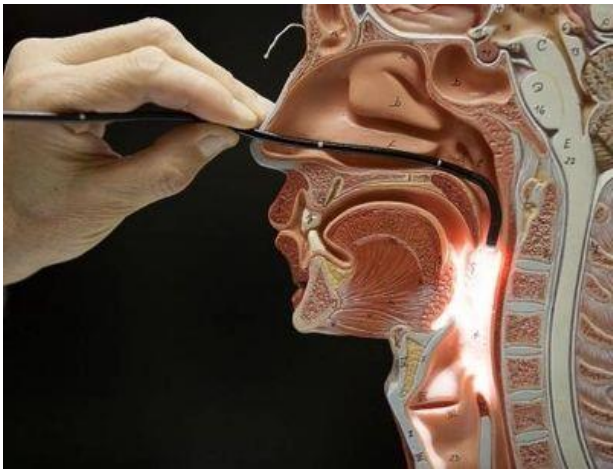


Figure 10: Placement of an endoscope (Sydney Swallowing Diagnostics, n.d.) Reproduced with permission

Oesophageal manometry (OM) can be used in children to assess the mobility of a bolus (food or fluid) or gastric reflux through the *pharynx and oesophagus* (Omari & Krishnan, 2020). A catheter containing pressure sensors is inserted into a nostril and pushed down through the lower oesophageal sphincter connecting the oesophagus with the stomach (see Figure 11). The catheter measures pressure at various points along the oesophagus, and these points are plotted on a pressure topography plot (see Figure 12). An experienced clinician interprets the changes in pressure as swallowing occurs to detect abnormality in the contraction of the pharyngeal or oesophageal musculature, which may be suggestive of structural abnormality or functional neuromuscular motility deficits (Omari & Krishnan, 2020).

Figure 11: Positioning of the catheter for oesophageal manometry (Singapore General Hospital, 2017). Reproduced with permission

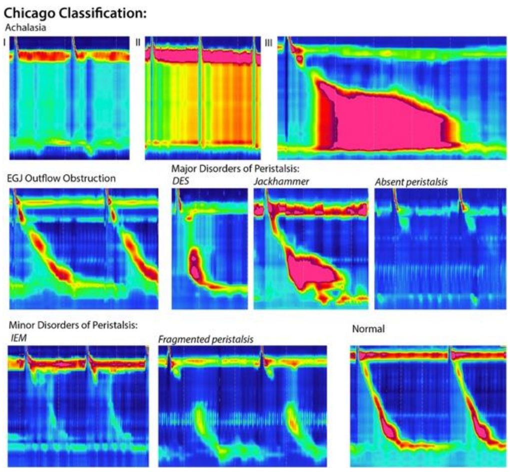


Figure 12: Examples of oesophageal manometry pressure topography plots (Rohof & Bredenoord, 2017). Reproduced with permission

Each of these instrumental assessments provides information on the swallowing mechanism as a dynamic video recording. However, the assessment is based on a child’s swallowing during a one-off occasion, which may not be a natural representation of their normal mealtime circumstances. During these procedures, the child’s functional swallowing may be affected by their physical (e.g., tired, muscle incoordination, refusal) and emotional (e.g., distressed by the procedure) state on the day of the assessment (Martin-Harris & Jones, 2008). In addition, variability of interpretation may occur among health professionals, resulting in differing diagnostic outcomes and intervention plans. An instrumental swallow assessment may not be available, accessible, or practical for some families because of their geographical location, access to a hospital that provides these services, waiting list times, or suitability of the child to undertake the assessment (Fabricio et al., 2020; Weir et al., 2007). As will be discussed in Part 2 of this chapter, medically complex children are likely to require tube feeding. These children have frequently undergone medical procedures, anaesthesia, and radiation exposure; therefore, the clinical reasoning to subject them to another potentially traumatic medical procedure must be sound (ASHA, n.d.-c).

The information gained from an instrumental swallowing assessment (if clinically indicated) should be used in conjunction with an observational swallowing assessment (which is standard practice) to understand a child’s functional swallowing capacity holistically.

Clinical Swallowing Examination

A speech pathologist undertakes clinical swallowing examinations to assess both the structural and functional components of swallowing. A structural assessment of the lips, tongue, and jaw occurs without food or fluids being offered. A functional assessment observes these structures when swallowing food and fluids of different textures (Delaney & Arvedson, 2008). The information from these observations is considered in conjunction with parent reports regarding feeding development milestones and information from instrumental assessments, if available (Dodrill & Gosa, 2015). Clinical feeding assessments do not allow observation of the pharyngeal or oesophageal phases of swallowing (Delaney & Arvedson, 2008). However, in some instances, a speech pathologist may assess swallowing sounds using cervical auscultation to support a differential diagnosis of dysphagia. Cervical auscultation uses a microphone and a stethoscope placed on the throat to detect swallow sounds before, during, and directly after swallowing (Cichero & Murdoch, 2002). It is non-invasive and has high inter- and intra-rater reliability, specificity, and sensitivity for detecting aspiration in children when performed by an experienced speech pathologist with additional training (Frakking, Chang, O’Grady, David & Weir, 2017).

In summary, the assessment of a child's swallowing function should be a dynamic process that incorporates information from parent reports, clinical observations, and instrumental evaluations (Dodrill & Gosa, 2015). If dysphagia is detected or suspected, a range of therapeutic strategies can be implemented and monitored by a speech pathologist.

Strategies to Improve Swallowing Safety and Support Dysphagia Management

Speech pathologists can use many strategies or combinations of strategies to develop a child's swallowing abilities to improve the function and safety of their feeding and eating abilities. It is outside the scope of this thesis to provide an in-depth overview of all of these strategies. However, to illustrate, I have provided some examples of strategies that are used clinically with tube-fed children to compensate for swallowing deficits and those that may be used therapeutically to develop and strengthen oral motor function. These can be generally classified into compensatory and therapeutic (rehabilitative) strategies, as outlined below.

Compensatory Strategies

Compensatory strategies can be implemented immediately to facilitate a functional swallow to the best of the child's physical ability. Once the specific swallowing impairments have been determined, the speech pathologist may trial and implement a range of compensatory strategies to support the identified deficit areas.

Compensatory approaches include consider changing the positioning of the child's head during feeding to a posture that supports the flow of food and fluids towards the oesophagus and away from the lungs. This requires the body to be upright, with the head in a neutral position and the chin tucked slightly under, which positions the tongue closer to the back of the throat, narrowing the airway entrance (Morris & Klein, 2000).

Another option is the pace at which a parent provides food or fluid. Allowing one suck per swallow rather than the typical two or three sucks slows the speed and amount of liquid in the mouth and supports babies to coordinate and finish one swallow cycle before the next is offered. This also improves breath maintenance to a consistent pace rather than gasping to keep up with a faster liquid flow. For an older child, limiting the amount of food on each spoonful and ensuring that one mouthful is swallowed before the next spoon is offered provides the same supportive pacing when offering solids (ASHA, n.d.-a).

In addition, food and fluid modification may be introduced as a compensatory strategy to support children with oral and pharyngeal phase swallowing difficulties (ASHA, n.d.-a; Dodrill & Gosa, 2015). This includes modifying the thickness of fluids, food textures, and the sensory properties of foods. Increasing the thickness of fluids allows for increased oral transit time, affording more time for muscle coordination in the oral and pharyngeal phases of swallowing. Providing puree, finely chopped, or single consistencies reduces the requirement for more complex biting, chewing, and bolus management (i.e., organising multiple pieces of food spreading across the tongue into a bolus) in the absence of oral skill and stamina to achieve this (Arvedson & Brodsky, 2002; Morris & Klein, 2000).

It may be deemed unsafe for some children to have oral intake because of the risk of acute or chronic aspiration and the associated health risks. Remaining nil by mouth may be recommended for children with an unsafe swallow. Many children have undergone lifesaving surgeries, and their priority is recovery. A period of non-oral feeding can allow a child to recover, grow, and develop strength without the additional stress of oral feeding (Arvedson & Brodsky, 2002; Liu, Abudusalamu, Yang & Su, 2022). In such instances, hydration and nutrition are provided via enteral means such as an orogastric tube (OGT), a nasogastric tube (NGT), or percutaneous endoscopic gastrostomy (PEG). These types of tubes are described in more detail in Part 2. Children receiving these interventions are at the centre of this research program.

Therapeutic or (Re)Habilitative Strategies

Implementing therapeutic or (re)habilitative strategies is a longer-term option involving developing oral sensory awareness and motor skills to support oral strength and stamina for eating and drinking. Oral motor therapy includes specific exercises to improve the strength and movement of the jaw, tongue, lips, and cheeks because these structures contribute to successful bolus preparation in the oral phase and safe bolus propulsion during the pharyngeal phase.

For example, a recent study on children with cerebral palsy showed that feeding and swallowing skills improved after receiving weekly oral motor therapy (Widman-Valencia et al., 2021). Statistically significant functional improvements were found in jaw mobility, breath control, and tongue movements, along with a reduction in abnormal reflexes, which improved the children's functional swallowing skills overall. Positive associations following oral motor therapy were also noted across nutrition and respiratory disease, with compromise reduced in both areas (Widman-Valencia et al., 2021).

Food and fluid modifications have been described above as a compensatory strategy; however, in the context of my clinical experience, I also value them as a therapeutic strategy. While amending texture is initially compensatory to suit the child's oral motor capacity, the gradual change in texture will progress the child's oral motor and oral sensory skills. Incremental changes in food texture and fluid thickness extend the child to develop the physical motor skills required to manipulate the new texture. This approach of introducing incremental functional feeding tasks to challenge a person's swallowing function is well documented as part of the McNeill Dysphagia Therapy Program (MDTP). This program is widely used with adults to progressively strengthen and coordinate movement patterns for swallowing (Carnaby-Mann & Crary, 2010).

However, some children reject food and fluids with modified textures because they are visually different from the food they find familiar or the foods they see their family eating. Some children dislike the taste of thickener or the sensory properties of certain textures (e.g., puree). Others learn to avoid foods of more complex textures because of the increased work required to manipulate them (e.g., diced chicken instead of pureed chicken). Therefore, close monitoring of acceptance of different textures and fluid thicknesses is required to ensure the child meets their nutrition and hydration goals (ASHA, n.d.-a).

The above sections detailed the intricacies of the fundamental skills required to develop safe swallowing, eating, and drinking that support early feeding competence. This section provided a brief summary of how swallowing can be assessed when dysfunctional, and it provided a brief overview of strategies to improve swallowing function. This is particularly relevant for tube-fed children with delayed or dysfunctional swallowing development. However, the biomechanics of successful and safe swallowing form only one aspect of being able to eat and drink. In addition, eating and drinking require more than just swallowing foods and fluids. Eating typically occurs within social and cultural environments to nourish emotional and physical requirements (Morris & Klein, 2000). Developing competence to feed and eat within a social setting may be more difficult for a child than it appears because of the influence of sensory inputs and the resultant effect on behaviour, which may affect the child's ability to maintain their attention on the task at hand (i.e., eating and drinking sufficient amounts to sustain health and growth). For this reason, teaching tube-fed children to eat and drink functionally also requires them to learn mealtime behaviours such as sitting at a table with others for increasing periods of time and learning to taste new foods. As with feeding and eating skills, mealtime skills mature with opportunity and practice. The many components that influence and contribute to successful mealtimes and functional eating and drinking are discussed below.

Development of Mealtime Skills

Mealtime skills and behaviours refer to the ability of a child to be an active participant and learner at the table during meals. Like other behaviours, mealtime behaviour is taught and evolves (Redsell, Slater, Rose, Olander & Matvienko-Sikar, 2021). It is shaped by the child's motor, sensory, and emotional skills, as well as intrinsic motivation, in conjunction with the cultural and social expectations surrounding them (Redsell et al., 2021). So how do healthy, typically developing children learn to eat? To provide context to the processes by which children learn how to eat, the following sections outline two approaches that are typically used by families when introducing breast or bottle feeding and later solids. Specifically, they address whether this process is parent-led (with minimal responsiveness to the child's reactions) or child-led (with attentive and responsive parent outcomes).

Feeding and Eating Development Following Parent-Led or Child-Led Principles

Nonresponsive/Traditional Feeding Approaches

Nonresponsive or traditional feeding describes the historically accepted way of feeding a baby on a schedule. This involves babies being fed prescribed amounts of fluid (if bottle fed) at predetermined intervals regardless of the infants' communicative cues (Hawdon, Beauregard, Slattery & Kennedy, 2007). Feeding via this method often incorporates interval timing (3 or 4 hourly) regardless of whether the baby is asleep or awake. It may support a new mother with predictability around when to feed their baby, or nursing staff to coordinate feeding schedules for all babies (Hawdon et al., 2007). However, if babies are not offered the breast or bottle when hungry, maternal milk supply, sleep, growth, appetite awareness, regulation, and non-nutritive bonding opportunities may be affected (Terreri, 2018). A large-scale study of over 10,000 mothers explored the effects of nonresponsive scheduled versus responsive (on-demand) feeding on mothers and children. The study controlled for 13 confounding variables, including maternal education, socioeconomic status, and breastfeeding expectations. It showed that the wellbeing (other than depression) of mothers who fed their babies via scheduled feeding was higher than for those who used responsive (on-demand) feeding practices (Iacovou & Sevilla, 2013). In contrast, greater cognitive and academic outcomes at all ages assessed (up to 14 years) were associated with babies who were fed on-demand (responsive feeding) compared with babies fed on a schedule (Iacovou & Sevilla, 2013). This means that while responsive feeding may affect a mother's wellbeing (e.g., sleep deprivation, exhaustion), their child is more likely to experience improved longer-term academic outcomes.

It has been suggested that babies who are fed to a schedule may perceive feeding as an act done *to* them rather than one in which they are active participants (Iacovou & Sevilla, 2013). This may be a result of nonresponsive strategies that are used to encourage a baby to feed and ingest more fluid. Strategies include moving the bottle in and out of the mouth to encourage increased sucking, wiggling the teat in the mouth, and stroking the infant's upper lip with the teat/nipple to stimulate a sucking reflex (Hawdon et al., 2007).

As children mature and solids are introduced, infant-scheduled feeding may subside; however, parents who use early traditional feeding strategies may replace these with longer-term *nonresponsive* feeding patterns as solids are introduced. *Nonresponsive* feeding is characterised by a lack of reciprocity (mutual care and respect) between the parent and the child. As children become more active in asserting their preferences at mealtimes and in general, parents may use food intentionally for reasons other than nutrition. The need for parents to regain control over the feeding environment is referred to as nonresponsive feeding. Four nonresponsive feeding strategies have been identified: (i) instrumental feeding (using food treats as a reward for other behaviour), (ii) pressurising a child to eat (more), (iii) restricting or controlling the intake of certain foods, and (iv) emotional feeding to calm or entertain a child rather than the child learning to self-regulate their emotions of upset or boredom through means other than food (Appleton et al., 2018;

Baughcum, Burklow, Deeks, Powers & Whitaker, 1998; Wang et al., 2022; Wardle & Carnell, 2007). For example, a child may use food to seek control over one aspect of their life. They may only eat a limited number of foods and may further control the brand or packaging in which the food must be presented before they accept it. Their parent may choose to provide only the favourite food for fear that their child will not otherwise eat, or they may restrict the availability of the preferred food to force them to eat nonpreferred foods, thus causing increased pressure and anxiety in the mealtime environment. In another example, a parent's desperation for their child to eat broccoli may culminate in bribing them with their favourite chocolate or iPad time. The child subsequently only eats one piece of broccoli when guaranteed the reward. Nonresponsive feeding may lead to increased mealtime pressure from the parents, force-feeding or, at the other end of the engagement spectrum, the parent may completely dissociate from their child during mealtimes (Black & Aboud, 2011; Redsell et al., 2021).

Consequently, nonresponsive feeding may affect a child's natural appetite and ability to self-regulate. Their internal signals of hunger and calm may be overridden by those of anxiety and stress (Ventura & Birch, 2008). Physiologically, an increase in emotional or social stress releases adrenaline and noradrenaline hormones. These hormones increase blood pressure and heart rate, while simultaneously decreasing blood flow to the digestive system, kidneys, and skin, and dampening appetite-stimulating hormones as the body prepares for a fight-or-flight response (Batterham et al., 2003). Being in a state of fight or flight (i.e., stress) is likely to contribute to a child not wanting to eat. When teaching a tube-fed child to eat, it is vital to keep the child emotionally regulated so that physiologically they recognise their hunger and can act upon it. If they are not regulated, they may miss significant opportunities for calorie consumption and the development of mealtime skills. These potential losses can be mitigated by parents being responsive to their child's mealtime needs; however, this requires understanding the behaviours that facilitate and hinder responsivity.

In the context of this research program and as described previously, tube-fed children often have a range of medical challenges, and concerns regarding their growth and weight are often at the forefront of many parents' and health professionals' minds (Cipolla et al., 2022; Dunitz-Scheer et al., 2009; Shalem et al., 2016). While this concern may be ongoing from birth, it becomes particularly relevant when considering tube weaning, because weight loss may be expected when transitioning from one form of calorie intake to another (i.e., non-oral to oral feeding) (Dunitz-Scheer & Scheer, 2022). For example, a systematic review of caregivers' concerns regarding their child's weight and nonresponsive feeding practices showed an increased risk of parents pressuring their *underweight* child to eat (Wang et al., 2022) by encouraging them to eat larger quantities or higher-calorie foods for weight gain. However, pressuring children to eat has been associated with increased undesirable emotions and reactions to food (e.g., fear, distress, disgust) and maintenance of low weight, which is counterproductive when tube weaning (Afonso et al., 2016). Instead, allowing feeding and mealtimes to be child-led, but with timely and appropriate parental responses, may be more likely to build the foundation for sustained successful autonomous eating and mealtime behaviours (Black et al., 2022). The principles of child autonomy and self-regulation form the basis of responsive feeding practices and are discussed below.

Responsive Feeding Approach

Responsive feeding provides an alternative to traditional (on-schedule) feeding methods. The principles of responsive feeding are grounded in the caregiver learning to identify, interpret, and respond to an infant's communication about their satiety, emotional regulation, and physical state during feeding. In doing so, the parents' focus changes from administering a prescribed amount of fluid to allowing the infant to decide the pace and volume of the feed (Shaker, 2013). In shifting their focus, parents have reported that their experiences of nurturing their child through a more enjoyable and satisfying feeding environment are enhanced (Kirk, Alder & King, 2007). In turn, the child's self-regulation during feeding, as well as the development of oral motor skills required for eating and drinking, is more likely to progress when allowed to develop at their pace (Black et al., 2022; Kirk et al., 2007).

Morag, Hendel, Karol, Geva & Tzipi (2019) explored the effectiveness of parental-guided responsive feeding on their child's transition from NGT feeding to oral feeding. They reported that infants were more likely to reach full oral feeds earlier when their parents were supported to use responsive feeding strategies than infants whose parents fed via a traditional, nonresponsive feeding approach. Specifically, infants fed via responsive feeding reached their baseline weight gain earlier and safely, showed fewer apnoea/bradycardic events, and were discharged home earlier than infants fed via traditional feeding methods (Morag et al., 2019). This research was carried out in a neonatal unit, and parents were not required to be present for all feed offerings. However, parents in the randomly allocated responsive feeding group were more likely to attend to and feed their infant by themselves, suggesting mutual enjoyment and engagement as their competence and confidence to feed their baby increased. This is in line with a study by Bakermans-Kranenburg and colleagues, who found that consistent, appropriate, prompt, and warm responses to children's cues facilitates a stronger parent–child attachment; which is the foundation for optimal child development (Bakermans-Kranenburg, van IJzendoorn & Juffer, 2003; Bowlby, 1978).

For older children, setting up the mealtime environment to facilitate child autonomy can be achieved by parents taking responsibility for providing structured mealtimes in a calm and predictable environment with various food choices available. Children then have the autonomy and choice to decide which foods and how much they may eat or explore based on their interoceptive cues (the internal state of their body) (Satter, 2007). This forms the basis for the tube-weaning program described in Chapter 7.

Responsive feeding gives the child the autonomy to attune to their internal cues, initiate food interactions, and spontaneously engage with new foods and mealtime experiences and relationships to build their skills and confidence (Black & Aboud, 2011; Rowell, Wong, Cormack & Moreland, 2020). The World Health Organization (WHO, 2018a) recommends responsive feeding in the Nurturing Care for Early Childhood Development framework. While guidelines have been proposed on what responsive feeding should involve (Rowell et al., 2020), globally accepted 'gold standard' measures of responsive feeding practices are yet to be determined (Black et al., 2022). This makes information sharing with parents inconsistent and dependent on individual health services and may contribute to the barriers faced by parents and professionals regarding education and implementation of early responsive feeding practices.

Barriers to Implementing Responsive Feeding

There are many barriers to implementing responsive feeding; some are intrinsic to the parent and some are extrinsic to the parent and child but affect their interaction (Redsell et al., 2021). Intrinsic barriers include (i) the parent's ability to recognise feeding cues, (ii) their knowledge of feeding, nutrition, and appetite, (iii) their attitude towards controlling the feeding process, and (iv) their perception of their child's nutritional needs (Redsell et al., 2021). The recognition of feeding cues may be influenced by the parent's emotional state, as evidenced, for example, by increased food refusal behaviour in infants at four months of age whose mothers were at risk of depressive or psychosocial conditions (Tambelli & Odorisio, 2014).

Extrinsic barriers to responsive feeding may encompass social influences on mealtimes, such as not eating family meals together or parents being distracted by digital media during feeding or mealtimes. In addition, educational barriers pose a risk because of the lack of information and support available for parents to establish responsive feeding patterns from birth, or the influence of marketing, such as the formula tin indicating the volume and frequency at which a baby should feed (Redsell et al., 2021).

Responsive feeding is a delicate balance between the parent learning and respecting their child's responses and the child building knowledge and trust in the mealtime process as they learn to understand and follow their internal cues for eating. Responsive feeding affords autonomy for the child to spontaneously explore, experiment, enjoy, and be in control of how much they choose to eat at mealtimes. This relies on trust in the child that they will respond appropriately to their internal hunger and thirst cues in time and with consistency. This may be challenging for new parents who are learning to feed their baby within an acute hospital environment under the direction of nurses and doctors. In this setting, not only are the volume and timing of feeds often dictated by the medical team, but parents may have limited opportunities to connect with their unwell baby (Serlachius et al., 2018).

Some parents may feel that allowing their child the choice and control of what and how much to eat is beyond their parenting capability (Bramhagen, Axelsson & Hallstrom, 2006). Often, parents of tube-fed children experience trauma, anxiety, or high levels of stress (Rogers, Kidokoro, Wallendorf & Inder, 2013), particularly regarding their child's growth and nutrition (Lively et al., 2022). These parental factors have implications for their ability to participate in responsive feeding.

Despite these potential challenges, a responsive feeding framework has been proposed by a group of professionals who base their practice in responsive feeding principles (Responsive Feeding Pro) and incorporate key findings from multiple bodies of research undertaken across many areas of child development (Rowell et al., 2020). These include the development of parent–child relationships and responsive parenting (attachment theory), and theories of development, psychology, neurobiology, and trauma physiology (Rowell et al., 2020), which are discussed in subsequent chapters.

The outcomes from the first two research projects presented in this thesis (see Chapters 2 and 5) suggest that tube weaning is likely dependent on more than biological characteristics. In addition, exploring different theories for learning and the role of the environment in skill acquisition led to further investigation of the parents' role during tube weaning because it is important to understand the variables that may influence parental capacity to facilitate tube weaning. One such skill is the parents' ability to be responsive to their child's emotions when their child cannot do so themselves. This becomes relevant when, for example, a tube-fed child becomes distressed at the table or when they are held in a position that may suggest breast- or bottle feeding is soon to be offered and it triggers panic in the baby. Children are likely to be unable to accept food or feed if they remain upset and, at this point, their parents may be required to respond appropriately to their emotional needs. As highlighted in the above section, parents may be nonresponsive mealtime partners and lead feeding and mealtimes by indicating how much and what their child will eat and drink. In addition, coercion may be used to encourage a greater volume of food or influence behaviour unrelated to feeding. Current health systems at times support nonresponsive, volume- and weight-orientated approaches, particularly for children with faltering growth. This may be conflicting for parents who want to feed responsively; however, parents may be encouraged to use nonresponsive practices.

In contrast, the suggested partnership for the longer-term development of healthy and functional mealtime skills is one of responsivity whereby parents are appropriately attentive to their child's communication cues at mealtimes and allow them the opportunity for autonomy and self-regulation. However, self-regulation develops as children master control of their emotional state—a process known as self- or emotional regulation. This process, which is outlined in the next section, commences with parents being responsive to their child's needs and physically assisting them during times of distress or anger before supporting the child to manage these feelings independently.

Emotional Regulation

Being able to recognise and act upon one's emotions is foundational to being able to interpret and respond to surrounding events. The ability to mould and adapt emotional responses (e.g., anger, fear, excitement, stress) by decreasing or increasing one's reaction to events allows the maintenance of a more consistent emotional state without extreme highs or lows. Emotional regulation forms a core foundational skill for many developmental tasks, including learning to eat and drink. If a child is unable to stay calm, interested, and engaged in an activity, it is likely to be more challenging for them to practice and master the competencies required. During tube weaning, the child must learn a new way of reaching satiation, which requires self-directed imitation and practicing observed mealtime behaviours. Parents must also practice emotional regulation, particularly when they may be frustrated or concerned about their child's feeding or mealtime behaviours. Therefore, it is essential to understand how children and parents become, and then remain, emotionally regulated when situations become challenging.

Intrinsic emotional regulation is the idea that a person can recognise and change their emotions—up and down—during or after a situation, independently of others (McRae & Gross, 2020). For example, a tube-fed child who displays functional intrinsic emotional regulation may be slightly upset at the unfamiliarity of a mealtime situation, but upon recognising that everyone else is calm, relaxed, and enjoying the experience, they may stop crying and cautiously engage in exploring the presented foods. In contrast, a child displaying poor internal emotional regulation may become distressed when sitting at the dinner table with a selection of foods that are foreign to them and none of their favourite toys, which they are used to having. To indicate their upset, they may scream until they are red in the face, with all attempts at soothing them only escalating the screaming further. The only way for them to calm down is to wait for an adult to remove them from the high chair and provide their favourite soother (e.g., dummy, toy, iPad, cuddle).

The process of self-regulation begins in childhood initially via co-regulation, because an infant's ability to restore their emotional balance is still limited and heavily dependent on their caregivers (Sroufe, 1997). Co-regulation—extrinsic regulation—involves supporting someone else to regulate their emotional state through acknowledgement, matching their state, and then using affect to repair connections (Tronick, 1989). For example, during mealtimes, a parent may use a narrative of their child's favourite topic to regain their attention. By using a calm and slow voice, the emotional state reflected by the parent can support the child to calm down without having to remove them from the table and give them their favourite toy or digital device. This process provides the scaffolding necessary for the child to master more sophisticated self-regulating strategies (Crugnola et al., 2013). Therefore, parents must be responsive to their child's cues for support to regulate their emotions. This may be as simple as a parent using their tone of voice or predictable, repetitive actions (e.g., singing a calming song) to help their child manage their emotions within the mealtime environment so they are more successful in developing their feeding skills.

As has been expanded upon in Chapter 2 (p. 85), tube-fed children frequently have underdeveloped sensory systems as a result of immature neurological systems and the sensory-stimulating neonatal intensive care unit (NICU) environment that many of them have spent time in (Mitchell, Moore, Roberts, Hachtel & Brown, 2015). The additional challenges experienced by tube-fed children make it vital to support parents in developing effective co-regulation strategies. In line with this, interventions targeting handling, caregiving, and parents' confidence in understanding their child's needs and cues have resulted in higher-quality care by parents in the NICU and are correlated with positive outcomes for caregiver–child bonding (Lean, Rogers, Paul & Gerstein, 2018).

Responsive feeding relies on a parent's capacity to regulate their emotional and physical state before being able to support their child's requirements. Establishing responsive patterns from birth may contribute to the ongoing development of functional mealtime skills, as discussed below.

Later Development of Eating and Drinking

As described above, the foundations for eating and drinking more textured foods and fluids begin with early feeding experiences. Whether these early experiences are responsive or nonresponsive experiences can guide the way for later mealtime behaviours. Parents reported that the later challenges they faced as a result of early feeding were characterised by nonresponsive feeding practices. These challenges included their child's food refusal and obstructive mealtime behaviours (e.g., eating with distraction, snacking frequently), which resulted in the need to withdraw previously used techniques and introduce responsive and structured mealtimes (Redsell et al., 2021). Most children best learn to eat through immersion in the social mealtime environment, which allows them to observe, imitate, and self-initiate eating behaviours such as reaching for a cup or picking up a spoon and bringing it to the mouth (Morris & Klein, 2000). This process begins between four and six months of age and incorporates physiological and psychological components.

Physiologically, as per early infant feeding, children register hunger and communicate this to their parents for their response (e.g., crying or 'hangry'), reaching towards food or requesting something to eat. Children develop core motor skills that enable them to hold their head up and sit upright, with various levels of supported seating (e.g., bouncer chair, high chair). Babies explore new foods with their hands to satisfy their sensory needs and the need to be comfortable with food before bringing it to their mouth. Upon doing so, they finesse their hand–mouth coordination. Once the food is in their mouth, babies experiment with the oral sensory feedback of food (e.g., flavour, temperature, texture) and the oral motor skills required for different sensory experiences (e.g., biting, chewing, munching) (Delaney & Arvedson, 2008; Morris & Klein, 2000). Oral sensory development commences in utero; as the intraoral space expands around six months of age due to the development of the lower jaw, so too does the area for sensory contact and tongue movements. Increased intraoral area and sensory receptors in the mouth coincide with the development of a more advanced chewing pattern and tolerance of more textured foods (Morris & Klein, 2000). Babies who are fearful of mouthing objects or food at this age miss out on critical neural connections in addition to opportunities for learning about flavours and tastes. Many tube-fed children may still be undergoing operations at this critical age for oral sensory development, often resulting in hypersensitive responses to oral stimuli. This can make introducing food and fluid flavours and textures even more challenging for them.

Psychologically, children must master their emotional regulation within the mealtime setting (as discussed above). When regulated, they actively engage in consuming food and fluids and indicate when they are satisfied. Through observation and engagement in the mealtime setting, they may initiate and imitate patterns of behaviour observed in others (e.g., licking a biscuit or dipping their finger in sauce) (Delaney & Arvedson, 2008; Morris & Klein, 2000). Children strive for independence despite not yet mastering the physical skills required for self-feeding.

In addition to the child's intrinsic physiological and psychological influencers, culture, family expectations, beliefs, and parents' responsiveness affect mealtime experiences. Moreover, as has been reported extensively in the literature, the natural flow and ability to come together as a family for meals are also affected by children's medical and developmental needs (e.g., Brotherton et al., 2007; Page et al., 2020; Pahsini et al., 2016; Smith et al., 2021). Multiple biological, physiological, and psychosocial variables may influence a child's ability to swallow safely and be engaged in a mealtime setting. In addition, psychological and psychosocial factors may affect parents' capacity to provide the responsive environment required for developing successful mealtime skills. These aspects will be explored in the next section.

Factors Influencing the Development of Safe Swallowing and Successful Mealtimes

This section will consider what happens when things go wrong. What is the outcome when the swallowing mechanism or sequence breaks down, or when mealtimes become an environment of unpleasantness or dread for both the child and the family? It is important to understand the variables that cause mealtime challenges because identifying these factors will contribute to establishing therapeutic goals to improve mealtime behaviour and oral eating and drinking skills.

Variables Affecting Successful Mealtimes in Younger Children

Often, a combination of factors rather than one single factor culminates in a child's ongoing refusal of oral offerings or insufficient calorie intake, resulting in the necessity for tube feeding. In the first year of life, many experiences may alter the typical development of swallowing and mealtime skills previously described. It is critical to discuss these experiences in the context of tube weaning because the cumulative effect of more than one may compound mistrust and displeasure in the feeding and eating process.

Many fragile babies require intensive medical care, and parents are not present 24 hours a day to provide feeds. Nursing staff change frequently, and they have different strategies for oral and enteral feeding. Repeated attempts to feed by many nurses in the hospital setting may be confusing for babies with differing amounts of effort, force, pace, and technique provided by each nurse (Morag et al., 2019). In addition, each nurse's patience and time availability may affect their decision to persist with oral experiences (for the babies for whom this is safe) or only provide enteral feeds. As a result, some babies remain partially tube fed and gradually transition to full oral feeds or complete tube dependency (Morag et al., 2019).

Traditional, nonresponsive feeding is still commonplace in NICU settings, resulting in volume-dictated feeds often being given in a prescribed timeframe and a 'medicalised' manner (Hawdon, Beauregard, Slattery & Kennedy, 2007; Morag et al., 2019). Strict volume and time routines can suppress a child's internal appetite drive, thus inhibiting their natural appetite and satiety regulation (Shaker, 2013). This makes it more difficult when these babies learn to eat because they must first learn to attune to their appetite signals.

Subtle signals of satiation that the baby gives, such as head turning, eye closing, wriggling, gagging, and hiccupping, may pass unrecognised by caregivers (Shaker, 2013). Even overt signals, such as vomiting and crying, might be overruled as caregivers and parents diligently follow prescribed medical advice to ensure sufficient growth. With the baby's communicative attempts to express satiety passing unnoticed, they learn that even when they feel 'full', they continue to be fed, thus overruling their intrinsic appetite regulation. As a result of overfeeding, when offered an oral feed, parents have reported that their babies do not feel hungry and are therefore less motivated to accept food offerings (Pahsini et al., 2016).

Overfeeding often results in frequent vomiting during or after feeding. Vomiting has been associated with unpleasant experiences such as acid burn to the throat, aspiration of stomach contents, and a general feeling of being unwell (Dent et al., 1999; Krom, de Winter & Kindermann, 2017). Many tube-fed babies are diagnosed with reflux and commence medication to manage this, which may reduce the acidity of reflux contents but often does not stop the vomiting (Dent et al., 1999). In combination with nonresponsive feeding to a specific volume often resulting in overfeeding, it may be hypothesised that ongoing vomiting is likely attributable, at least in part, to the feeding tube holding open the lower oesophageal sphincter. The lower oesophageal sphincter has two components—a ligament and a muscle—that form a tight seal at the top of the stomach to stop aspirate and stomach acid from re-entering the oesophagus (Rosen & Winters, 2022). In many medically complex children, generalised hypotonia (i.e., low muscle tone) contributes to decreased strength of this smooth muscle. Gastroesophageal reflux disorder (GERD) is also highly prevalent in babies requiring NICU intervention. A study in the United States examined data from nearly 19,000 babies admitted to the NICU. The data showed that 1 in every 10 babies was diagnosed with GERD (Jadcherla et al., 2013). GERD results from an incompetent lower oesophageal sphincter and may be associated with hypotonia and feeding tube location. Anecdotally, I have observed that vomiting resolves once NGT feeding volumes are noticeably reduced or NGTs are removed. As such, I consider vomiting one of the first complications of tube feeding requiring immediate resolution to support the longer-term plan of tube weaning.

An aspect of OGT/NGT feeding that cannot be resolved easily is the regular tube changes required to ensure sterility or when the tube is dislodged. Reinsertion of an OGT/NGT involves a child being held down while a tube is inserted into their nose and throat. This task is generally undertaken by nurses; however, parents can also be trained to reinsert OGT/NG tubes. The adverse experience of tube placement may result in oral hypersensitivity, which has implications for the development of oral eating and drinking skills in later months and years (Arvedson & Brodsky, 2002; Dodrill et al., 2004; Wolf & Glass, 1992). In addition to oral hypersensitivity, a child may become suspicious of any adult who comes towards them both during mealtimes and at other times. If a parent reinserts a displaced OGT/NGT, the child may lose trust in the parent's ability to protect them from invasive procedures, which has ongoing consequences for trusting their parent during mealtime experiences.

In addition to tube changes, medically fragile babies are often subjected to frequent handling during many procedures involving needles and bright lights. These experiences have associated sensory inputs that are not experienced in utero and are not typical of a healthy newborn baby's environment (Grunau, Holsti & Peters, 2006). These sensory-overloading experiences can impair the baby's physiological responses during critical brain development, resulting in hyper- or hyposensitive responses that may affect later developmental processes (Mitchell et al., 2015). In particular, oral hypersensitivity and aversion may be exacerbated by ongoing medical trauma relating to reinserting an OGT/NGT and other medically invasive procedures. Oral aversion may influence the pace at which a child progresses with oral intake and therefore the time it takes them to transition from tube to oral eating.

Oral aversion is defined as the '*reluctance or refusal of a child to be breastfed or eat, manifested as gagging, vomiting, turning head away from food, or avoidance of sensation in or around the mouth (i.e., toothbrushing or face-washing)*' (National Library of Medicine, 2022). In response, the child may limit the amount of oral exploration they engage in to protect themselves from any potential discomfort or pain (i.e., mouthing fingers or toys), or remain wary of adults bringing objects near their face and mouth, thus further limiting opportunities for these sensory-processing skills to develop (Dodrill et al., 2004). These memories may remain with the baby for months or years and can be an ongoing barrier to developing their oral skills.

Once oral feeding is introduced, signs of aspiration may become apparent. As described above, aspiration results when liquid or solid food enters the lungs rather than the stomach during swallowing. It may also result from the reflux of stomach contents upwards through the oesophagus and into the lungs (WebMD, 2022a). As the feeding tube relaxes the usually tight upper oesophageal sphincter muscle, the pathway for reflux has less resistance in a child who is being NGT- or OGT-fed (Mahoney, Liu & Rosen, 2019). Aspiration may be overt or silent. Children with overt aspiration give audible and visual signals that food or fluid has 'gone the wrong way'. They may cough, display a change in the sound of their breathing or vocalisations, or develop watery eyes (Dodrill & Gosa, 2015). Children who silently aspirate do not cough to clear the foreign liquid or food that has entered the lungs; therefore, it is more difficult for an external observer without specialist knowledge to detect aspiration. Aspirating can be painful, and ongoing aspiration may contribute to infection and illness, both of which further affect a child's feeding abilities (WebMD, 2022a). Children may protect themselves from the discomfort or pain of aspiration by refusing the activity that causes it, such as refusing the bottle, breast, or food.

Another less visible reason for feed or food refusal is gastrointestinal conditions. Many babies who are born prematurely have immature gastrointestinal (GI) systems, which are prone to intestinal disease (e.g., necrotising enterocolitis), infection, and food intolerances (Jadcherla et al., 2010). Given the delicate nature of their GI tract, they may not tolerate commercial formulas, formulas with increased calorie concentration (to increase calorie intake), or breast or formula milk with specific ingredients (e.g., soy, dairy) (Abraham & Rejiya, 2016; Mason, Harris & Blissett, 2005). A process of trial and error of expressed breast milk (if available) or commercial formulas can help determine which option is tolerated best by the baby. However, this often takes time to implement and contributes to the baby's ongoing adverse association with oral feeding and, for some, increasing oral refusal.

The effect on the typical timeline for swallowing development remains unclear for children who are born prematurely (Jadcherla, Wang, Vijayapal & Leuthner, 2010). Swallowing and subsequent mealtime development can be further compromised by a range of environmental (e.g., traditional feeding with multiple carers), gastrointestinal (e.g., allergy, vomiting), and respiratory (e.g., aspiration) compromises in addition to repeat medical trauma (e.g., oral aversion, poor appetite regulation). The factors that have influenced a child's feeding from birth may be more obvious than those for older children, who may have eaten orally but now require a tube to supplement oral intake or provide complete nutrition. To this end, the reasons that older children may require tube feeding are explored below.

Variables Affecting Successful Mealtimes in Older Children

Older children who have previously been oral eaters and drinkers may gradually reduce oral intake to amounts that are not nutritionally sustainable. At this point, tube feeding is required to augment any remaining oral intake or to provide complete nutrition and hydration if oral intake is refused or significantly restricted.

In addition to the reasons identified for younger children, food refusal in older children may be attributed to trauma for various reasons (National Child Traumatic Stress Network [NCTSN], n.d.). Examples include a significant change in the child's environment (e.g., loss of a parent, family separation, parent mental health) or ongoing trauma from an experience of choking or an invasive procedure often related to the gastrointestinal tract (Reilly, Brown, Gray, Kaye & Menzel, 2019). In addition to pain association, trauma decreases serotonin production, which contributes to mood, appetite and sleep regulation, behaviour, and motor skills (De Bellis & Zisk, 2014). As described above, responsive feeding contributes to successful mealtimes by developing and maintaining emotional regulation. Circadian rhythms, attention, and behaviour also contribute to successful mealtimes; however, environmental trauma often affects these skills and regulation. Children frequently rely upon co-regulation from a trusted adult in situations of death, family conflict, or a parent's declining health; however, if that is not available, extended periods of dysregulation can affect appetite, among other areas (De Bellis & Zisk, 2014). When transitioning these children from tube feeding back to oral eating, the underlying trauma may maintain tube feeding unless it is addressed. It is important to remain cognisant that trauma may affect both the child and the parents; therefore, the situation is complicated by the child requiring support, which may not be readily provided by the parent/s because of their own mental health needs.

The developing sensory-processing system may also be influenced by how memories of traumatic events are programmed (Robinson & Brown, 2016), and therefore how these play out in other situations. Our sensory systems mature with time to be able to process a range of sensory inputs relating to noise (auditory), sight (visual), smell (olfactory), touch (tactile), and taste (gustatory), as well as movement (vestibular) and internal feelings such as hunger and pain (interoception) (Malhi, Saini, Bharti, Attri & Sankhyan, 2021). Sensory processing is explained in detail in Chapter 2; however, in brief, children's sensory systems may become attuned to specific stimuli as they develop. Environmental sensory stimuli may pass undetected by one person but be heightened in another as a result of the associated memories between the stimuli and, for example, a traumatic event. In the context of tube feeding and weaning, these memories can affect a child's acceptance of previously eaten foods, with subsequent limitation of their oral intake to a small and select number of foods, often with predictable properties (Malhi et al., 2021). Consider McDonald's chips—their taste is consistent as a result of purchasing and cooking protocols. However, home-cooked chips will vary depending on the brand, the cooking method, and who has cooked them. Opting for the trustworthy McDonald's chip, whose consistent sensory properties will more likely help the child maintain their emotional regulation, is likely to be perceived by the child as the 'safe' option. Some children employ this 'food by food' safety strategy, which may lead to a diagnosis of a feeding disorder with differing intervention pathways pending clinical assessment. Understanding the inherent cause of food restriction or refusal is important for goal setting to reintroduce 'lost' foods (i.e., previously accepted) and re-establish trust and confidence with oral eating and drinking. Until this occurs, one such intervention may be to insert an enteral feeding tube to provide vital calories and hydration if oral intake remains clinically compromised.

Summary

Being able to 'take a bite' is not as easy as once thought. The previous sections highlighted some reasons why a child may have challenges with swallowing, or why their mealtime behaviours and skills are affected and non-functional. These include biological, physiological, psychological, and psychosocial variables. Often, the interplay between multiple factors influences the outcomes. This illustrates that each child–family unit brings a unique presentation and set of challenges that are grounded in their specific familial contexts. Despite knowing that feeding and eating challenges are complex, differential diagnosis has traditionally focused on the child's deficits and difficulties (e.g., Diagnostic and Statistical Manual of Mental Disorders IV diagnosis of feeding disorder, infantile anorexia). However, more recently, diagnoses of feeding disorders have begun to encapsulate the numerous variables that may influence a child's ability to feed and eat successfully. The next section provides an overview of the current diagnoses that may apply to persisting swallowing and feeding difficulties. These should be interpreted in the context of whether the presenting deficits are intrinsic to the child, whether they are better explained by the extrinsic and environmental factors maintaining them (e.g., mental health capacity of the parents), or whether they co-occur.

Avoidant Restrictive Food Intake Disorder

In 2013, the American Psychiatric Association updated the diagnosis of *feeding disorder* to *avoidant restrictive food intake disorder* (ARFID) to more closely reflect the multifaceted nature of feeding disorders from infancy through adulthood (DSM V, 2013). The challenges reflected in ARFID include a disinterest in eating or food, food avoidance based on sensory characteristics, and a child's concern about the potentially aversive consequences of eating (e.g., nausea, diarrhoea). In addition, concerns with weight, nutrition, enteral tube dependency, and psychosocial abilities are considered. However, this diagnosis does not apply to children with medical conditions or mental health disorders. This may be seen as conflicting given that the diagnosis incorporates tube dependency and those with psychosocial challenges. While it may be relevant for older children who cease oral intake for reasons explained above, ARFID has limited functionality for other cohorts, such as medically compromised babies who never established oral feeding from birth. As such, an additional definition—paediatric feeding disorder—that reflects the interplay between the possible aetiologies of feeding disorders may be relevant.

Paediatric Feeding Disorder

Goday et al. (2019) proposed a more inclusive diagnosis for disorders of paediatric feeding, which, unlike ARFID, recognises that successful feeding requires engagement from six biological and physiological body systems (nervous, musculoskeletal, cardiopulmonary, gastrointestinal, and oropharyngeal systems plus craniofacial). The authors defined *paediatric feeding disorder* (PFD) as '*restricted oral intake that is not age appropriate and leads to dysfunction in at least one of the four closely related, complementary domains*'—namely medical, nutritional, feeding skills (oral sensory, oral and/or pharyngeal motor, developmental delay), and psychosocial factors (Goday et al., 2019, pg. 128). A deficit in one of these areas can have a flow-on effect on challenges in other domains. This definition has now become more accepted, as evidenced by its inclusion in the International Classification of Disease (ICD-10, 2021) from October 2021 (Feeding Matters, n.d.). It is clinically relevant for children from birth to 17 years of age who experience both acute and chronic feeding disorders. Hopwood et al. (2021) recognised the value of the definition of this term for research and education and expanded the definition to include those who are tube-fed.

Paediatric Feeding Disorder—Tube (PFD-T)

Hopwood et al. (2021) proposed that identifying tube-dependent children as a subset of PFD rather than a discreet diagnostic entity will enable improved research and understanding of their unique challenges. The authors proposed a definition of paediatric feeding disorder—tube (PFD-T) as '*children with PFD who require tube-feeding for more than two weeks*' (Hopwood et al., 2021, pg. 183). This allows a distinction between those requiring short-term acute enteral feeding (e.g., for a hospital admission) and those requiring tube feeding as part of their treatment. They identified that the clinical presentation of these children varies from those with a PFD who are not tube fed. These characteristics include the influence of their specific healthcare experiences and needs, and the feeding experience from tube initiation, thriving with tube feeding, weaning, or transitioning to longer-term tube feeding (Hopwood et al., 2021). Therefore, it is valuable to identify this subgroup to guide their intervention and contribute to a deeper understanding of the feeding disorders prevalent in tube-fed children. In the event of successful tube weaning, these children may still experience the challenges of PFD. However, these challenges are no longer exacerbated by the additional challenges arising from PDF-T. These challenges are reported in Effects of Enteral Tube Dependency (page 64).

Summary—Part 1

To summarise, Part 1 has illustrated the multiple factors contributing to the development of the critical skills that underpin safe swallowing, successful mealtimes, and how mealtime development may become disrupted. These biological, physiological, psychological, and psychosocial components may affect the structures and functions required for successful eating and drinking. Assessments to determine the cause of swallowing and feeding disorders may incorporate instrumental and observational assessments in conjunction with family reports. Differential diagnoses should consider the influence of characteristics of both the child and the family, because each influences the other. The outcomes of swallowing and mealtime assessment contribute to therapeutic goal setting to support the growth and development of children who cannot sustain their growth and nutrition on oral intake alone. Internationally accepted diagnostic criteria that have recently been agreed upon will enable better recognition of the challenges that tube-fed children may experience, and will contribute to targeted therapeutic support.

Part 2 will outline contemporary strategies to support children to remain hydrated, nourished, and developing in circumstances when functional swallowing or mealtimes break down.

Part 2: Feeding Tubes—An Alternative to Oral Eating and Drinking

Enteral Tube Feeding

Part 1 explored the critical skills required for successful swallowing and mealtimes and the possible outcomes should these break down. In instances when feeding and eating become dysfunctional and health concerns are raised, nutrition may be introduced via tube feeding. Feeding via a tube is referred to as *enteral feeding*, where enteral means '*involving or passing through the intestine*' (Oxford Dictionary, n.d.). In this thesis, the terms *enteral feeding* and *feeding tube* are used interchangeably.

An enteral feeding tube provides an alternative to oral eating and drinking by offering a pathway—in the form of a flexible tube—directly to the stomach or intestinal tract (see Figure 13). Within the paediatric population, seven different types of feeding tubes are available for placement directly into the gastrointestinal tract to provide the medication, nutrition, and hydration a child may require (Best, 2019). As described below, feeding tubes may terminate in the gastric (stomach) or intestinal system.

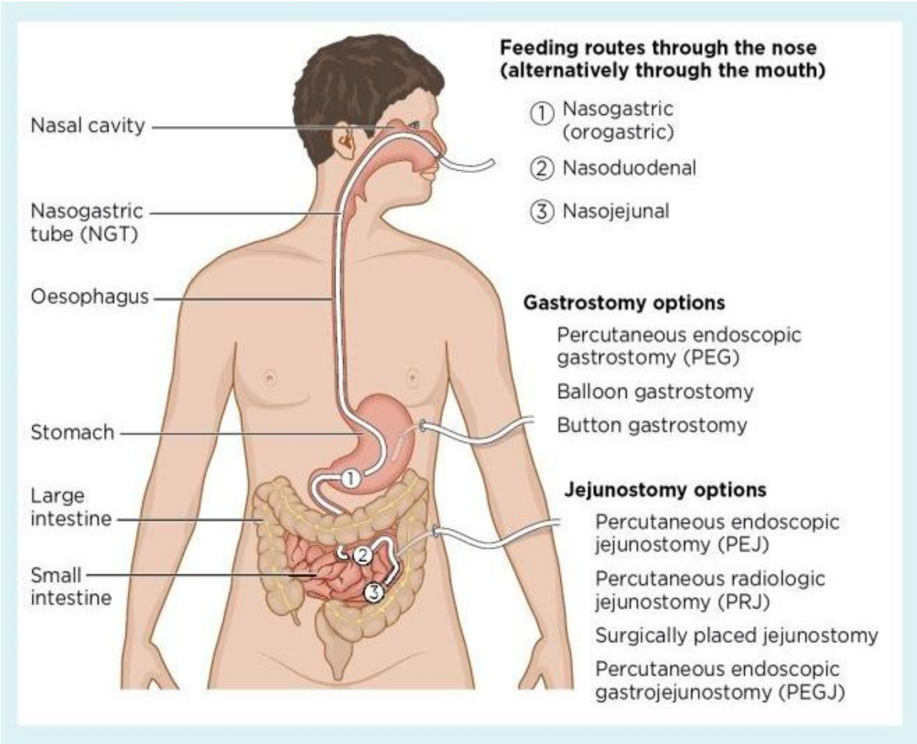


Figure 13: Examples of enteral feeding tube routes (Lamb as cited in Best, 2019). Reproduced with permission

Enteral Feeding Terminating in the Gastric System

1. Orogastric tube

OGTs are thin, flexible tubes placed (while the patient is awake) by a trained nurse, parent, or doctor. They are placed via the mouth and pharynx into the oesophagus before terminating in the stomach. OGTs are referred to by their outer diameter and may be from 8 to 16 French (Fr) (Best, 2019). They are secured to the face with tape, and placement must be checked before each use in case of dislodgement. OGTs are mainly used as a short-term feeding option (4–6 weeks) for providing fluids, medications, and commercial formulas in neonates (Lord, 2018; National Institute for Health and Care Excellence, 2006). OGTs are used with caution in infants and older children because they may easily be bitten or dislodged by the tongue (Best, 2019). When and where possible, OGTs are replaced by NGTs.

2. Nasogastric tube

NGTs are sited via the nasal cavity and pharynx to the oesophagus and into the stomach by a trained nurse, doctor, or parent. Like an OGT, an NGT is a thin and flexible tube placed when the child is awake, and it is secured to the face with tape. The placement of an NGT must be checked using stomach aspirate and pH paper before feeding, because it may be misdirected or become dislodged and result in the formula, fluid, or medication being directed to the lungs rather than the stomach (Lord, 2018). As with OGTs, NGTs are referred to by their outer diameter, varying from 3.5 to 12 Fr. Any tube larger than a 12 Fr (up to 18 Fr) may cause additional discomfort (Best, 2019). NGTs are recommended for short-term use (4–6 weeks) in adults (Lord, 2018; National Institute for Health and Care Excellence, 2006). Clear guidelines around the duration of use in children are lacking, and the length of use before transitioning to another form of tube feeding varies between feeding tube management teams (Pearce & Duncan, 2002). A PEG may be considered if nasogastric feeding is not tolerated and longer-term tube feeding is indicated.

3. Percutaneous endoscopy gastrostomy

PEG tubes are surgically inserted from the outer stomach wall directly into the stomach under endoscopic guidance. They provide long-term enteral feeding options for children and only require replacement every 2–3 years (Best, 2019). PEG tubes are larger than OGTs and NGTs and vary from 12 to 30 Fr in diameter (Lord, 2018). For this reason, PEG tubes may be used to administer medications, fluids, formula, and blended food diets. As per Figures 14 and 15, PEG tubes may be long tubes with incremental markings to indicate placement from the stomach wall. The length of the tube poses a concern to many parents because children may play with it, or it may become caught and dislodged, requiring immediate presentation at the hospital to have it reinserted. A low-profile button tube that sits flush against the abdominal wall provides an alternative to the longer PEG tube (Lord, 2018).

Figure 14: Example of a PEG tube (Lord, 2018). Reproduced with permission

Figure 15: Low-profile button PEG tube (Lord, 2018). Reproduced with permission

4. Radiologically inserted gastrostomy

A radiologically inserted gastrostomy (RIG) is placed by a surgeon under X-ray guidance when a PEG is not possible, such as in the case of a child with a compromised airway, a failed attempt at PEG placement, or the presence of a physical anomaly impacting endoscopy (e.g., pharyngeal stricture) (Busch, Hermann, Adam & Habermann, 2016). RIG surgery involves suturing the stomach to the abdominal wall to provide a pathway for a tube to be placed directly into the stomach (Best, 2019). RIGs can provide medication, fluids, formula, and blended food diets.

The most common tubes used for RIGs are balloon and low-profile button tubes. Balloon tubes are positioned against the abdominal wall and held in place by a water-inflated balloon (see Figure 16). As with long PEG tubes, the potential for balloon tubes to become dislodged is a concern for parents (Hopwood et al., 2020), and a button tube may be a safer alternative.

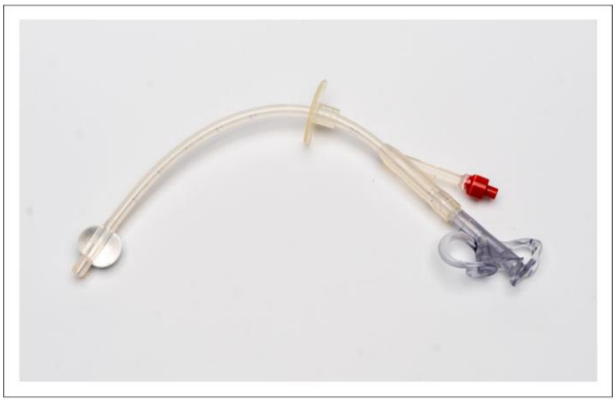


Figure 16: Example of a balloon tube (Brown as cited in Lord, 2018). Reproduced with permission

A button tube sits flush against the abdomen and is much shorter in length than a balloon tube; therefore, it is preferred by many parents because of the potential downfalls of long tubes identified above (see Figure 17) (Best, 2019).

Figure 17: Example of a button tube (Best, 2019). Reproduced with permission

The balloon and low-profile button tube are often combined for children for a more discreet option and to reduce the risk of dislodging a longer tube during play (Berman et al., 2022; Best, 2019) (see Figure 18).

Figure 18: Example of a combined balloon and button tube (Brown as cited in Lord, 2018). Reproduced with permission

The tubes described above are used by children who can tolerate nutrition and hydration being provided directly into the stomach. Those who are unable to manage gastric feeding may require feeding directly into the small or large intestine.

Enteral Feeding Terminating in the Intestinal System (Post-Pyloric)

Some children cannot tolerate the volume of nutrition they require in their stomach because of delayed gastric emptying, gastroparesis, or the risk of aspiration of stomach contents into the trachea (Lord, 2018).

Delayed emptying of stomach contents and gastroparesis (slow gastric motility) manifest as bloating, vomiting, and nausea during or even after a tube feed is provided. These complications are mitigated by bypassing the stomach and providing formula and hydration directly into the intestinal tract (Braegger et al., 2010). The following post-pyloric systems may be used to provide fluids and nutrition; however, medical supervision is required to administer medications directly into the intestine. This is because the intestine's pH, absorption, and osmolarity may interfere with certain medications (Lord, 2018). This is a consideration for many tube-fed children who require medications for comorbid complications (e.g., reflux, delayed gastric emptying).

5. <u>Naso-jejunal tube</u>

Naso-jejunal tubes (NJTs) may be used as a short-term enteral feeding solution when children cannot tolerate nutrition directly into their gastric system and require more hydrolysed formula directly into their small intestine—most commonly the jejunum (Best, 2019). Placement of the NJT is confirmed using centimetre markers (marked on the tube) at the nose. Unlike OGTs and NGTs, it is impossible to aspirate intestinal contents because there is a lack of fluid pool in the jejunum (National Institute for Health and Care Excellence, 2006). Once in place, the NJT is secured to the cheek with tape.

6. <u>Percutaneous endoscopic jejunostomy</u>

A percutaneous endoscopic jejunostomy (PEJ) tube is surgically placed directly from the abdomen to the small intestine (Best, 2019). PEJ tubes are frequently smaller in diameter and longer than PEG tubes. Therefore, additional care must be taken to avoid blockages (e.g., using liquid formula rather than home-blended formula).

7. <u>Percutaneous endoscopic gastrojejunostomy</u>

The percutaneous endoscopic gastrojejunostomy (PEGJ) is an extension tube from a PEG into the small intestine and therefore requires a PEG placement initially. A PEGJ tube may provide all of the necessary hydration and nutrition directly into the small intestine or may have a gastric and jejunal port whereby a portion of nutrition may be provided to the stomach (as tolerated) and a portion to the small intestine (Lord, 2018). The advantages of maintaining a level of gastric digestion where possible are twofold. First, the mechanical and chemical stages of digestion occur in the stomach, thus maintaining a level of typical physiological function (National Institute of Diabetes and Digestive and Kidney Diseases, n.d.). Second, when learning to eat and drink orally, food and fluids must pass through the stomach and cannot bypass directly to the intestine to be digested.

The purpose of describing the different types of feeding tubes is to highlight the responsibility that parents feel to select the type that is right for their child. While all serve the same purpose of providing nutrition and hydration, options include feeding tubes passed via the nose and those placed directly into the stomach or small intestine. The advantages and disadvantages of the different tubes are individual to each child based on their reason for requiring tube feeding. Gastric tubes are more commonly used for infants and children (Khalil et al., 2017), and this best mirrors the typical pathway for digestion once food reaches the stomach. Although it is not my clinical experience, some children who have difficulties tolerating bolus tube feeds (i.e., feeds delivered in less than thirty minutes) may find it difficult to tolerate oral eating and drinking from a gastrointestinal perspective.Therefore, it can be a trial-and-error approach to determine which tube is best tolerated by a child, and this is influenced by the length of time that tube feeding is required and the child's medical complexities.

In addition to the physical properties, parents' perception of the permanency of one type of tube over another, along with the visibility of the tube, may help determine the most appropriate type of tube. The decision on which tube is the most appropriate and the person responsible for making that decision likely varies between health services and may be dependent on the medical expertise of each healthcare team.

Which Tube to Choose?

Comparable with the rest of the tube-feeding journey, the type of tube used tends to evolve as tube feeding becomes more ingrained in daily life. What may start as a short-term option for nutrition can transform into a longer-term necessity, which requires a review of the best tube fit. The purpose best served by one tube may be a limiting factor for other areas of development. For example, while an NGT may be more convenient for the family because they can reinsert it if required, it may exacerbate oral aversion in the child and place additional pressure on the parent–child relationship. A PEG may be functionally better for a child to develop their oral sensory and motor skills, but it may pose a psychological hurdle for parents to accept the longer-term nature of their child's disability. In addition, PEG insertion requires a general anaesthetic, which may place already vulnerable children at additional surgical risk.

In North America, decision-making regarding which type of tube to place reportedly differs from service to service, as does the length of time each service will allow an OGT, NGT, or NJT before considering a gastrostomy (Abdelhadi et al., 2021). In a survey undertaken by 258 clinicians caring for tube-fed neonates or children, most reported no standardised timeframes for transitioning from an NGT to a gastrostomy tube (GT). Respondents indicated that the transition would occur between 6 weeks and 12 months of using an NGT, with 3 months being the most common transition timeframe (Abdelhadi et al., 2021). The ASPEN (American Society for Parenteral and Enteral Nutrition, 2002) and ESPGHAN (European Society for Pediatric Gastroenterology, Hepatology and Nutrition) guidelines suggest that if infants are unlikely to feed orally within 2–3 months of requiring enteral feeding, then a GT should be considered (ASPEN, 2002; Braegger et al., 2010 for the ESPGHAN committee).

Remaining with an NGT for longer than three months did not preclude a child from weaning, with one study showing that within six months of discharge from an American hospital, 71.4% of infants fed via an NGT had transitioned to full oral feeds compared with 19.3% of infants fed via a gastrostomy (Khalil et al., 2017). These infants did not transition from an NGT to a GT at three months, as suggested by the ASPEN guidelines. However, an important consideration is the quality of mealtime functionality. Although the children weaned from tube feeding, children fed via an NGT were more likely to show higher levels of food refusal and poorer growth than children who transitioned to GTs after three months of NGT use (Ricciuto, Baird & Sant'Anna, 2015). This may be related to the regular oral invasiveness and pain associated with frequent replacement of NGTs.

No studies have objectively explored the discomfort endured when children have OGTs or NGTs sited. However, NGT placement has been described in the adult population as the most painful procedure performed in an emergency department (ED) with low or no use of anaesthesia to reduce the pain (Juhl & Conners, 2005; Singer, Richman, Kowalska & Thode, 1999). This can have cumulative adverse effects for children with longer-term OGT/NGT/NJT feeding and who require tube changes frequently (6–8 weekly) for hygiene or when their tube is dislodged (ESPGHAN, n.d.).

Advantages of Gastrostomy Tube Feeding

Following the insertion of a GT, improved growth is often observed in specific cohorts of children, namely those with neurodevelopmental comorbidities, cystic fibrosis, ultrashort gut, and Pierre Robin sequence (Puia-Dumitrescu et al., 2020). This may be attributed to a reduction in vomiting and subsequent increased absorption of calories and nutrients. In contrast, NGT placement facilitates the relaxation of the usually tight upper oesophageal sphincter muscle, making it easier for a liquid formula to reflux out of the stomach towards the oesophagus and result in vomiting (Mahoney et al., 2019).

GT insertion has been positively associated with improved oral sensitivity and oral intake in children who were previously fed via an NGT (Dodrill et al., 2004). No statistical differences have been found regarding food aversion symptoms for children with a GT versus an NGT (Wilken, Bartmann, Dovey & Bagci, 2018).

Child wellbeing and happiness (as described by their parent/s), parent wellbeing and happiness, and parent–child communication during meals have maintained improvements at 18 months' post-GT insertion (Åvitsland, Birketvedt, Bjornland & Emblem, 2013). Within the same timeframe, minimal changes in measures of child and parent wellbeing and happiness have been reported following NGT insertion (Åvitsland et al., 2013).

Despite the potential for positive changes in growth, oral sensitivity, and wellbeing, many barriers remain for health professionals and family members to transition from NGT/OGT tubes to PEG/PEJ/PEGJ tubes.

At the tertiary level, hospitals report challenges regarding access to surgical lists to perform the procedure (perceived as elective surgery), the ongoing medical care required, and appropriately trained paediatric surgeons to perform the procedure (Abdelhadi et al., 2021).

Professionally, concerns that have been put forward by physicians include access to and the risk of anaesthesia to specific clients, disagreement from the surgeon that the procedure is required, or reluctance of the child's primary doctor to refer for the procedure. Furthermore, anatomical anomalies may make it dangerous to attempt PEG insertion (e.g., exomphalos) (Abdelhadi et al., 2021; Radford, Marshall, Herbert, Irving & Weir, 2020).

At times of helplessness (e.g., when in acute medical care), parents may feel compelled to accept medical advice without completely understanding or processing the health professionals' recommendation (Dadich et al., 2021). Parents who have attempted to stand up to health professionals for what they believe is best for their child have been threatened with social services (Page et al., 2020). Transitioning from one type of tube to another, rather than from a tube to oral eating, may feel like a backward step for some parents and may extend the length of time a child remains on one type of tube. In Australia, anecdotally, some children have maintained NGT feeding for over three years, possibly because of the above institutional and professional barriers. Other factors influencing the decision to transition include parents' fear of anaesthesia and surgical intervention for their child (Abdelhadi et al., 2021), and concerns about their ability to provide the ongoing care associated with GT feeding (Abdelhadi et al., 2021). For other parents, their perceived guilt of 'failing' in weaning their child from NGT feeding, their perception that a PEG is 'permanent', and their fear that oral intake will be further compromised can influence their decision to change from an NGT to a GT (Abdelhadi et al., 2021; Åvitsland et al., 2013).

Summary

The advantages and disadvantages of the different types of tubes have been highlighted above, including considerations regarding the anticipated length of tube feeding, effect on oral engagement, physical characteristics of tubes, and parents' perception of what the tube means for their child's prognosis. The perception of a tube being permanent compared with a tube being a temporary requirement highlights one of the many factors that parents and professionals must consider when supporting tube-fed children and contributes to the importance of transitioning children off an NGT if longer-term tube feeding is indicated. If the transition to more permanent tube feeding is indicated, it must occur in conjunction with detailed planning for tube weaning to alleviate parents' common fear regarding the permanence and dependency on PEG tube feeding (Ricciuto et al., 2015).

When parents or the team have decided that surgical tube insertion is required the opportunity of what is given via the tube expands. As indicated above, GTs have a wider diameter than OGTs and NGTs, and this increases the option to provide a 'real food' home-blended formula in addition to milk or formula feeds. For some parents, the opportunity to cook and prepare food for their tube-fed child—as they would for other family members—is a valuable contributor to a sense of 'normality' and contributes to their decision as to what to feed their child via their feeding tube.

How Is Nutrition Provided Via an Enteral Feeding Tube?

Tube feeding has been part of medical interventions for the last 230 years and has been a lifeline for providing medication, fluids, and nutrition for people who are unable to swallow (Randall, 1984). Tube feeding originated in 1790 when an OGT was used to provide a blend of jelly, beaten eggs, sugar, milk, and wine to recovering patients (Randall, 1984). In the early 1900s, the first post-pyloric tube was successfully sited (nasoduodenal), and absorption and tolerance of drop-by-drop feeds (mainly milk, egg, and sugar) were explored (Harkness, 2002). By the 1930s and 1940s, formulas had become more sophisticated through the addition of electrolytes, vitamins, and partially digested nutrients to support absorption. It was not until the 1950s that commercially prepared powdered mixtures were developed using powdered whole milk, non-fat milk solids, dextrose, vitamins, and minerals (Pareira, Conrad, Hicks & Elman, 1954). At this time, there was continued debate regarding the superiority of more medically sound, nutritional, and cost-effective blenderised tube feed (BTF) made in hospital kitchens using beef, liver, eggs, milk, fruits, and vegetables (Barron & Falls, 1953) compared with powdered mixtures.

Liquid formulas became popular in the 1960s as a source of adequate nutrition without affecting physiological function or wellbeing (Wintz et al., 1970). As a result of the rising cost of labour in the 1970s and inconsistent guarantees regarding the physical (e.g., viscosity, sterility) and nutritional properties of BTF, commercially produced formulas were favoured (Gormican & Catli, 1972).

Tube-feeding formulas have gone full circle in the last 20–30 years, with an increased awareness of and shift towards providing BTF whole foods again (Campbell, 2006; Skipper & Rotman, 1990). A study undertaken in 2017 reported that BTF is used in some capacity by 90% of the paediatric and 66% of the adult tube-fed population (Epp, Lammert, Vallumsetla, Hurt & Mundi, 2017). Johnson, Spurlock, Epp, Hurt & Mundi (2018) surveyed the parents of tube-fed children and reported the main reasons parents chose to provide BTF, including observed benefits for their child such as reduced vomiting, improved stooling, growth, and oral interest/intake. Preparing and providing meals as they would for other family members gave parents a sense of providing a more natural option for nutrition (Johnson et al., 2018). For many parents, these positives outweigh the potential challenges of BTF, such as ensuring adequate nutritional composition, maintaining a sterile blend, the potential for tube clogging, increased cost of ingredients, and the time taken to prepare the foods (Bobo, 2016).

In summary, although clinical nutrition advice is provided by health professionals, it is the family's decision regarding what they choose to feed their child, either orally or via a tube. Having a choice and control over one aspect of tube feeding may help mitigate the conflicting emotions often experienced by parents who need to tube feed their child (Johnson et al., 2018). The need to tube feed may eventuate from one or many factors and equally may be maintained by one or many factors. Tube feeding may be short or long term; for any given child, the reasons for tube feeding may change over time. For example, a premature baby may have required tube feeding from birth but then established oral feeding. Over time, slow growth and nonresponsive mealtime partners may result in the need for tube feeding again. In the context of understanding the challenges experienced by tube-fed children, the next section delineates the many reasons why children may require tube feeding. These reasons should be considered when exploring tube-weaning readiness and oral eating and drinking opportunities.

Who Uses a Tube?

The clinical reasons for requiring tube feeding differ from child to child, and even children with the same diagnosis may have different capacities for oral intake. Feeding tubes may be required in hundreds of conditions affecting children (Adams et al., 2014). For the purpose of this thesis, and to highlight the theoretical differences of why some children require tube feeding, I have conceptually grouped the reasons into 1) children with dysphagia, 2) children requiring habilitation of eating and drinking skills, and 3) children requiring rehabilitation of eating and drinking skills. These categories are not mutually exclusive but rather a sliding continuum, and they demonstrate that tubes may be inserted at any stage of a child's life from birth. The following paragraphs illustrate the characteristics of children within each of these three conceptual categories.

Children with Dysphagia

As described in 'Swallowing Impairment in Infancy' (page 16), dysphagia may result from impairment of any part of the oropharyngeal tract, and as described in 'Strategies to Support Dysphagia Management' (page 23-25), compensatory techniques have varying success. These children are often caught in a challenging space of either remaining nil by mouth following a diagnosis of aspiration and/or choking risk via VFSS or requiring fluid and diet modifications, which they may not accept (Arvedson, Clark, Lazarus, Schooling & Frymark, 2010).

Children with dysphagia and an NGT in place must navigate swallowing with a physiologically challenged system *and* with a foreign tube in their nose and throat. Little research has explored the physiological changes to swallowing biomechanics that may occur in children with an OGT or NGT. However, the positioning of an NGT may result in reduced sensitivity in the oropharyngeal tract, consequently delaying the trigger of the swallow sequence and subsequent aspiration (Arvedson & Brodsky, 2002; Morris & Klein, 2000; Wolf & Glass, 1992). Altered sensation and swallow trigger points have been shown for adults with an NGT in place, as well as nasal irritation, ulceration of the mucosa, and aspiration (Cataldi-Betcher, Seltzer, Slocum & Jones, 1983). A comparison between pre-term infants who required NGT feeding for a long duration (3–6 weeks) versus a short duration (<2 weeks) highlighted an increase in feeding delays and facial sensory tolerance the longer the tube feeding persisted (Dodrill et al., 2004). Therefore, in addition to the underlying dysphagia, babies fed via an NGT may be at risk of increased facial sensory defensiveness and delayed feeding skills, which ultimately may affect their ability to learn to eat and drink orally.

For children with dysphagia to learn how to swallow (more) safely, they must be allowed to practice; however, clinicians may be cautious in recommending oral intake. Concerns about a child's health and safety and the potential litigation that may ensue should a child become unwell with aspiration pneumonia, malnutrition, or dehydration are often at the forefront of health professionals' minds (Rogus-Pulia & Hind, 2015).

It remains a clinical dilemma that learning to coordinate the muscles required for safely swallowing food and fluids is unlikely to develop spontaneously if tube-fed children remain nil by mouth. This is because, for tube-fed children with no oral intake, the efficacy of oral motor stimulation with non-food items does not compare with introducing therapeutically managed oral food and fluids (Manno, Fox, Eicher & Kerwin, 2005). However, introducing oral intake to an at-risk child can be conflicting for parents and therapists alike and requires informed decision-making that considers the best medical interests of both the child and the family (Radford et al., 2020).

While some children receive a formal dysphagia diagnosis, other children present with a safe swallow (i.e., able to swallow sips of water or small amounts of puree food) but do not have the functional mealtime skills described above for successful eating and drinking. These children need to learn the value and purpose of mealtimes and oral intake and develop their trust and confidence with the volume and variety of foods they engage with. I refer to these children as needing habilitating into mealtimes because they have the physical skill but have not yet mastered putting that skill into functional practice.

Children Requiring Habilitation of Eating

This cohort of children has the physical ability to swallow (i.e., they can manage their saliva and may engage in small tastes of food or fluid); however, they have not yet consciously decided to actively participate in feeding or mealtimes, often because of past experience or trauma, as described previously ('Factors Influencing the Development of Safe Swallowing and Successful Mealtimes' p. 36). Therefore, these children require habilitation to teach them the trust, success, and enjoyment of mealtimes.

All babies are born with a natural satiation cycle, which is moulded through the delicate interpretation of the baby's communication cues by the caregivers within their environment (Stern, 1985). Orally fed babies learn that the pain of hunger is alleviated by acceptance of a breast or bottle and subsequent contentedness. Babies learn to regulate their appetite through 'trial and error' of how much they ingest at each breast or bottle offering. Unfortunately, the physiology of appetite regulation in babies with feeding tubes is often overruled from soon after birth. These babies are often fed on regular schedules day and night (as per traditional feeding methods described above, p. 26), with volumes of formula/breast milk prescribed much like medication (Morag et al., 2019). They are afforded limited opportunities to feel the effects of hunger and are often unaware that they can resolve this themselves. In learning to eat and drink orally, these babies must learn the feelings and impact of hunger and how to resolve these themselves (Dunitz-Scheer & Scheer, 2022).

Many of these babies may not feel hungry, not only because of the inflexible feeding routines, but also because of under-reactive pain sensitivity. With many of them experiencing noxious stimuli in their acute hospital phases, their sensory systems become overloaded. However, not all children do this all of the time; some may 'shut down' their body's sensory system to dissociate from, and survive, the pain (Kara, Sahin, Kara & Arslan, 2020). When teaching these children to eat and drink, the importance of routine food offerings becomes paramount to co-regulating their appetite because they may be unable to register or recognise these feelings themselves.

While poor appetite regulation is one reason that tube-fed babies struggle to learn to eat, trauma associated with the mouth and face may also be a factor, as discussed in the factors affecting successful swallowing and mealtimes (page 36). Repeated medical examinations and invasive interventions may result in the child learning to distrust the many unfamiliar faces that become part of their daily care. As such, these children often display *oral aversion*, which is the diagnostic term used to describe feeding refusal behaviours. Such behaviours include head turning, back arching, falling asleep at feed time, or screaming when something (food or non-food) or someone approaches the vicinity of their face or mouth (Arvedson & Brodsky, 2002; de Moor, Didden & Korzilius, 2007; Morris & Klein, 2000; Wolf & Glass, 1992). An alternative term could be *oral protection*. Given that the baby has experienced many unpleasant interactions involving their face/mouth/throat, they skilfully and intentionally protect themselves from other aversive experiences. In addition to aversive experiences, some tube-fed children present with oral aversion as a direct result of inexperience and abstinence from eating and drinking; subsequently, they miss out on vital learning opportunities at critical periods of development (Hawdon et al., 2007).

While children in this category of 'habilitation' have a safe swallow and perhaps small amounts of oral experience with food and fluids, they require support to transition from the psychological and physiological association they have with tube feeding to oral eating and drinking. On the surface, they may not appear to differ from children who require rehabilitation for eating because they, too, have physical swallowing abilities but psychological barriers to eating. The difference is that children who require rehabilitation of eating have previously been successful with oral intake and have coordinated and functional swallowing skills. Psychologically, something has triggered them to regress with their oral intake to require tube feeding. Rather than being psychologically dependent on tube feeding, the psychology of the mealtime or feeding environment, as well as participants or physical barriers, has resulted in the need for tube feeding. These children require rehabilitative support to rebuild their trust and success in mealtimes, much like a child who has undergone immunotherapy for a life-threatening allergy must learn to trust that the allergen no longer causes a severe reaction.

Children Requiring Rehabilitation of Eating

For other children, an enteral tube may have been placed as a treatment strategy for necessary medical interventions (i.e., cancer treatment, organ removal) or faltering growth in the early years. Faltering growth in infants and preschoolers is the pattern of slower-than-expected weight gain for age and gender (National Institute for Health and Care Excellence, 2017). These children are likely to consume a small, select range of foods and drinks; however, attempts to broaden their variety, introduce nutritional supplementation, or increase the volume of their intake are refused. At this point, tube feeding may be introduced (National Institute for Health and Care Excellence, 2017). Faltering growth is most likely a result of inadequate nutritional intake, which may be the culmination of a range of physiological and psychosocial factors.

Physiological Factors Affecting Growth

Physiological influences may interrupt a child's ability to continue to eat and drink safely. These influences include physical anomalies (e.g., cleft palate, airway disturbances such as laryngomalacia) and physiological anomalies (e.g., recurrent infection, undiagnosed/late diagnosis of food allergies) in the absence of any other diagnosed conditions (Abraham & Rejiya, 2016). The effect of frequent incoordination of swallowing or insult to the respiratory and gastrointestinal system can reinforce within the child from an early age that eating and drinking cause discomfort and therefore should be avoided (Jadcherla et al., 2010). Once the underlying anomaly is treated, it may take a child time to rebuild their confidence that eating will no longer cause the pain it did previously.

Psychosocial Factors Affecting Growth

As described in Part 1, eating and drinking are social experiences founded upon a relationship between the child and the parent (p. 10). Ideally, the parent responds to the baby's cues, and the baby's behaviour is shaped by this response (Redsell et al., 2021). In the early months of life, a baby builds their understanding of relationships based on the behaviour of their primary caregivers and whether they are attuned and responsive to the baby's needs. For example, when a baby cries, the parent may respond by checking the baby's nappy, helping them to sleep, or feeding them to alleviate hunger. The baby learns that crying helps them achieve their desired outcome.

This relationship may be interrupted for reasons related to the child's or parent's medical or mental health complications (e.g., trauma, depression, attachment, previous lived experience). The delicate balance of the parent's interpretation of their child's mealtime cues may be misjudged or ignored (Christie, Hamilton-Giachritsis, Alves-Costa, Tomlinson & Halligan, 2019; Murray, Cooper & Hipwell, 2003; Wilken, 2012).

To gain acknowledgement and a response, the child may resort to other communication strategies such as head turning, gagging, vomiting, falling asleep, or refusing food and drink. These strategies become more sophisticated as children age, including refusing to eat certain foods or accepting a specific food brand presented in an exact way. Subsequently, this may result in either increased attempts by adults to 'get it in' or further dismissal of these cues (Feldman, Keren, Gross-Rozval & Tyano, 2004). Low responsiveness to a child's requests or cues can result in heightened anxiety or stress for the child and physiological alteration to their hunger cycles and growth. Children's hunger cues are dampened by high levels of adrenaline released directly from their fight-or-flight response to being engaged in a stressful situation (Didehbani, Kelly, Austin & Wiechmann, 2011). If ongoing food refusal or minimal food intake persists, a feeding tube may be inserted for faltering growth. Unless the impacting psychosocial variables are addressed, any attempts at weaning from the tube may be short-lived. Rehabilitating tube-fed children back to oral intake requires respectful responsivity to their mealtime behaviours while repairing previous mealtime associations.

Children who require rehabilitation of eating and mealtimes *have* the physical ability to swallow and *have* previous mealtime experience to draw upon. Therefore, these children require a supportive environment to incorporate these skills into functional mealtimes and maintainable eating habits.

Children may require feeding tubes for a variety of reasons. Tube use in children with no oral skills, limited oral skills, or developed but not functional oral skills may last for weeks, months, or even years (Bazyk, 1990; Mason et al., 2005; Wilken, Cremer, Berry & Bartmann, 2013). Many of these children will rely indefinitely on tube feeds to provide energy and hydration if they cannot manage satiation via oral intake. Over the last 10 years, this phenomenon has become more recognised as *tube dependency*, and it has additional implications not only for the child but also for the family and the greater community (Dunitz-Scheer et al., 2009).

What Is Enteral Tube Dependency?

Enteral tube dependency was first defined as the ongoing reliance on tube feeding beyond medical necessity and in the absence of any structural obstruction or developmental condition affecting safe chewing and swallowing (Dunitz-Scheer et al., 2009).

Dovey et al. (2018) proposed a definition of tube dependency that encapsulates the *physiological* (i.e., survival) and *psychological* (i.e., overreliance) aspects of dependency: *'The reliance on a feeding tube to provide nutrition support to ensure growth and/or sustenance, which may function as a ratio of energy (e.g., calorie) required through the tube against the amount of food eaten orally to aid recovery and/or maintain developmental trajectory*' (p. 501).

As previously described (page 29), successful eating and drinking are built upon trust, mutual enjoyment, and autonomy. From this platform, babies and children can watch and imitate the actions of people they trust in the mealtime environment. This is evidenced by infants intently watching another sibling or adult's mouth while eating, visually following utensils from the plate to the mouth as someone else is eating or reaching out towards food (Morris & Klein, 2000). However, many tube-fed babies are fed in isolation and often with entertainment such as toys or TV to keep them occupied during the duration of the feed because the often-prescriptive nature of tube-feeding regimens frequently misaligns with family mealtimes (Dadich et al., 2021). As such, they miss the vital learning opportunities, cues, and prompts that naturally become part of the daily routine for orally fed babies and help babies to anticipate what will happen next (Akpan, 2020). Instead of learning about spoons, cups, holding finger foods, and varying tastes and temperatures of food, tube-fed babies have different feeding experiences. They may come to anticipate the sound of the syringe packet being opened, an adult shaking a bottle of formula/milk before holding a syringe above their head (to allow gravity to assist the flow of liquid), or connecting the tube directly to their stomach (if fed via a PEG). They depend on an adult to provide their nutrition rather than associating typical mealtime cues and prompts with their ability to address their hunger. When learning to eat and drink orally, they must learn new mealtime associations and their role in their satiation independent from adults.

Children must also develop a sense of trust that the mealtime environment and the foods offered are safe, that there will be enough food on offer, and that the food or drink will not cause them pain or discomfort. Most importantly, children must feel in control of what happens to their bodies, including if they eat and what and how much they choose to eat (Satter, 1990). They must understand that being at the table or sharing a feeding experience with their family or peers is a time of social interaction and enjoyment—not an experience to fear or dread. Tube-fed children who fear the mealtime process and lack trust are likely to avoid this environment where possible and remain dependent on the tube (Dunitz-Scheer & Scheer, 2022).

In addition to these environmental and psychological considerations, the specific challenges of tube dependency are explored below in the context of the above three conceptual categories of why children may require tube feeding.

Children with Dysphagia

The overriding concern for children with dysphagia is the aspiration of food or fluid into the lungs, potentially causing infection or longer-term damage. For this reason, they require nutrition via an enteral tube from birth or soon after, and it may be recommended that they remain ‘nil by mouth’, whereby no foods or fluids are to be offered orally. Remaining nil by mouth affords tube-fed children minimal opportunity to develop the intricate sequence of suck/swallow/breathe or how to chew and swallow other than swallowing their saliva or practicing on a dummy or finger. As described above, learning to feed and eat is both a developmental motor skill and a cognitive process. However, given a lack of opportunity to develop the motor patterns, muscle stamina, and strength required for safe swallowing, children remain physically dependent on the tube for nutrition, hydration, and growth. Ongoing physical dependency may spiral into ongoing cognitive or psychological dependency because tube feeding is reinforced as their ‘norm’. This differs from children who do not have a physical dependency but remain psychologically reliant on tube feedings, such as those requiring habilitation of eating and drinking.

Children Requiring Habilitation of Eating

As described above, these children have frequently been tube fed from an early age, but unlike children with dysphagia, they have a physically safe swallow and may have a level of oral experience or interest. They have limited exposure to the developmental stages described above, when children learn the sensory and motor skills to eat. They may have small tastes of foods or sips of fluids, but they see this as a novelty rather than a necessity. Their psychological association with feeding is aligned with a tube and their carer providing satiation rather than understanding that they can regulate their appetite themselves through oral intake (Dunitz-Scheer et al., 2009). Their dependency remains psychological because, physically, they have the ability to ingest foods and fluids safely. Similarly, children who require support to rehabilitate their eating and mealtime skills also remain psychologically dependent, although the psychology of why they require a tube may differ from the reasons described above.

Children Requiring Rehabilitation of Eating

This cohort of children has previously been oral eaters and drinkers. Therefore, they have the motor skills required to manipulate food and fluid, as well as a level of mealtime experience to draw upon. What makes this group unique from the other two groups is the initial disruption they experienced, leading to declining oral acceptance and the requirement for enteral feeding. When children experience disruption to feeding, such as pain, trauma, or nonresponsive feeding (as described above), they may disengage from the experience. Intrusive feeding options such as constant pressure to eat and drink or force-feeding may result from parents' increased desperation for their child to eat. Some parents only provide favourite foods to entice their child and alleviate growth and nutrition concerns, which may cause a child to eat even less (Dunitz-Scheer et al., 2011). In time, tube feeding may be required to supplement what (if any) oral intake remains and reduce or remove the pressure on the child to eat or drink. If the child learns that this is a safer form of nutrition and hydration, they may gradually avoid the mealtime environment, refuse all oral intake, and rely solely on tube feeding.

While children who require rehabilitation of eating and drinking may have the physical ability to eat and drink orally, careful consideration and support must be provided to the underlying and perhaps maintaining behaviours and causes of tube feeding in the first instance. In the absence of addressing these causes as described previously, ongoing reliance on tube feeding for growth and nutrition may result in tube dependency and the subsequent effects of this.

Effects of Enteral Tube Dependency

Ongoing maintenance of tube feeding has physical, emotional, and financial costs for the child, the family, and the healthcare system (Hopwood et al., 2021). It is in the best interests of all involved that the transition from tube to oral feeding be discussed and planned as early as possible into the tube feeding journey to alleviate the effects of ongoing reliance on tube feeding (Syrmis et al., 2020). To understand that tube dependency sits deeper than 'just using a tube for food', some of the effects on the child, family, and healthcare system are summarised in the next section.

Effects and Sequalae of Tube Dependency on the Child

While lifesaving for these children, tube feeding produces an additional set of challenges and unintended consequences that are often unanticipated by parents (Brotherton et al., 2007) and health professionals.

Tube feeding is often administered in a prescribed amount, which may be more than the child's requirements at that time and can result in children losing some or all of their ability to regulate their appetite (e.g., overfeeding). This means that during tube weaning, children must first learn and acknowledge the feelings and symptoms of hunger. *Overfeeding* also results in frequent vomiting and can further reinforce that being satiated is an adverse experience (Pearce & Duncan, 2002).

For some children, despite tube feeding the exact amounts as prescribed by professionals, *growth* may deviate from the trajectory as predicted or expected by objective measures such as growth charts (Ishizaki, Hironaka, Tatsuno & Mukai, 2013; Pearce & Duncan, 2002). Concern by professionals regarding insufficient growth may result in the introduction of fortified formulas or high-calorie supplements to assist a child in reaching the ideal growth parameters. Calorie-dense formulas may not be tolerated by the child, with vomiting resulting in a net effect of a similar growth pattern as previously. Fortified formulas may increase the stress and length of time associated with each feed, with no additional benefits to growth (Ishizaki et al., 2013).

The formulas prescribed by health professionals can impact *digestion*. These commercially prepared chemical formulas ensure a complete micro- and macronutrient composition; however, they lack phytonutrients (antioxidants), fibre, and dietary diversity for the gut (Chandrasekar, Dehlsen, Leach & Krishnan, 2021). This can result in erratic bowel movements that may be too hard or loose, influencing ongoing gut tolerance (Chandrasekar et al., 2021). Appetite regulation is affected for tube-fed children when they learn to eat when they feel 'full', even though this feeling may be caused by constipation.

Delays in the *physical development* of gross and fine motor skills may be evident because many tube-fed children have prolonged hospital admissions or preterm deliveries (Pedersen, Sommerfelt & Markestad, 2000). In addition, the consequence of frequent vomiting, reflux, and nausea means that these children often cannot tolerate much movement or large amounts of time on their stomachs or in positions other than upright. Their exposure to and experience with core strengthening activities, such as lying on their stomach and learning to raise their head, balance for sitting, or even learning to walk, can be limited

(Pedersen et al., 2000). Head control and core support for body control are prerequisites for a child to learn to eat and drink successfully and safely.

As per impacts on physical development, extended hospitalisations and preterm birth may shape children's *cognitive development*. With 50% of extremely low birth-weight infants (<1,000 g) experiencing an ongoing cognitive disability, many find it challenging to learn the skills for eating and drinking (Bhutta, Cleves, Casey, Craddock & Anand, 2002; Pedersen et al., 2000). This may be partly because the child is becoming more cognitively aware that they are tube fed rather than an oral eater. From birth, orally fed babies learn that having a teat or nipple in their mouth alleviates hunger. Tube-fed babies learn the visual association that another person holding a syringe attached to their tube alleviates their hunger. The more the tube feeding continues, the stronger the mental representation becomes that they are fed via a tube—not the mouth. Tube-fed children must internalise the psychological transition from tube to mouth when they are being taught to eat.

As described above in 'Which Tube to Choose?' (p. 50), children who require frequent NGT or OGT changes are subjected to *invasive*, forceful, and uncomfortable experiences, which may result in oral aversion (or oral protection). This can influence their ability to trust adults attempting to bring objects to their mouths or confidence in themselves to mouth objects. A spoon, which we know to be safe, may be a perceived threat to a child who endures an unfamiliar adult pushing a tube up their nose and down their throat, which has ongoing implications when they learn to eat and drink orally (Dodrill et al., 2004).

The effects of tube dependency on the child are many and varied. However, side effects may be observed across motor (fine, gross, and oral motor), psychological (cognition, identity, aversion), and physiological (overfeeding, digestion, bowels, growth) development. Tube dependency has a broader reach than the child alone and can additionally contribute to challenges among siblings.

Effects of Tube Dependency on Siblings

Siblings are an important part of the mealtime context for the tube-dependent child and for parents with siblings who anecdotally often become the 'second mother' to their brother or sister with a disability as they assume the roles of helper, carer, and friend (Yasgur, 2017). Siblings feel the effects of having a brother or sister with additional medical or developmental needs equally to their parents and over a longer period of their lifetime (Giallo, Gavidia-Payne, Minett & Kappor, 2012; Yasgur, 2017). Given the demands of having a child with a disability, parents are likely to experience less one-on-one time with their other offspring (Giallo et al., 2012). This may result in the healthy child expressing anger, resentment, jealousy, or guilt towards their disabled sibling (Milevsky, 2016). The cumulative effect of these emotions and behaviours experienced by the sibling of a disabled child contributes to their increased risk of emotional, functional, and behavioural challenges in the future (Fisman, Wolf, Ellison & Freeman, 2000; Giallo et al., 2012). Many have extensively researched sibling wellbeing, stress, adjustment, anxiety, and behaviour (Marquis, McGrail & Hayes, 2019). High levels of hyperactivity, distractibility, and impulsivity have been reported, which may be related to the ongoing stress experienced by the family (Giallo et al., 2012). While parents may tend to focus on the health of the disabled child, research has shown an increase in mental health and depressive conditions in the siblings of children with a developmental disability or Down syndrome (Fisman et al., 2000; Marquis et al., 2019).

Siblings may frequently be left in the care of others while their parents attend the many health appointments often required by tube-fed children (Gallo et al., 1991). This can leave siblings feeling rejected and, in turn, they seek strategies to gain attention from their parents. They may use acting out behaviours or display anger towards their sibling. Other children may try to be the ‘perfect child’ to alleviate further stress on their parents or as compensation for their sibling’s disability (Yasgur, 2017).

Social experiences and activities such as parties, a trip to the playground, or participating in the weekly food shopping may be limited for siblings of a tube-fed child. Families may avoid social outings because of the additional demands of maintaining and transporting sterile equipment to provide tube feeds, the potential impact of profuse vomiting post-feed, or having to manage inquisitive people (Brotherton et al., 2007; Hopwood, Elliot, Moraby & Dadich, 2020; Lively et al., 2022). The loss of these typical childhood experiences for the sibling may be thought to contribute to delays in social skill development; however, recent studies have shown the opposite. The ability of siblings of children with a disability to understand the thoughts and feelings of others (cognitive empathy) may be greater than that of their peers because of their lived experience (Rum et al., 2022). Cognitive empathy, in turn, is an essential foundation for developing social skills.

The resultant effect on a sibling of a disabled child missing experiences in one area yet gaining maturity in other areas remains unclear. What is clear is that the loss of 'normal' family life can affect the mental health and behaviour of siblings of children who require tube feeding. It also has ramifications for the parents of a disabled child, which are explored below.

Effects of Tube Dependency on Parents

Many parents report feeling a loss of typical parenting and a disruption to the parent–child bond when their child is tube fed (Lively et al., 2022; Satter, 1990). Scenarios include the lack of opportunity to hold their baby during breast or bottle feeds, and the physical appearance of their child with a tube taped to their face. Some parents dread having to feed their child because the equipment and the process for providing nutrition via a tube results in feeding-related anxiety (Pederson et al., 2004). In addition, acknowledging and accepting any diagnoses associated with tube feeding and concern for what the future holds often contribute to feelings of failure as a parent (Edwards, Gibbons & Gray, 2015; Fisman et al., 2000; Thiele et al., 2016).

Studies have reported that parenting a child with a disability or additional needs can strain parental and wider family relationships (Dunitz-Scheer et al., 2009; Read & Rattenbury, 2018; Wolf, Noh, Fisman & Speechley, 1989). Other studies have shown an improvement in marital relationships as parents come together to share the physical and emotional challenges that may arise (Raghavan, Weisner & Patel, 1999). Regardless, parenting a child with additional needs is likely to create additional emotional considerations than parenting a child without additional needs.

Many parents report feeling exhausted with little respite or time to pursue their own activities and interests. The physical and emotional demands of their child's medical needs (e.g., managing overnight tube feeds, attending appointments) while caring for other siblings and essential daily duties contribute to parents' fatigue (Aldiss et al., 2021; Brotherton et al., 2007; Lively et al., 2022; Whiting, 2013).

Parents are often thrust into the medical management of their child's requirements. In time, they learn to recognise their child's responses to procedures, medications, and feed volumes. However, they often do not have a background in medicine or nursing interventions and must therefore learn on the job (Aldiss et al., 2021; Whiting, 2013). This requires parents to make important decisions about their child's care and future with a strong sense of the 'unknown' (Aldiss et al., 2021). In taking on the role of primary carer, many families need to compromise on paid employment and income, leading to potential financial difficulties and further stress (Hewitt-Taylor, 2007).

While many parents are desperate to remove their child's tube, some appreciate the tube as *their* safety net and reassurance of their child's growth and the nutrients and hydration they receive (Cipolla et al., 2022; Lively et al., 2022). In a way, the term 'tube dependency' can be applied to both children *and* parents; therefore, tube weaning may be daunting for parents. They must build confidence in their child's oral intake, even if it is not the complete nutrition that was provided by the tube. They must learn to manage illness in their child without the tube to depend upon for administering medications or fluids. These hurdles must be experienced by parents for them to build their confidence in their child's ability to manage without a tube as a 'backup' (Clouzeau et al., 2021).

Tube dependency significantly affects many parents physically, emotionally, and psychologically. It throws them into an arena that requires them to become their child's medical expert without having the necessary training. Targeted support may be required for parents to address the secondary tube dependency that parents may form from the reassurance that tube feeding provides. Additional parental support for childhood tube feeding is a cost to the community that may not always be considered. Other implications of tube dependency for the health system are described below.

Effects of Tube Dependency on the Health System

Tube dependency results in financial and health-related costs for the health system (Callahan, Buchanan & Stump, 2001; Clouzeau et al., 2021; Singh, Pardy, Kelly & Yardley, 2021), including costs associated with providing equipment and health professionals to oversee tube feeding, and the physical, developmental, emotional, and mental health costs to the children and their families as described above.

A recent cost analysis was undertaken in the United Kingdom to determine the annual financial cost of maintaining gastrostomy feeding in children aged 0–17. Costs varied based on the type of device and the child's age; however, the mean cost was £710 per year (~AU$1,300) (Singh et al., 2021). This included nursing support via the phone or home visits but no other therapy or medical costs; therefore, the financial cost of tube feeding would be substantially higher. A study in the United States over 20 years ago placed the median annual cost of gastrostomy feeding for one adult (>60 years) at US$12,227 (~ AU$18,000), which included surgical, formula, and medical follow-up for complications, but did not include feeding therapy costs (Callahan et al., 2001). Extrapolating from this aged data, the annual cost to the health system in Australia for an adult to be maintained on tube feeding would be more than AU$20,000. I anticipate that this annual cost would be higher for children when the cost of allied health therapy to support children and their families with the transition from tube feeding is factored in.

Tube feeding and best practice tube weaning require input from multiple disciplines, including gastroenterology, paediatrics, dietetics, nursing, speech pathology, emergency physicians, mental health therapists, and physiotherapists (Clouzeau et al., 2021). A large team of health professionals is required to coordinate care for children who continue to be tube fed. To do so competently requires the continued development of health professionals' knowledge and skills in tube feeding and weaning. This is an ongoing training cost for public and private health systems.

In addition to financial costs, the emotional cost to siblings' and parents' mental health was highlighted above. If left unacknowledged, the mental health of the greater family may have a spiralling effect on the care and development of the tube-fed child. The provision of mental health support to families or the consequences of not providing this support and the effect on the tube-fed child (e.g., declining health, stagnant development) becomes an ongoing cost to the health system.

As outlined, the effects of tube dependency are felt across many areas directly related to the child, the family, and the broader health system, hence the desire to move towards a more typical feeding method. However, the options for tube weaning in Australia are limited and are primarily dependent on the options (if any) offered by the hospital or therapy centres that the family has access to (Gardiner, Fuller &

Vuillermin, 2014). In addition, weaning services may depend on the expertise and motivation or passion of the individual staff at any one time (Syrmis et al., 2020). There has been increased awareness recently for professionals to discuss and develop tube exit plans among themselves and with families at the time of tube insertion (Syrmis, Frederiksen & Reilly, 2019). However, this remains a developing process that shows inconsistency throughout Australia and internationally (Gardiner, Fuller & Vuillermin, 2014; Syrmis et al., 2019). With such variability regarding when to remove the tube, it can be difficult to know whose role it is to decide when a child and their family are ready and on what parameters this decision is made.

Summary—Part 2

Seven different types of feeding tubes may be considered for use in children who are unable to maintain their nutrition, hydration, or growth safely or successfully on oral intake alone. This may be a result of a range of anatomical, physiological, and psychological reasons. The advantages and challenges of each type of tube make the decision challenging for parents who are often guided by health professionals. Ongoing feeding tube use may result in feeding tube dependency, which may have long-reaching effects on the child, their family, and the community. Therefore, it is in the best interests of these groups that children learn to transition from tube feeding to oral eating and drinking when it is appropriate to do so.

Part 3: Tube Removal

What is Weaning?

The period of adapting to something different was referred to in Anglo-Saxon times as *wenian*; hence, the word 'weaning' has been used in English for the last 1,000 years (Macmillan Dictionary Blog, n.d.). From a medical perspective, weaning refers to '*the permanent deprivation of breast milk and commencement of nourishment with other food*' and '*gradual withdrawal of a patient from dependence on a form of therapy*' (Medical Dictionary for the Health Professions and Nursing, 2022). In typical eating development, weaning commences at about six months (World Health Organization, n.d.-b). The process commences with substituting one breast or bottle feed with an offering of solids, followed by the opportunity to top up the infant's energy requirements with a milk feed (Lawrence & Lawrence, 2022). In this way, the infant gradually learns to moderate their appetite requirements as they learn to eat more and not depend on milk for satiation.

In tube dependency, weaning refers to the gradual removal of breastmilk or formula via an enteral tube to achieve nourishment via oral foods and fluids. To this end, weaning is on a continuum of development and is not a standalone event that occurs and is complete at once. Tube weaning has been more definitively stated as '*all of the processes and interventions required to transition an individual from a dependency on a nasogastric/gastrostomy tube to oral eating of solid or functionally appropriate food that would be considered age appropriate in a typically developing cohort and meets all of his or her nutrition requirements without disproportionately affecting their development, social environment and family*' (Dovey et al., 2018, p. 502).

The concept of an 'age-appropriate' diet in this definition is challenging because it does not reflect children with developmental delays who cannot perform at their chronological age because of medical or developmental challenges. Likewise, as previously discussed (p. 56 & 74), tube-fed children are likely to show delayed oral motor and sensory skills resulting from their early experiences. Consideration of a child's developmental or physical skill capacity may be more appropriate and would support parents to value what their child can achieve rather than compare their child with other children of the same age who have not experienced the same challenges. Additionally, this would support health professionals with goal setting and the celebration of incremental developmental gains utilising a growth mindset approach rather than a skills deficit approach (see Principle 2, Chapter 11).

As discussed in the 'Development of Swallowing' (page 14), an infant is anatomically and physiologically primed to learn chewing skills around six months. Chewing requires tongue and mouth patterns that differ from those required for sucking (Lawrence & Lawrence, 2022); however, for many tube-fed babies, oral stimulation is limited to only swallowing their saliva. Because the experience of sucking and successfully controlling a liquid of increasing volumes is diminished and oral exposure to taste and texture is limited, swallowing coordination becomes dysfunctional after permanent tube feeding (Kamen, 1990). However, during weaning, tube-dependent children must gradually transition from one form of nutrition to another while simultaneously developing the oral, sensory, and regulatory skills to do so (Edwards, Davis et al., 2015). This differs from oral babies transitioning from the breast or bottle to more solid food because they have experience with oral skills and sensory processing upon which to develop and accept a new form of nourishment.

Tube weaning refers to a tube-dependent child reducing their reliance on tube feeding to provide nutrition and hydration by developing a new set of oral motor and sensory skills. Some may argue that it is best to wait until a child has developed the skills mentioned above, while others believe that these skills develop by virtue of the weaning process. When is the right time, then, to start this transition?

Tube-Weaning Readiness Indicators

With the realisation that their child has become dependent on tube feeding, parents (and professionals) may explore whether a child is ready to be weaned from the tube. Guidelines for weaning readiness incorporating physical and psychological factors have been proposed. These guidelines include medical and nutritional stability, appropriate oral motor and swallowing skills, and caregiver readiness (Schauster & Dwyer, 1996). In 2021, a multidisciplinary working group comprising French medical and allied health professionals developed clinical recommendations for tube weaning (Clouzeau et al., 2021). They recommended that weaning should be considered upon meeting all of the following conditions: (i) medical stability with no short- or medium-term requirement for surgery; (ii) stable weight or adequate nutrition categorised as weight-for-height z-score of -2.0 or greater; (iii) safe and functional swallow; and (iv) family engagement and motivation for weaning.

A survey of Australian and international tube weaning programs indicated variability between eligibility criteria; however, all 12 weaning programs reported prerequisites of medical stability and a safe swallow. Most agreed that family readiness was important (Gardiner et al., 2014). More recently, Syrmis et al. (2020) explored the knowledge of healthcare providers working in an Australian tertiary hospital. A range of health professionals reported 16 indicators for tube weaning, including, the ability to take medications orally, consumption of a greater range of food tastes, and the type of feeding tube (Syrmis et al., 2020).

Schauster and Dwyer's (1996) guidelines suggest '*adequate weight for height with some nutrition reserves present'*; however, subsequent research has shown that children can successfully wean if this is not the case (Lively, McAllister & Doeltgen, 2019). Moreover, three weaning teams have proposed weaning when enteral feeding no longer provides the desired benefits of weight gain and nutrition (Gardiner et al., 2014).

In addition, Schauster and Dwyer's (1996) suggestion that '*appropriate oral-motor skills*' are required before commencing weaning remains ambiguous. As previously highlighted, these children often lack oral motor skills due to inexperience; however, this does not preclude them from successfully learning to eat and drink (Lively et al., 2019). Additionally, measures of oral sensitivity may need to be considered, as no oral sensory processing challenges are a requirement in one British and two Australian weaning programs (Gardiner et al., 2014).

Dovey, Wilken, Martin & Meyer (2018) added to Schauster and Dwyer's (1996) readiness criteria by including criteria for discontinuing weaning when the child has lost '*too much weight too quickly*'. No further data were provided to quantify these terms. Other teams include cognition, age, and interest in eating as primary considerations for readiness to wean (Gardiner et al., 2014).

In summary, current tube-weaning guidelines are ambiguous, and weaning readiness may be reflective of the expertise of clinicians in the child's therapy team and based on a range of factors, including family availability, medical and swallow stability, cognition, and age. Given the unique combination of factors for each child, family, and community, the decision to wean varies from child to child and between therapy teams. Some children may remain tube fed for longer than is necessary because of individual team approaches and experience (Gardiner et al., 2014, 2017). Evidence-based weaning readiness guidelines would facilitate evidence-based practice (EBP) by contributing research evidence in conjunction with clinical experience and the needs and wishes of the child and the family. The prospect of tube weaning may be daunting for parents who have a high level of hope and fear in the process of teaching their child to eat (Cipolla et al., 2022; Lively et al., 2022). When the team agrees that tube weaning is the next clinical intervention, families must decide how this will occur.

Options for Tube Weaning

For some parents, knowing there is only one pathway is the pathway they follow. Others place importance on knowing all of the choices and weighing up the best option for them. The child's team may provide information on tube weaning; however, this relies on team members being aware of the possibilities that are available (Syrmis et al., 2019). To augment any information the team provides, many parents seek advice from the internet and social media support groups regarding tube-weaning options and to learn about the experiences of other families (Aldiss et al., 2021).

As mentioned, a systematic search of research-based outcomes and expert opinions was published to propose clinical practice recommendations for tube weaning (Clouzeau et al., 2021). This is the most comprehensive attempt to strengthen EBP for weaning to date, and it is much needed because each program currently uses its own approach and reports its success rates based on variables it has chosen to measure (Lively et al., 2021). Thus, it is difficult for health professionals and parents to understand the differences between programs and what may be most suitable for a specific child and family.

Weaning programs are offered through public and private health systems internationally, with varying levels of therapeutic support provided. Parents may have the financial means to fund a weaning program offered by a private organisation either online or in person. Costs vary significantly, from AU$9,395 (NoTube online, n.d.) plus ongoing monthly support at AU$1,450/month to AU$5,200 (Growing Independent Eaters, n.d.), and while some parents may be able to fund this, the costs may preclude other families from this option. Additionally, most are based in Europe or the United States and may have a time zone component to consider. If private tube-weaning options are unaffordable for families, they must join public waiting lists to access the services offered by their local hospital or community health service. This can be fraught with concern and frustration for parents, and it limits the choice regarding which program to access.

Although a child may receive health services from a tertiary hospital in Australia, there are variations in the extent of tube-weaning offered. For example, many international tertiary hospitals provide home enteral nutrition (HEN) services, which include nursing support for tube supplies and syringes, troubleshooting tube blockages or displacement, and a dietitian. In addition, some families have access to a feeding team that mainly comprises a dietitian, a speech pathologist, and sometimes a paediatrician. Despite placing and overseeing the maintenance of feeding tubes, these services do not necessarily have structured programs for teaching mealtime skills to enable tube removal (Gardiner et al., 2014). Despite accessing medical and health services from within the hospital that offers a weaning program, some families may not be able to access tube weaning programs due to geographical boundaries for service provision stipulated by the health service (Gardiner et al., 2014).

In circumstances where families do not live within the zoned area for a hospital offering a dedicated tube-weaning program for which a child meets the criteria, or do not have the financial means for private tube weaning, the supported options for a tube-dependent child learning to eat and drink are sparse. However, if families have the means to access other weaning programs, they must consider the differences outlined below.

Setting: Parents are faced with options relating to the setting. Tube weaning may be undertaken in various settings, including community clinics, hospitals (inpatient and outpatient), and homes (e.g. Blackman & Nelson, 1985; Davis et al., 2016; Kindermann et al., 2008; Lively et al., 2019; Taylor, Purdy, Jackson, Phillips & Virues-Ortega, 2019; Trabi, Dunitz-Scheer, Kratky, Beckenbach & Scheer, 2010), and via in-person consultations or telehealth (net coaching) (Marinschek, Dunitz-Scheer, Pahsini, Geher & Scheer, 2014).

Rate: The rate of tube-feed reduction differs among programs. Rapid weans often involve a fast reduction in tube-feed volumes provided to initiate a hunger drive. As a result, a change in oral interest and mealtime behaviours may be observed within weeks. Some parents and professionals fear unacceptable weight loss with a rapid wean (Dunitz-Scheer & Scheer, 2022). Slower weans reduce tube volumes over time, and while this may be suitable for some children—particularly those with compromised motor skills (e.g., cerebral palsy)—others may acclimatise to the lower number of calories provided without any noticeable change in oral intake. For children who respond to a slower reduction of calories, changes in oral behaviours may occur over months or years (Dipasquale et al., 2021; Williams et al., 2017; Wright, McNair, Milligan, Livingstone & Fraser, 2022).

Type: The type of approach often dictates the range of professionals involved (multidisciplinary or single discipline) and the frequency of support from the therapy team. Summarised here, but explained in detail in Chapter 4 (p. 119), approaches to weaning are those grounded in behavioural principles, those using a biomedical or other approach, and those incorporating a child- and family-centred approach (Lively et al., 2021).

Parents are faced with many decisions about how to proceed when they understand that their child will not instinctively begin eating and drinking, and a more proactive approach to transitioning from tube feeding is required. This may occur when they reflect on their child's capability with oral eating and drinking or when they are informed by their health professional team that their child is ready to wean. One of their first considerations may be whether they have access to a weaning program within their current health service. Further decisions must be made regarding the location and frequency of therapy, the speed with which tube feeds are reduced, the approach underlying the weaning program, and the cost. The approach that families choose, or have access to, can potentially affect the outcome of the child learning to eat and drink orally.

Summary - Chapter 1

This chapter provided an evidence-based platform to support the three research projects exploring aspects of tube weaning that influence children and their families. These are detailed in subsequent chapters (Chapters 4, 7 and 9). This chapter provided information regarding the foundations of learning to eat and drink successfully, why tube feeding may be required, and what may happen if tube feeding becomes 'the norm'. This chapter started to highlight the consequences of sustained tube feeding, contributed to knowledge regarding the challenges experienced by tube-fed children and their families, and highlighted the need for more active tube-weaning planning.

A scoping review of the published literature relating to tube-weaning programs was undertaken to delineate the tube-weaning approaches available to children and their families, as well as the learning theory underlying their philosophies. As described in the following chapters (Chapters 4, 6, 7, 8, 9), the differences in philosophies may influence a family's decision regarding how to proceed with tube weaning, and may ultimately influence how each child learns to eat and drink.

CHAPTER 2: THEORIES OF DEVELOPMENT

Learning to eat and drink is a developmental skill similar to learning to walk and talk. Yet tube-fed children may have little or no oral experience regarding food and fluid intake. In addition to their limited oral skills, their knowledge and capacity in the many other facets that make up successful mealtimes (as described in Chapter 1) require development. Therefore, it is essential to understand the context within which learning takes place, as well as the effect of the environment a child resides in, because this research program centres around a child- and family-focused model of teaching tube-fed children to eat.

Learning will be referred to throughout this chapter in the context of the different theories presented; therefore, a working definition of learning is outlined first. Learning is an active, continuous, and iterative process that results from absorbing new knowledge and testing and refining it (Kolb, 1984). Learning can be considered a product (e.g., observable changes in behaviour or actions) and a process (e.g., internal learning that may not result in a change in observable behaviour) that leads to lasting change (De Houwer, Barnes-Holmes & Moors, 2013). For the purposes of learning as it occurs when a child begins the transition from tube to oral intake, both the process and the product are important for the child and the parents.

Over the last two centuries, many theories have evolved to explain how development, and therefore learning, occurs. The earliest of these was proposed by Sigmund Freud, who suggested that personality development is the foundation of how children learn (Freud, 1910). While many other theories have likely been used to explain development, Figure 19 illustrates the theories I have used to explain how children learn to eat and drink. I have used a historical timeline to illustrate how these theories link to each other, and I describe below how they relate to tube weaning.

1910	1913	1938	1950	1963	1969	1977	1977	1985
Freud	Watson	Skinner	Erikson	Ayres	Bowlby	Bandura	Bronfenbrenner	Ryan & Deci
Personality	Classical conditioning	Operant conditioning	Psychosocial	Sensory	Attachment	Social cognitive	Ecological	Self-determination

Figure 19: Timeline of theories of learning and development used to interpret how children learn to eat and drink

Each theory on its own may not have sufficient explanatory power to explain how a child and parent navigate the complex process of tube weaning. Therefore, concepts from multiple theories are described and incorporated into subsequent chapters to explain the different international approaches to tube weaning. In addition, the unique internal and external factors that may affect a child's learning as they develop the skills to eat and wean from a feeding tube are discussed in this chapter. This includes theories that focus on responses within the child (internal characteristics) without considering the influence of the people and environment around them (Group A). These theories include Freud's Psychodynamic Child Development Theory and Ayres' Sensory Integration Theory. The second group of development and learning theories discussed (Group B) reflects external variables that influence a child's responses and subsequent learning (e.g., Bowlby's Attachment Theory, Bandura's Social Cognitive Theory, and Bronfenbrenner's Ecological Systems Theory). My clinical experience suggests that both Group A and B influence a child and their parents as the child learns to eat and drink.

To illustrate, consider a child with sensory-processing challenges (Ayres' Sensory Integration Theory, Group A) who displays an ambivalent insecure attachment pattern (Bowlby's Attachment Theory—Group B). They may not be calmed by their primary caregiver when sensory input becomes too intense (e.g., the feeling of sticky puree on their hands). With a reduced ability to self-regulate and co-regulate (using an adult to calm themselves), their imitation of new experiences within their environment (Social Cognitive Theory, Ecological Systems Theory—both Group B) will be limited (e.g., copying licking food from their fingers). In another environment with different caregivers (e.g., childcare), the child may use environmental supports (i.e., peers, alternate caregivers) to maintain emotional regulation (Ecological Systems Theory, Attachment Theory—both Group B). This scenario allows different engagement in mealtime routines than when in the presence of their primary caregiver. How a child and parent respond to and learn new strategies highly depends on the personality and learning characteristics of everyone engaged in the interaction. The process of developing, trialling, and evaluating strategies during tube weaning to maximise a child's ability to learn to eat and drink is unique to each family. This is because of the interactions between a child's (and parent's) internal characteristics with external influences. The next section discusses the underpinnings and evolution of each of the theories I have chosen to help describe how this interactive learning occurs.

Freud's Psychodynamic Child Development Theory

In the early 1900s, development was considered in relation to how one's personality advanced. In any given individual, personality is defined as the behaviours, cognition, and emotional responses that result from biological and environmental factors (Corr & Matthews, 2009). While personality is thought to remain relatively stable over a person's lifespan, it is subject to change with the influence of motivation, learning, habits, and engagement with environmental surroundings (Corr & Matthews, 2009; Sadock, Sadock & Ruiz, 2017). In the context of Psychodynamic Child Development Theory, it stands to reason that learning and development advance through the influence of intrinsic and extrinsic variables.

The work of Freud aimed to understand how personality develops in the first five years of life through the concept of five distinct psychosexual developmental stages that pose internal conflicts for the child to resolve (Freud, 1910). By striving to meet their biological and social needs, a child's personality and psychological development mature upon mastery of each of the five stages. Failure to master any of the stages may result in a child not learning at the rate of their peers, presenting with behaviours much younger than their chronological age, and stagnant development (Zamanian, 2011).

Freud's work predominantly placed the child at the centre of their personality development and, therefore, the behaviours they displayed. Despite believing that a healthy and robust attachment was important for an infant to learn to function as an individual, independent of its mother, Freud did not emphasise the influence of the environment within which the child was raised (Zamanian, 2011). This concept—Attachment Theory—was explored in detail some 60 years later by John Bowlby (1969; described below). As discussed below, Freud's Psychodynamic Child Development Theory is an historically important foundational concept; however, it has been built upon by more contemporary and multidimensional theories.

Behavioural Theories

Early behaviourism was proposed a few years after Freud's work and contrasted with Freud's proposed theory that learning occurs through the development of personality. Behavioural Theory suggests that emerging behaviour results from environmental stimuli rather than internal thoughts and motivations (Watson, 1913). John Watson, Ivan Pavlov, and Burrhus Frederic Skinner were instrumental behaviourists who proposed that operant and classical conditioning can change behaviour by using associations, rewards, and punishments (McLeod, 2016).

Classical conditioning was the concept that resulted from Watson's reflections on Pavlov's experiment with dogs in the 1890s. Watson proposed that all behaviour resulted from learned patterns of stimulus and response, and that the mind or conscious decision-making did not play a part. As such, he believed it is possible to teach any new skill regardless of a person's predisposition or natural aptitude (Watson, 1913).

Classical conditioning involves pairing a neutral stimulus with a naturally occurring automatic involuntary behaviour. Once an association between the stimulus and behaviour forms, the neutral stimulus evokes the same response in the absence of the naturally occurring stimulus (White, Hayes & Livesey, 2016). Support to overcome anxiety and aversion frequently uses these principles (Akpan, 2020); however, published tube-weaning outcomes more commonly refer to the use of operant rather than classical conditioning (Silverman, 2015).

The principles of operant conditioning, proposed by Skinner in 1938, can be used to develop voluntary behaviour by providing consequences to a current behaviour. This is commonly known as the antecedent–behaviour–consequence model (ABC). Favourable behaviour is rewarded and reinforced; therefore, it is more likely to reoccur. Non-favourable behaviour is punished; therefore, it is less likely to reappear in the future (Akpan, 2020). While much general research focused on operant conditioning in the 1970s and early 1980s, by the mid-1990s, publications on the use of operant conditioning for learning diminished despite the ongoing utilisation of the principles in clinical practice for a range of behaviour challenges (McInerney, 2005). This is perhaps due to a deeper understanding of the interplay between internal and external learning influences rather than the sole focus on the ABC sequence. However, Behaviour Theory principles continue to be used in current published tube-weaning programs (e.g., Pollow et al., 2018; Sharp et al., 2020; Taylor et al., 2019) and are particularly apparent in the literature published in North America (Lively et al., 2021; Schreck & Williams, 2006).

Operant and classical conditioning principles form the basis of applied behavioural analysis (ABA), which is an approach to teaching new behaviours across many realms of development, including communication, toileting, eating, fine and gross motor skills, and social acceptance (Baer, Wolf & Risley, 1968). ABA is widely used in feeding therapy for children with a narrow range of food choices (i.e., food selectivity), particularly those with autism spectrum disorders (Anderson & McMillan, 2001; Gale, Eikeseth & Rudrud, 2011). Behavioural theorists believe that parental responses to a child's behaviour at mealtimes contribute to developing and maintaining inappropriate mealtime behaviours (Bachmeyer et al., 2009). Therefore, to reduce problem behaviour and 'increase the number of bites', behavioural strategies such as escape extinction and reinforcement are used (Piazza, Patel, Gulotta, Sevin & Layer, 2003; Reed et al., 2004).

Feeding therapy based on a behavioural approach commences with a trained therapist (e.g., psychologist) implementing set behaviour strategies to target goal behaviours. Upon reaching the predetermined criteria, parent training starts with therapists transferring newly learned feeding behaviours into different environments and with other caregivers. Training of the child and parent initially occurs within the therapy setting, and the strategies are then applied to all home meals (Seiverling et al., 2019). Behavioural feeding therapy programs have been shown to improve feeding behaviours such as bite acceptance, chewing, swallowing, and self-feeding in clinical settings (Silverman, 2015). However, the maintenance of new behaviours in the home and school environments is less clear. The transfer of skills may be affected by aspects of the intervention that some parents may find aversive to implement (Silverman, 2015). For example, parents may be instructed to use chin or jaw prompting, which involves holding rejected food to the child's lips or into their mouth and holding their jaw closed until the food is swallowed (Silverman, 2015). Once parents have mastered the pre-identified and required levels of training, they are provided with a hierarchy of methods that are suitable to implement at home. However, if implemented incorrectly, the frequency and severity of undesired mealtime behaviours may increase (Silverman, 2015). Behavioural theories explain how behaviour develops as a learned consequence of specific environmental influences. However, in the absence of the prescribed conditions (e.g., the parent being unable to implement the strategy as prescribed), the environment is also known to affect a child's learning. The influence of the environment on learning is a focus of many learning theories; some that are relevant to tube weaning are described below.

Erikson's Psychosocial Development Theory

Erik Erikson proposed that development continues to occur from infancy throughout adulthood until death, and, like Freud, this development occurs in stages. His work used the principles of Freud's Psychodynamic Child Development Theory but drew upon the importance of social environments in shaping a child's psychological development (Erikson, 1950). Unlike behaviourism, which solely uses the environment to teach a new behaviour, Psychosocial Development Theory incorporates the social aspect of learning to describe eight stages of development (see Figure 20). Three components characterise each stage, namely ego identity (changing sense of self), ego strength (mastery at each stage), and conflict (serves as a turning point for a change) (Orenstein & Lewis, 2020).

Stage	Age	Major Question	Virtue
Trust versus mistrust	0–2 years	'Can I trust the world?'	Hope
Autonomy versus shame and doubt	2–4 years	'Can I do things myself, or must I rely on others?'	Will
Initiative versus guilt	4–5 years	'Is it okay for me to do things?'	Purpose
Industry versus inferiority	5–12 years	'How can I be good?'	Competence
Identity versus role confusion	13–19 years	'Who am I?'	Fidelity
Intimacy versus isolation	20–40 years	'Can I love and be loved?'	Love
Generativity versus stagnation	40–65 years	'What can I contribute to the world?'	Care

Integrity versus despair	65–death	'Was my life a good one?'	Wisdom

Figure 20: Erikson's 8 Stages of Development (Cherry, 2014). Reproduced with permission

The principles of Psychosocial Development Theory value the actions of those in the environment in shaping the child's perception at each designated stage. The first three ages and stages relate closely to the steps of a baby learning to eat, and in the context of tube weaning, these stages align with the child- and family-centred programs described in Chapters 4, 7, and 9 of this research program.

Stage 1 (0–2 years)—trust versus mistrust—relates to a baby initially learning that a breast or bottle in their mouth, and later a spoon or finger foods, can be a source of comfort and enjoyment rather than a source of pain or intrusion (Satter, 1990). Autonomy versus shame and doubt (Stage 2, 2–4 years) relates to a child being allowed to self-feed and make choices regarding food intake (volume and variety), and the resulting success. This contrasts with a parent insisting on feeding the child themselves for efficiency and cleanliness. This stage of development aligns with Self-Determination Theory (discussed below) as the child strives for autonomy, competence, and relatedness (Ryan, Patrick, Deci & Williams, 2008). Mealtime choices relating to initiative (Stage 3, 4–5 years), such as '*this food is not exactly how I like, but I can fix it to be acceptable for me*', become necessary as the child matures. This behaviour differs from Erikson's proposed phase of guilt (Stage 3), which, as per the above scenario, might be a child responding with '*you have not given me food exactly how I like it, so I cannot/will not eat it*'.

In the above examples, the often spontaneous and unscripted actions and responses of the parents in the environment either promote or hinder the child's subsequent perception or response, and the child plays a role in determining the outcome. This outcome may differ depending on the situation. In contrast, behavioural approaches to teaching a child to eat begin with predetermined adult responses to specific child behaviours. These responses are targeted to adjust the child's response in a specific direction as detailed by the therapy hierarchy. Therefore, specific outcomes are expected for each mealtime scenario, with the child having limited influence over what that outcome may be (Akpan, 2020).

At a similar time to Erikson's work on the effect of the child's social environment, Anna Jean Ayres began researching the effect of specific sensory inputs on a child's development. In particular, her work focused on understanding the effect of children's responses to sensory inputs in their environment on their behaviour and personality. In the early 1960s, Ayres published her Sensory Integration Theory and developed the therapy to support identified deficits.

Ayres' Sensory Integration Theory

In the 1950s, Ayres began exploring how the change in brain function for people with neurological conditions (e.g., cerebral palsy, cerebrovascular accident) affected their learning, behaviour, and ability to relearn and undertake daily personal tasks (Mailloux & Miller-Kuhaneck, 2014). Her findings demonstrated that brain function and dysfunction could be partly attributable to an individual's tactile, proprioceptive, and vestibular sensory systems. Ayres' research deepened over the next 10 years as she explored learning challenges, such as development learning delays, that may be less obvious than brain injury. Ayres reported under- or over-responsiveness in the sensory system's ability to interpret and respond to visual, movement, and touch inputs (Ayres, 1964). In conjunction with her research, she explored the response to therapeutic sensory inputs provided to address under- or over-responsiveness (Mailloux & Miller-Kuhaneck, 2014). In doing so, she developed Sensory Integration Therapy, which aims to mould and adapt future behaviour responses based on previous experiences and reactions to a given situation (Akpan, 2020).

Understanding that an individual's sensory system is unique helps explain how an individual's response to an experience may contrast with that of another person's response to the same experience. Ayres' Sensory Integration Theory contributes valuable insights into how tube-fed children respond when learning to eat and drink, because mealtimes present a dense sensory environment. The body uses eight sensory systems (outlined below) to process information both within and around the body. However, many tube-fed children experience sensory-processing difficulties as a result of prematurity affecting the development of the neurological systems in utero, and constant exposure to potentially aversive stimuli in the NICU (Mitchell et al., 2015). The next section describes the complex interplay of sensory inputs during mealtimes that may assist or hinder tube weaning and the application of Sensory Integration Theory to learning to eat and drink.

The Familiar 5 Senses

Each time a person eats or drinks, they use the five basic senses of vision (sight), auditory (sound), gustatory (taste), tactile (touch), and olfactory (smell). For example, to bite, chew, and swallow food, a child must be able to tolerate the look of the food, the feeling of it in their hands or mouth, the sound that the food makes in their mouth as they manipulate it, and the smell and taste of the food.

In addition to the sensory properties of engaging with food, children must be able to process and tolerate the sensory properties of the mealtime environment within which they participate. These sensory inputs include people sitting close to them, the sounds and odours of cooking, people talking, cutlery scraping, and people eating non-preferred foods close to them. A breakdown in any of these areas of sensory processing may lead to the child refusing to be in the mealtime setting or not trying the food and therefore maintaining a limited and restricted food repertoire (Chistol et al., 2018; Malhi et al., 2021; Nadon, Feldman, Dunn & Gizel, 2011).

Many babies that are born prematurely have underdeveloped and immature sensory systems or sensory responses reflective of the intensive care environment they spend time in (Mitchell et al., 2015). The first two years of a baby’s life are crucial for learning to detect and interpret sensory information and, in turn, use that information to develop gross and fine motor skills, daily life skills, and social competence (Als et al., 2004). Buffone, Eickman & Lima (2016) highlighted the increased alteration of sensory processing in this population in their study exploring the association between prematurity and sensory processing in infants. They showed that even when accounting for prematurity, there was an increased likelihood that an infant with altered sensory processing would experience impairments in cognitive development. Extended hospital admissions frequently characterise the first two years of a tube-fed child’s life because they remain in a state of medical fragility and have restricted access to the outside world (Page et al., 2020). This may have implications for the developing sensory and cognitive systems and their role in mealtime skill development.

Feeding problems associated with sensory defensiveness also occur in typically developing children (Smith, Roux, Naidoo & Venter, 2005) and frequently in children (aged 3–10 years) with an autism spectrum disorder with tactile, taste, smell, visual, or auditory sensitivities. These children are more likely to display food selectivity and eat a restricted variety of foods than children with a typical sensory-processing profile. This is directly related to their challenges with food's tactile, olfactory, and visual/auditory inputs (Malhi et al., 2021; Nadon et al., 2011).

The Less Familiar 3 Senses

As the subheading suggests, there are three senses that are less well known, perhaps because they are internal responses to stimuli (e.g., hunger) rather than responses to obvious external influences (e.g., the smell of food). These senses are known as proprioception, the vestibular system, and interoception.

In addition to the five well-known senses described above, the body interprets sensory inputs via the proprioceptive sensory receptors in the skin, muscles, and joints to determine its position in space. Challenges with proprioception may affect self-regulation, coordination, concentration, body awareness, and speech (Heroux, Butler, Robertson, Fisher & Gandevia, 2022). In the context of mealtimes, proprioception assists a child in remaining engaged and alert throughout a meal, accurately placing food or utensils into their mouth, being aware of how much food is in the mouth at any one time, and interacting socially with others.

Proprioception works with the body's vestibular system, which is responsible for sensing movement and knowing whether the body is up/down and moving fast or slow (Casale, Browne, Murray & Gupta, 2022). The vestibular system may affect posture, balance, movement, coordination, attention, and arousal. These essential skills are required to help a child stay in their seat at the table, master self-feeding with cutlery (including motor skills for cutlery use and hand–mouth coordination skills), and maintain engagement for the duration of meals.

Despite first being proposed in 1906 by Dr Charles Sherrington and referred to as '*sensations from the interior of the body*' (Sherrington, 1906), interoception has only more recently been regarded as fundamental to an individual's ability to participate in daily life activities (Hample, Mahler & Amspacher, 2020). Quigley, Kanoski, Grill, Barrett & Tsakiris (2021) refined Sherrington's definition of interoception to refer to '*the process of how the nervous system senses, interprets and integrates signals originating from* *within the body*' (p. 29). Interpretation involves the complex integration of internal sensory information identified by the body and communicated with the brain via the central nervous system. The brain interprets this message against a bank of prior experience (when available) to maintain homeostasis (Price & Hooven, 2018). Interoception is founded upon the brain trusting that the body will generate consistent and relevant sensations (Price & Hooven, 2018).

Among other activities of daily life, interoception provides vital cues relating to hunger and satiety that require situation-specific interpretation. However, the often-necessary invasive medical interventions that many tube-fed children have experienced interrupt the body's natural reaction to sensation and circadian rhythms of sleep and appetite. Tube-fed children may not produce reliable internal signals or may misinterpret them, making it difficult to generate meaningful responses (Schmitt & Schoen, 2022). This was highlighted by Mitchell et al. (2015), who found an increased risk of altered interoceptive awareness and under-/over-sensitivity in infants born prematurely. Interoceptive sensations are not under conscious monitoring by humans but are noticed only when the body acts to maintain homeostasis (Köteles, 2021). In the context of learning to eat, this may present as a child eating only a small amount of food at each meal because their stomach sensory receptors have a low threshold for registering satiety. Alternatively, a child may not appear to register hunger, as evidenced by long periods between food acceptance or provision (in the case of tube feeding) with no outward protest.

Mealtimes remain one of daily life's most sensory-challenging environments because they require the acknowledgement and interpretation of sensory information from all eight senses. A challenge in one or more sensory-processing areas may interfere with an individual's ability to progress through the texture, taste, or volume of food and fluids consumed, and may therefore directly affect a tube-fed child's transition to oral intake.

Both Freud and Ayres provided important foundations for understanding that a child's behaviour may result directly from their intrinsic biological predisposition. While they do not deny that the environment affects the expression of individuality, they do not acknowledge that a child initially reacts based on their experiences in their environment. In the 1950s, Erikson first proposed how social environments contribute to a child's psychological development. It was not until nearly two decades later that the importance of the relationship—referred to as attachment—between the parent and child for social and emotional development was described.

Attachment Theory

In the mid-1960s, psychologists reported on the innate sociability of babies from soon after birth following observations of their unique ways of interacting with and responding to their environment (Schaffer & Emerson, 1964). This, in part, may be influenced by their unique sensory system and corresponding responses to stimuli (Ayres, 1964). Bowlby was the first psychoanalyst to explore the psychological theory of attachment. He referred to attachment as seeking proximity and connectedness to a more robust or wiser person (Bowlby, 1969). When becoming attached to someone, a child becomes enmeshed in the influence this relationship provides. In developing his Attachment Theory, Bowlby (1969) observed the effects of separation between infants and their parents and incorporated Freud's view that a healthy and robust attachment allows for optimal learning and Erikson's stance on the importance of social environments.

Attachment Theory explains that a child's personality is a product of their relationships with significant carers in their environment. Personality continues to evolve at 12 months of age and, while always dynamic, becomes more stable by 18 months (Holmes, 2014) (see Figure 21). Attachment Theory allows for the potential change and development of social and emotional skills from childhood to adulthood, depending on the quality of the engagement and responsiveness of the caregiver (Bowlby, 1969). This contrasts with Freud, who viewed personality development as a result of mastery of internal conflict and did not consider the role of the caregiver. In the following explanations of attachment style, the word 'parent' may be interchanged with 'caregiver' and 'attachment figure'.

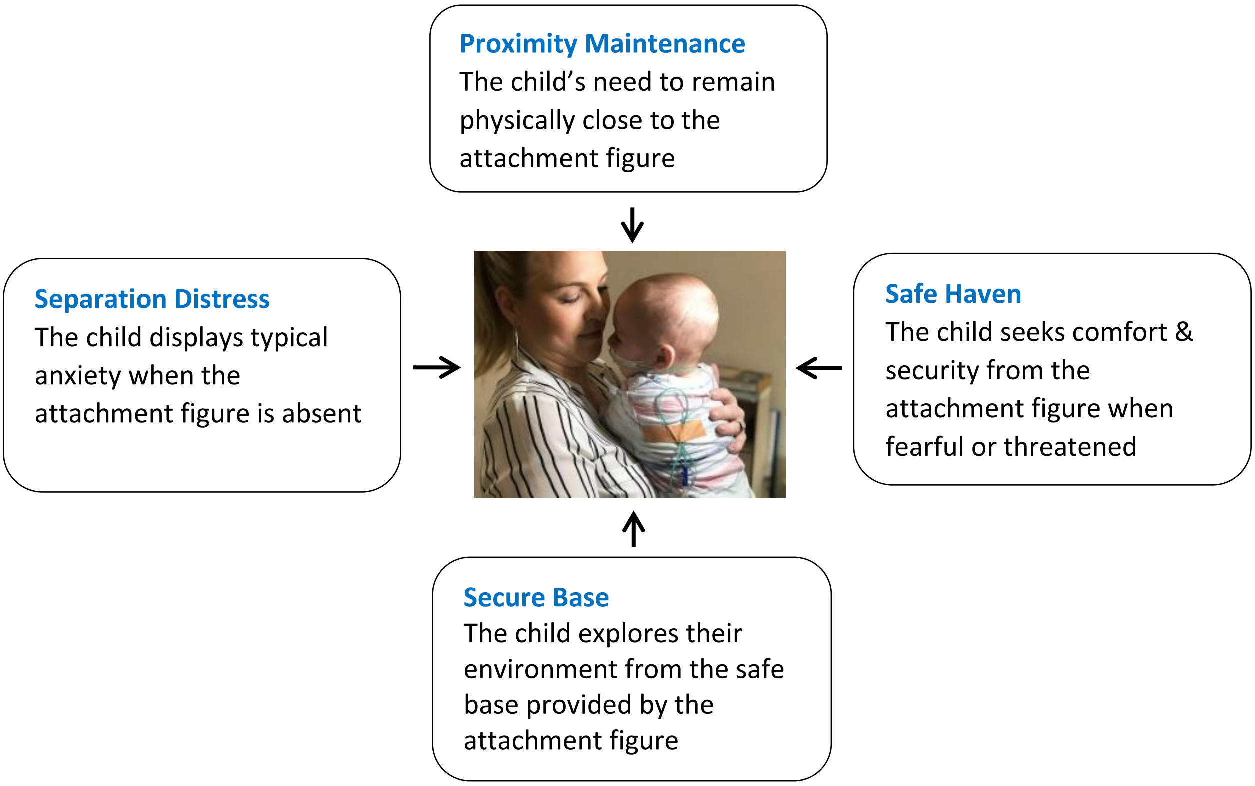


Figure 21: Characteristics of Attachment as Described by Bowlby (adapted from First Discoverers, n.d.)

Active, reciprocal interaction facilitates the development of a child's personality (behaviour, cognition, and emotional responses) (Rutter, 1981). Because interactions are dynamic, the nature of attachment may change over time as circumstances and experiences change. In addition, mother–child and father–child interactions may differ within the same family environment; therefore, the child may display different responses to the same situation (Rutter, 1981).

In the context of feeding development, which is necessary for tube weaning, a child may have adverse associations with mealtimes because of past medical trauma. The effects of medical trauma are discussed further in Chapter 6; however, in summary, invasive medical procedures (e.g., inserting an NGT) may influence the child's trust in placing anything near or in their mouth, including foods and utensils. In desperation to support their child learning to 'take a bite', their parent may frequently offer food and drink with well-meaning but intrusive strategies. These strategies may affect the safety and security of the parent as a base from which their child can safely explore their environment (see Figure 21). Teaching the parent how to provide a consistent, predictable, and reliable mealtime environment adjusts the interaction to facilitate trust and exploration.

Mary Ainsworth expanded on Bowlby's theory by recognising that the quality of attachment rather than the quantity of engagement was a key factor in learning and development (Ainsworth, 1978). Her research observed 12-month-old babies left in the company of a friendly stranger for three minutes before being reunited with their mother. In her attempt to explain how an infant's relationship with their mother influenced their exploratory behaviour, Ainsworth (1978) described three observed response patterns, and a fourth pattern was later identified (Main & Solomon, 1990). The next section details the attachment patterns described by Ainsworth, and Main and Solomon and will be discussed in subsequent chapters when discussing the effect of trauma on attachment and the development of mealtime skills (see Chapters 8 and 9).

Patterns of Attachment

Secure Attachment ('B')

Children with a secure attachment to their parents usually become distressed when separated from that person but greet them upon their return. They are calmed by their parent's comfort and happily return to playing contently. The consistency with which these parents respond to their child's verbal and nonverbal communication cues contributes to the child's secure attachment to them (Main & Western, 1982).

Insecure Attachment—Avoidant ('A')

Children with an insecure attachment to their parent are not upset upon separation from them and show a limited reaction when they return, even on repeat separations. Despite appearing avoidant, insecure children remain hypervigilant of what their parent is doing, and their exploratory play is restricted (Ainsworth, 1978). Parents of avoidant children are described as unresponsive and mildly rejecting of their child's requests and behaviours (Main & Western, 1982).

Insecure Attachment—Ambivalent ('C')

Mothers of children with ambivalent attachment are inconsistently responsive to their child's needs (Main & Western, 1982). Ambivalent children become highly distressed when separated from their parent and do not quickly calm down upon the parent's return. Although they seek contact from their parent and sometimes cling to them, they do not readily accept comfort and may actively resist any attempts of comfort given (Ainsworth, 1978). Like avoidant attachment, these children have inhibited exploratory play (Main & Western, 1982).

Insecure Attachment—Disorganised ('D')

Main and Solomon (1990) identified a fourth attachment category after observing children with communicative behaviours not reflected in the above descriptions. Common behaviours displayed by children with disorganised attachment include 'freezing', seemingly distant or dissociated, or repetitive stereotypical movements (i.e., rocking backwards and forwards, curling their body into a ball) upon reunification with their parent. Unlike children with a secure base from which to explore their environment, children with disorganised attachment may fear their parent, which results from the parent's consistent lack of appropriate response to the child's distress or fear (Pelly, 2019).

Early attachment research centred on mothers as the primary caregiver. Historically, the mother and baby remained physically close because of the mother's ability to supply breastmilk frequently (Freud, 1910). As per Freud's (2010) psychosexual stages of development, this close relationship allowed the baby to satisfy the first (oral) stage and, in time, progress to the next stage of development. Attachment Theory can be applied to any significant caregiver in an adult–child dyad, particularly considering the diversity of families, including children in kinship, same-sex, and heterosexual parenting in which the father assumes the primary caregiver role (West et al., 2009). It is important to consider the differences between parents' attachment and engagement with the tube-fed child learning to eat.

As described in Chapter 1 ('Development of Mealtime Skills', p. 29), learning to eat and drink occurs best within an environment with responsive mealtime participants. Being appropriately responsive relates directly to the principles of Attachment Theory and the consistency and relevance of parents' responses to their child's communication. Non-tube-fed babies learn to feed and eat from birth and over the first 12–18 months of life, corresponding with the time when attachment to a parent develops. During this time, attachments form depending on the interactions provided by the parent and the resultant reaction of the child. As described in Chapter 1 (‘Learning to Eat’, p. 10, and ‘Responsive Feeding’, p. 29), learning to eat and drink requires an accurate and timely interpretation of the child’s physical and emotional cues. This may be affected by the interaction style (attachment) between the child and parent, particularly in the case of a tube-fed child and their parent/s, all of whom may have experienced medical trauma and interact in highly medicalised environments. The physiology of trauma is described in Chapter 8 (p. 169); however, to highlight its effect on attachment, trauma may manifest as over-arousal; poor concentration, sleep and appetite; and emotional dysregulation (Diagnostic and Statistical Manual of Mental Health-5, 2013; DSM-5). It may result from a parent’s reaction following their child’s diagnosis or witnessing their child receiving invasive medical procedures. A child may be traumatised by repeated invasive interventions in a sensory-stimulating environment such as an intensive care unit (Toof, Wong & Devlin, 2020). As described further in Chapter 8 (p. 172), medical trauma may affect the child’s and parent’s functioning and result in an insecure attachment. A child may provide inconsistent and confusing mealtime cues, and parents may overlook or misinterpret them, thus jeopardising the child’s ability to develop sustainable mealtime skills and a positive feeding relationship.

As researchers continued to reflect on the influence of significant caregivers in a child’s development, awareness of the influence of the broader community on child development increased. Around the time that Ainsworth described the types of attachment between mother and child, theories evolved that incorporated the influence of broader relationships—namely, Social Learning/Cognitive and Ecological Systems Theory. While children can develop within the cocoon of their home, their experiences and opportunities are broadened through interactions with the outside world—particularly the development of eating and drinking, which best occurs in social environments (Morris & Klein, 2000). These may occur through educational, childcare, and social settings. Theories of learning that incorporate more than the child and their immediate environment provide valuable information when considering tube-weaning program design and strategies to teach tube-dependent children to eat and drink.

Social Learning Theory/Social Cognitive Theory

Albert Bandura proposed that behaviour and emotion were more complex than a response to a stimulus and that, unlike behavioural theory approaches, children could observe others and *not* make a subsequent change to their behaviour (Bandura, 1977). While he acknowledged the contribution of operant and classical conditioning to behaviour change, he also considered how both environmental and cognitive components interact to influence learning, and he called this Social Learning Theory. In the 1980s, it was renamed Social Cognitive Theory (SCT) to reflect the intentionality in a child's behaviour (McLeod, 2016). SCT helps to make sense of a child's observation and *intentional* imitation of the emotional, physical, and social behaviour of those in their environment across various situations. The child may intentionally decide whether to imitate and adopt a behaviour and, as a result, receive positive or negative reinforcement, with positive reinforcement leading to an increase in those behaviours (as per operant conditioning).

Bandura (1977) described the importance of agency in a child's development of self-efficacy as believing in their capacity to control and master their abilities to achieve success. Self-efficacy is supported by early learning experiences that promote emotional literacy, and through observing the success of others and receiving positive feedback (Bandura, 1997).

SCT informs mealtime practices, as evidenced by early childhood education and care settings in Queensland, Australia, recognising the importance of educators as agents. Educators are well positioned '*to exert intentional influence over one's functioning and the course of events by one's actions*' (Bandura, 2012, p. 11). With children spending considerable time (15–20 hours each week) in these settings (Baxter, 2015), some centres have incorporated the principles of SCT to optimise the development of feeding behaviours during mealtimes (McGuire, Irvine, Smith & Gallegos, 2021). Facilitation of the child's agency (choice, decision-making, and influence) within tube-weaning programs forms an essential component of the tube-weaning program described as part of this research program (see Chapters 7 and 9) and highlights the importance of the mealtime environment above and beyond only the food and drink.

Around the time that SCT was described, Russian–American Psychologist Urie Bronfenbrenner (1977) explored the influence of the greater community and culture on how children learn. While SCT highlighted the importance of the environment as an agency for children to develop their skills intentionally, Bronfenbrenner proposed a theory that incorporated multidirectional influences of the environment within which a child is raised. His studies led to the development of Ecological Systems Theory.

Ecological Systems Theory

Bronfenbrenner expanded upon Attachment Theory and SCT principles to include the influence of all of the external relationships that may interact in varying manners on a child. This includes the effects of the child's family, peers, society, culture, and customs on development and learning. He proposed that a child's development is influenced at any one time by the different contexts and combinations of environments (ecological systems), as well as the child's influence on their surrounding environments (Bronfenbrenner, 1977).

Bronfenbrenner (1977) described the child as nestled within layers of systems with increasing proximity to the child (see Figure 22). A bidirectional effect exists in the immediate environment whereby the microsystem influences the child, and the child may influence those in the microsystem, including parents, carers, education settings, extended family, and religious communities (Bronfenbrenner, 1977). An overly fastidious parent who insists on cleaning every surface and mess may inadvertently reduce their child's sensory tolerance of 'mess' on their hands/face. In the context of tube weaning, the child may need to overcome their reluctance to food mess before they are comfortable holding a finger food and bringing it to their mouth.

The mesosystem reflects interactions within the child's microsystem and their immediate effect on the child. For example, a child's childcare support worker may have developed successful ways of helping the child to engage with food or to eat. To facilitate consistent strategies across multiple environments, they may discuss their approach with the child's parents for implementation at home.

The exo-, macro-, and chrono-systems indirectly influence the child by influencing the environment and people around the child (Guy-Evans, 2020). In the above example, consider the childcare centre implementing a policy that encourages all children to self-feed (as much as possible) and has a multicultural menu on offer. Through immersion in this environment, the tube-fed child experiences natural exposure to foods of varying colours, textures and flavours, as well as cutlery use, hand–mouth coordination and loading a spoon with food at a level they can manage.

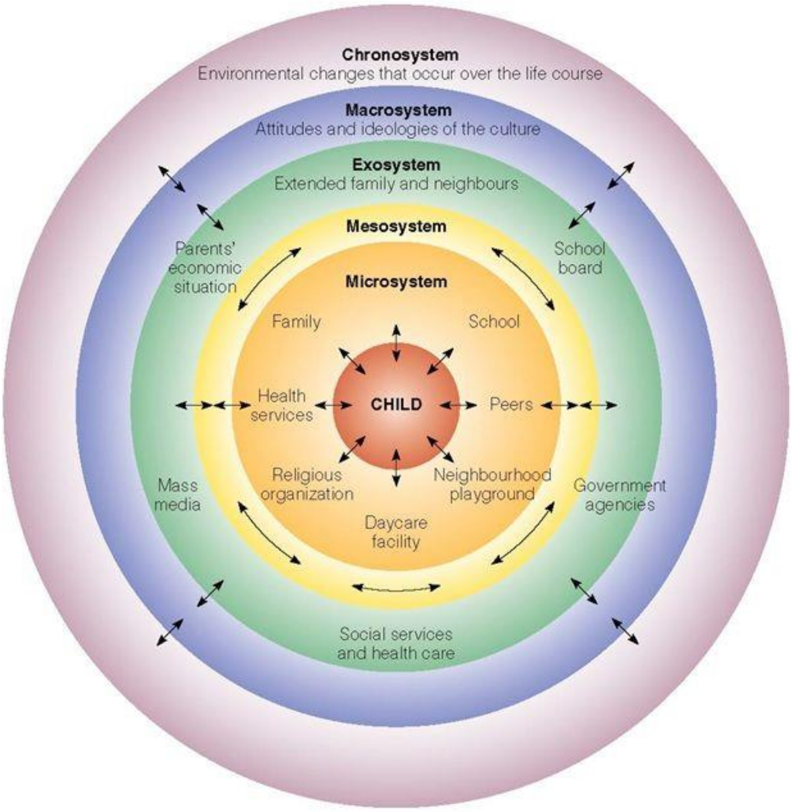


Figure 22: Bronfenbrenner's 5 Ecological Systems (Guy-Evans, 2020). Reproduced with permission

Immersing children within various environments provides them with an opportunity for observation, interpretation, reflection, and response across multiple levels of influence (Bauman, Sallis, Dzewaltowski & Owen, 2002). Children may assimilate closer to the behaviours they observe in others or remain passive to change (Ryan & Deci, 2000). Why are some children and parents proactive and persistent with change, while others remain passive? Ecological Systems Theory provides an environment for potential behaviour imitation (as described in SCT), but what provides the intrinsic motivation that drives behaviour change? This question will be explored further through Self-Determination Theory (SDT), which is described below.

Self-Determination Theory

SDT was proposed as a way of explaining a person's fundamental intrinsic desire and motivation to initiate, improve, and maintain new behaviours over time (Deci & Ryan, 1985). Autonomy, competence, and relatedness have been described as the three fundamental needs that can motivate the initiation of behaviour change and learning within people (Ryan & Deci, 2000; Ryan et al., 2008). As described at the start of the chapter, learning in the context of SDT refers in the first instance to the *process* (i.e., internal learning) rather than the product. The internal process of a tube-fed child learning to eat will be considered within the framework of the three fundamental needs (autonomy, competence, and relatedness) required for learning, as per the principles of SDT.

Autonomy as it Relates to Learning to Eat and Drink

Autonomy relates to an individual feeling in control of their choices and the subsequent consequences of their decisions and resultant actions or behaviours. Achieving autonomy is influenced twofold: first, autonomous motivation, whereby an individual is motivated to drive behaviour change; and second, autonomy support, in which another person helps facilitate autonomy, competence, and relatedness (Ryan et al., 2008). To illustrate, visualise the delicate interplay between the child and parent when a tube-fed child shows interest in learning to eat and drink (motivation), with the parent allowing them to practice to the best of their ability (support). The child’s ability may not yet be efficient or effective; however, giving them an opportunity to practice provides them with a sense of independence, value, and achievement, which further encourages them to persist. This is at the core of a person striving for competence.

Competence as it Relates to Learning to Eat and Drink

A child and parents’ experience of competence is thought to influence their ability to internalise and integrate new learning and behaviours (Ryan et al., 2008). Supportive therapy environments that promote confidence and competence form part of the child- and family-centred approaches to tube weaning. When a child and parent are motivated to attempt an unfamiliar skill, their competence is supported by an environment that provides the right amount of challenge for them to remain engaged and yet still work to master the new skill (Ryan et al., 2008). If the challenge is too great, they are less likely to persist with the task. As per the principles of SDT, both competence and self-motivation are proposed as important facilitators for integrating new learning. As an example, a tube-fed child with a history of dysphagia and aspiration of thin fluids may lack both volition and confidence to drink water because of the discomfort they know it will bring. When thickened fluids are provided in a supportive environment (e.g., parent tasting thickened water from a spoon with their finger), the child may feel confident enough to copy their parent and dip their finger in the thickened water and lick it. A child's feelings of self-competence, confidence, and trust improve each time they lick thickened water and it does not result in coughing and chest pain (as may happen during aspiration). This example demonstrates the importance of the right amount of challenge and a supportive environment—provided by a person the child trusts and feels connected to—in providing the foundation for the child to attempt an unfamiliar activity. The feeling of connectedness relates to the third fundamental need of SDT.

Relatedness as it Relates to Learning to Eat and Drink

Relatedness refers to feeling understood and cared for by others (Deci & Ryan, 1985). As per Attachment Theory, feeling acknowledged and respected forms the basis of a secure attachment between a child and their parent. In addition, responsive feeding practices likely result in feelings of relatedness for both the child and the parent. When people feel connected to and trust others, they are more likely to seek to align with the behaviours and beliefs that those trusted people display (Ryan et al., 2008). In the early stages of introducing oral feeds, many tube-fed babies experience repeated stressful events. These can include aspiration or oxygen desaturation and can lead to ongoing oral aversion lasting many years (Kirk et al., 2007; Samara, Johnson, Lamberts, Marlow & Wolke, 2010). To overcome the complex aversive feelings and reactions previously associated with feeding (Dunitz-Scheer & Scheer, 2022), tube-fed children need to develop trust in their primary caregiver and feel that their discomfort and communication cues are being heard and responded to. As they come to learn to eat, they require time, respect, and compassion from the adults in their environment to develop trust in mealtimes and be able to progress at their own pace.

SDT has been used extensively across many areas of healthcare to promote change within individuals, and supportive environments that facilitate self-determination have been associated with an increase in an individual's perceived competence (Ng et al., 2012; Ridgway, Hickson & Lind, 2016). Hopwood et al. (2020) explored the strategies that families use to manage the additional demands and challenges of enterally feeding their child and thrive in their role as parents rather than surviving the day-to-day. They demonstrated the importance of health professionals in providing advice and strategies to support the parents of tube-fed children in providing autonomy-supportive mealtime environments (Hopwood et al., 2020). To best tailor the most helpful resources and support strategies, we need to understand what influences weaning success, including how parents experience the weaning journey.

In addition to a supportive environment, motivation and personality affect people's inner desire to strive to achieve the new behaviours they observe in their surroundings. From birth, healthy children show curiosity and inquisitiveness without requiring specific rewards (Harter, 1978). This contrasts with behaviourism, in which tangible rewards are an integral component of teaching new behaviours. Natural curiosity contributes to the exploration and mastery of skills that contribute to social and cognitive development (Csikszentmihalyi & Rathunde, 1993). However, these intrinsic tendencies can be easily disrupted by non-conducive influences (e.g., trauma or neglect), which are described further in Chapter 8, and can be maintained and enhanced into adulthood (Ryan & Deci, 2000). In addition to influencing a child, trauma may affect parents who have witnessed their child's challenging medical experiences. Because parents play a vital role in tube weaning in the program described in Chapter 7, it is essential to understand how they learn and develop new mealtime skills, which in turn facilitate the development of oral skills for their tube-dependent child.

Learning Theory as it Relates to Adults

This chapter explored how children learn as a result of internal (Ayres' Sensory Integration Theory, p. 85; Freud's Psychodynamic Child Development Theory, p. 80; SDT, p. 96) and external (Behavioural Theory, p. 81) influences, including their interactions with their close caregivers (Attachment Theory) and others in their environment (SCT, Ecological Systems Theory, SDT, Psychosocial Theory). Learning to eat and drink is a dynamic and multimodal experience shaped by the parents' ability to interpret a child's hunger cues and facilitate a mealtime opportunity for them. Given the potential challenges highlighted in Chapter 1 (Effects and Sequalae of Enteral Tube Dependency), the usual strategies for supporting an oral baby to accept breast or bottle feeding and then transition to solids may not be successful. Therefore, parents must undertake considerable learning when they are thrust into the special care hospital system and, among other medical care, must learn to manage tube feeding (Hopwood et al., 2020; Serlachius et al., 2018). This is often at a time when parents feel grief, disempowered, detached from the care of their baby, and isolated (Serlachius et al., 2018), which may affect their learning capacity and information retention.

How Do Adults Learn?

In 1968, Malcolm Knowles suggested that the way adults learn is different from that of children's learning and is distinguished from pre-adult learning theory by the following six assumptions: (1) an adult shows self-directedness; (2) adults have accumulated experience on which to base new learning; (3) adults possess a readiness to learn; (4) adults desire to learn what is relevant and applicable rather than general learning about a topic; (5) adults have internal motivation to learn and improve their knowledge or performance; and (6) adults hold an inquisitive desire to know why something should be learned (Knowles, 1984). However, having explored the theories of child learning and development above, one could argue that adult learning is not dissimilar to child learning (excluding point 6). The theories discussed thus far—relating to how a child learns—are equally relevant to parents learning how to facilitate their child to wean from tube feeding successfully. However, parents are different in that adults have more or different learning or experiences to reflect and build upon.

To illustrate how an adult's learning may be shaped, I will draw on the example provided at the beginning of this chapter relating to a child with a sensory-processing disorder and an insecure ambivalent attachment to their parent (p. 79). The parent may not tolerate mess, and to meet their sensory needs (i.e., cleanliness), they constantly clean their child or do not allow them to explore or play with food. Teaching the child to tolerate the sensation of mess also involves the parent learning to tolerate mess. In the same example, a parent who is not well attached to their child will find it challenging to recognise their child's cues and then learn to respond appropriately. The parent must first learn how to recognise and then respond meaningfully to their child before the child will allow comfort from them at times of challenge. They may also need to develop the skills of being able to reflect on their own actions and the reactions these may trigger in their child.

Rather than traditional teaching methods (i.e., passive instruction and information giving), multiple opportunities to practice, review, and revise parental engagement at mealtimes in a scaffolded and collaborative learning environment should occur. For parents to learn new mealtime strategies to support the development of their child's oral skills, learning opportunities could incorporate 'hands-on' practice with guided feedback, reflection, action, feeling and thinking, which in turn supports the transfer of learning to new situations (Kolb & Kolb, 2005).

How Does the State of the Parents' Mental Health Affect Their Learning?

Facilitation of parents' learning by health professionals should embrace Attachment Theory, whereby the parents' potential shame is reduced, and trust can develop, allowing parents to explore alternative options for their interactions at meals (Mezirow, 1995). Compassion and awareness of external factors as per Ecological Systems Theory (e.g., parental mental health), which may affect a parent's learning, is essential; however, it does not always translate to behaviour change (Nightingale, Friedl & Swallow, 2015).

While adults may be more aware of their learning preferences, teaching to someone's preferred learning style does not guarantee improved performance because adults' learning may be affected by their mental health state (Rogowsky, Calhoun & Tallal, 2020). Fear, guilt, and post-traumatic stress are common among parents with a child with a disability (Christie et al., 2019; Nightingale et al., 2015) and may influence learning, as discussed further in Chapters 8 and 11. Although parents may not be irrational in their fear or stress, these states may create a barrier to learning because of the physiological rise in cortisol levels in the body (Lindauer, Olff, van Meijel, Carlier & Gersons, 2006). Studies have shown conflicting results for the change in cortisol levels following post-traumatic stress (Lindauer et al., 2006; Lindley, Carlson & Benoit, 2004; Yehuda, 2002). However, increased cortisol levels may contribute to a weakened immune system and altered sleep and appetite cycles, as well as memory, learning, and motivation challenges, all of which affect learning capacity (Felder & Brent, 2005; Lindauer et al., 2006; Thau, Gandhi & Sharma, 2022). The research program presented in this thesis places importance on the parents' learning to facilitate mealtime environments that support their tube-fed child to learn to eat and drink. This contrasts with programs that use behavioural principles and require a direct teaching approach between the health professional and the child. The capacity of parents to participate in tube weaning is explored further in Chapter 9, and considers how their lived experience and challenges may influences their ability to learn new mealtime routines.

Summary—Chapter 2

From birth, children have an innate desire to learn. Some researchers have proposed that a child's learning is the result of an intrinsic desire to meet their internal needs (Deci & Ryan, 1985; Freud, 1910) and that internal needs are influenced by their sensory-processing ability (Ayres, 1964). In contrast, behaviouralists believe that learning is a direct result of environmental stimuli rather than internal thoughts and motivations (Watson, 1913). Others suggest that a child's learning and behaviour are shaped by the attachments they form with their close caregivers (e.g., parents) in the first few months and years of life (Bowlby, 1978; Deci & Ryan, 1985). Depending on the quality of these attachments, a child may develop trusting and confident relationships with their parents within which they are encouraged to attempt new skills, knowing that they have support around them to help them succeed (Deci & Ryan, 1985). Other children may feel like they must go it alone because of the fear or doubt they hold for their parents. Not only do the close attachments with parents influence a child's learning style, but the modelling and feedback from others in their environment, culture, and community are also thought to guide children's acquisition of new skills (Bandura, 1977; Bronfenbrenner, 1977; Deci & Ryan, 1985; Erikson, 1950).

Fundamentally, adults and children learn in similar ways but with differing life experiences as their foundation. Both participants play an essential role in developing successful mealtime skills, as described in the tube weaning program in Chapters 7 and 9. Incorporating aspects of many learning theories—in particular Attachment Theory, SCT, Ecological Systems Theory, and SDT—offers a dynamic framework to explore how tube-fed children learn to eat and drink. Consideration of multiple theories is required to understand tube weaning to reflect on individual factors of the child, parents, and significant others as they interact with multilevel contextual influences in the wider community. Learning to eat is a reciprocal experience between the parent and child—not a skill for the child to master in isolation (Hardy, 2011). Therefore, incorporating observations across the multiple layers of influence should facilitate effective intervention design (Sallis et al., 2008).

Understanding the theoretical foundation of tube-weaning program design, how this contributes to weaning outcomes, and the interactive role of individuals and the environment form the basis of the research aims presented in the next chapter.

CHAPTER 3: RESEARCH AIMS AND OBJECTIVES

Overall Research Objective and Rationale

The research program presented in this thesis aims to investigate clinical questions relating to enteral tube weaning in the paediatric population. Specifically, this thesis focuses on understanding the challenges experienced by tube-fed children, their families, and health professionals as they progress on their tube-weaning journey. Tube weaning is not a medical procedure to be performed on a child (Dunitz-Scheer & Scheer, 2022). Instead, learning to eat and drink is a developmental task that involves physical and emotional energy from children and parents alike.

Providing nutrition and hydration via an external feeding tube is lifesaving for children (and adults) who are unable to safely consume these orally. This may be due to several reasons, such as dysphagia, medical complications (e.g., respiratory and heart), gastrointestinal challenges, prematurity affecting an infant's ability to feed safely, and faltering growth (Daveluy et al., 2006; Miller, 2009; Rudolph & Link, 2002). To support the child and family towards a greater sense of normality, it is suggested that weaning a child from the tube and establishing oral feeding should occur as early as possible when medically appropriate (Dunitz-Scheer & Scheer, 2022). Doing so will help normalise social mealtimes, develop oral skills, and reduce any effects on the parent–child relationship, parenting capacity, and family stress (Krom et al., 2019; Pederson, Parsons & Dewey, 2004; Wilken, 2012).

However, varying tube-weaning approaches are used internationally, and with no universally agreed-upon weaning protocols, it may be difficult for professionals and families to know the most effective way to tube wean. In addition, parents may be supported in their decision-making regarding tube weaning if they have information regarding the physical characteristics that may be predictive of success.

A position paper developed by a multidisciplinary group of paediatric specialists, including paediatricians, gastroenterologists, psychologists, speech pathologists, dietitians, and occupational therapists, provided the strongest recommendations to date (Clouzeau et al., 2021). These are comprehensive and encompass many areas directly related to the child, including weaning readiness and cessation criteria, how tube feeding is used, and the mode of weaning. They mention '*preparing parents for adequate investment in* *weaning*' (Clouzeau et al., 2021, p. 507) but give no further reference to what this entails, the critical role of parents, or the effect of tube feeding and weaning on parents. Hence, the research presented in this thesis is important to highlight the role of and toll on the child and the parents during tube weaning.

This research program aims to contribute to the body of knowledge regarding best practice for paediatric tube weaning. Understanding the challenges experienced by children and parents during tube feeding and weaning is the beginning of acknowledging where clinical change can occur. Partaking in any form of treatment should require a clear description of the philosophy underlying the procedure. Yet, decision-making may confuse parents if clear foundational protocols and rationale for tube-weaning programs are not clearly understood or communicated.

The next section outlines the research aims, questions, rationale, and significance of the three research studies undertaken and presented in this thesis.

Characterising International Approaches to Weaning Children from Tube Feeding: A Scoping Review—Chapter 4

Research Project 1 Aims

1. To identify the main philosophies underpinning intervention design of published tube-weaning programs.

2. To identify the main outcome variables used to demonstrate the success of existing tube-weaning programs.

Research Questions

1. What are the current approaches to tube-weaning intervention?

2. What are the outcome variables measured by tube-weaning programs?

Rationale and Significance

Approaches to tube-weaning enterally fed children, and the outcomes used to evaluate the effectiveness of a program, vary widely. This limits the utility of research for identifying 'what works' and successfully implementing research outcomes. Providing clear information relating to the above research questions can guide clinical tube-weaning service development and clinical decision-making regarding tube-weaning readiness. In addition, this information may be used by parents to inform their options for tube weaning their child and give breadth to the many areas across which development occurs when learning to eat and drink. In this way, the sole focus of weaning shifts from whether the tube remains in use to the progress that each child makes across the many areas identified in Chapter 1 which are known to influence mealtime skill development. The findings make significant contributions to providing clear information to parents and professionals regarding weaning program options to support decision-making in both undertaking and providing tube-weaning programs.

Variables Affecting the Time Taken to Wean Children from Enteral Tube Feeding to Oral Intake—Chapter 7

Research Project 2 Aims

1. To investigate biological factors which may influence the time it takes for children to wean from enteral feeding to oral intake.

Research Questions

1. Do biological factors, which are usually considered to impact successful tube weaning (e.g., weight, the volume of oral intake, oral skill, or mealtime behaviours), influence the time it takes children to wean?

2. Which biological factors are associated with the time it takes a child to wean?

Rationale and Significance

The decision to wean a child depends on the eligibility criteria set by each program or team that offers tube weaning. This results in inconsistent access and opportunities for some children to transition from tube feeding. Prior research has shown that a child's medical complexity, the type of tube used for feeding, and age can influence weaning outcomes (Bazyk, 1990; Ishizaki et al., 2013). Health professionals may also consider whether weaning success is influenced by factors such as the child's pre-weaning weight, their ability to accept and swallow food or fluid, their sensory and regulatory capabilities, and oral motor skills. There is limited research evidence that explores *whether* these variables influence weaning outcomes and, if so, *which* factors are important in learning to eat and drink. To address these questions, this study investigated biological variables that may affect the time taken to wean children participating in an intensive interdisciplinary inpatient tube-weaning program. The findings of this may, in the future, contribute to a set of internationally agreed guidelines regarding weaning readiness and suitability, and may contribute to consistency across services regarding who is offered an opportunity to learn to eat and drink orally.

Parents' Experiences of Their Child's Transition from Tube to Oral Feeding During an Intensive Intervention Program—Chapter 9

Research Project 3 Aims

1. To investigate the thoughts, experiences, and reflections of parents as they decided to, and then participated in, an intensive tube-weaning program.

Research Questions

1. What were the parents' thoughts, experiences, and reflections before, during, and after participating in an intensive tube-weaning program?

Rationale and Significance

Tube dependency can affect parent–child relationships and sibling and family dynamics, and place additional medical demands upon parents (Krom et al., 2019; Pederson et al., 2004; Wilken, 2012). Outcomes from this research project suggested that factors other than biological considerations affected the time children took to learn to eat and drink orally. It was hypothesised that a contributing factor may be the influence of the parents during tube weaning. However, there is minimal research on the experiences of children and parents during the actual weaning process. Research has been undertaken with mothers only to explore their experiences and perceptions while participating in tube weaning their child (Cipolla et al., 2022). However, the barriers, facilitators, and emotional journey that mothers and fathers experience during the tube-weaning process are not yet well understood. Understanding the overall experience of parents, from decision-making to participating in tube weaning and then transitioning home, will help facilitate targeted and timely healthcare. This is vital to improving the experiences and outcomes for the child and the family.

Summary – Chapter 3

In summary, this research program aims to answer the above questions to contribute to an understanding of the philosophies underpinning weaning program design and the individual biological factors that influence the time it takes for a child to wean from a feeding tube. In addition, this program aims to understand the tube-weaning experience from the parents' perspective. This information has been used to derive clinically focused principles (see Chapter 11) that can, in turn, inform and enhance clinical tube-weaning practice for both parents and health professionals. In addition, this information has contributed to international guidelines regarding tube weaning (Clouzeau et al., 2021) and considers how health professionals can support families of tube-fed children as per the recommendation from Hopwood et al. (2020).

CHAPTER 4: SCOPING LITERATURE REVIEW

This chapter was peer-reviewed and published online in the *Journal of Parenteral and Enteral Nutrition* in 2020 and subsequently in print. The aim of this study was to map the therapeutic tube-weaning options provided internationally to understand the breadth of different weaning approaches being offered around the world.

The published article was originally prepared with the American Medical Association (AMA) referencing format as per the journal specifications. References in this chapter have been reformatted in line with the requirements of this thesis.

This paper was co-authored with the contribution of each author being as follows:

Ms Emily Lively—60% concept development and project design; 70% data collection, data analysis, and interpretation; 60% drafted and finalised manuscript, submitted for publication.

Professor Sue McAllister—20% concept development and project design; 15% data interpretation; 20% edited manuscript.

Associate Professor Sebastian Doeltgen—20% concept development and project design; 15% data interpretation; 20% edited manuscript.

Introduction

The survival rate of infants born prematurely or with a range of medical complications has increased over the last 30 years as a result of improved medical treatments. This includes the use of enteral nutrition in the early months when infants are unable/unsafe to feed orally (Hack et al., 2005). For some of these children, the reliance on tube feeding beyond the period of medical necessity has resulted in dependence on enteral feeding for ongoing nutrition and growth in the absence of any medical reason to do so (Dunitz-Scheer et al., 2011). Whilst tube feeding can be lifesaving, it may contribute to ongoing complications such as vomiting, oral aversion, fussy or demanding mealtime behaviours, discomfort, gagging and retching. These in turn may provide a constant cause of stress not only to the children but also to parents (Fortuneto, Darbari, Mitchell, Thompson & Cuffari, 2005; Nijs & Cahill, 2010).

It is therefore important to transition children from enteral tube feeding dependency to oral intake at a time when they no longer rely on enteral feeding to maintain medical stability, nutrition and/or growth. Tube weaning programs have been established internationally and are led by various disciplines involved in the management of enteral feeding, including speech and language therapists, occupational therapists, psychologists, paediatricians and dietitians (Wilken, Cremer & Echtermeyer, 2015). Anecdotally, tube weaning programs/centres tend to follow their own protocols. The type of approach taken to construct the weaning process, the principles and evidence drawn upon in the design, the role of various stakeholders in the process and the definitions of tube weaning success, vary widely. In addition, there is considerable inconsistency in the outcome measures used, the approaches taken to weaning children from enteral feeding, and the definition of weaning success (Dovey et al., 2018). For example, some programs report on change in number of bites swallowed/mouth cleans (Gibbons, Williams & Riegel, 2007; Lamm & Greer, 1988). Others evaluate changes in pre- and post-weaning weight or body mass index (BMI) in isolation (Benoit, Wang & Zlotkin, 2000; Blackman & Nelson, 1985; Brown et al., 2014; Byars et al., 2003; Cornwell, Kelly & Austin, 2010; Davis et al., 2016; Hartdorff et al., 2015; Kindermann et al., 2008; Wright, Smith & Morrsion, 2011) or in the context of changes in the child's behaviour and feeding capacity (Burmucic, Trabi, Deutschmann, Scheer & Dunitz-Scheer, 2006; Clawson, Palinski & Elliott, 2006; Lively et al., 2019; Silverman et al., 2013; Trabi et al., 2010; Wilken et al., 2015). Success rates may also depend on the specific definition of what it means to be weaned (no tube use) or not weaned (continuing tube use in some capacity) (Marinschek et al., 2014; Mirete et al., 2018; Shalem et al., 2016; Williams et al., 2017). Length of follow-up varies between studies, with some reporting only immediate changes at the time of weaning (Cornwell et al., 2010; Marinschek et al., 2014; Shine, Finn, Allen & McMahon, 2018), and others following progress over the subsequent months and year (Brown et al., 2014; Hartdorff et al., 2015; Kindermann et al., 2008; Lively et al., 2019; Pollow et al., 2018; Shalem et al., 2016; Silverman et al., 2013; Wilken et al., 2013; Williams et al., 2017; Wright et al., 2011).

Due to this variability, it is difficult to compare program outcomes and identify best practice in this area by comparing approaches to weaning, as well as their advantages and success rates across published research. Attempts have been made to develop consensus on core principles that govern weaning practices and related outcome measures (Dovey et al., 2018). For example, comparison reviews regarding tube weaning programs have been undertaken but are limited in the number and type of studies included (e.g., Sharp, Volkert, Scahill, McCracken & McElhanon, 2017). However, to date a broad scale review of all published tube weaning programs and the key outcome measures usually assessed to define weaning success, is yet to be undertaken. This information would support the development and implementation of a consensus to inform research and practice regarding the design and evaluation of interventions for tube weaning. Therefore, the objectives of this qualitative Scoping Review were to capture all reported approaches to tube weaning with a view to identifying whether there are key principles underlying their design. In addition, we sought to identify what outcomes are reported and how these might relate to intervention designs. The aim is to support considered design of intervention programs along with clear reporting of design principles and identification of outcomes that assess their success. In this process, we were guided by the following research questions:

1. What approaches are used to weaning children from enteral to oral feeding internationally?
2. What outcome variables are reported by existing tube weaning programs and how are these measured?

Method

A qualitative Scoping Review methodology was selected as the most appropriate strategy given the breadth of the research questions and the varying quality of the literature available. This supported our aim to comprehensively collate, describe and offer a useful interpretation of all available data regarding tube weaning approaches and outcome measures. The Scoping Review method (Peters et al., 2015) and the Joanna Briggs Institute (JBI) (2017) involves the following key steps involving at least two reviewers to manage bias: 1. Design of a search protocol based on a broad research question; 2. Search of the international literature in a manner which is '*rigorous, replicable and extensive*' (Peters et al., 2015); 3. Mapping the range of evidence sourced (both qualitative and quantitative) without synthesising the evidence.

The aim of this review was to map the available evidence base with a view to better understand the focus of research endeavours, program design and outcomes of interest to identify directions to support future high-quality research. Therefore, appraisal of the methodological quality of each study was not part of this process (Peters et al., 2015).

Inclusion Criteria

Studies were included in this scoping review if they were published in English and included the key search terms as listed in Appendix 1. The first search for this project was initiated in June 2016. This search informed the generation of search terms for the subsequent search of the scientific and grey literature. The main searches were conducted in February 2017 and May 2018 with the most recent search conducted in June 2019. Each search was conducted without restrictions on dates of publication. Systematic reviews and papers that referred to tube weaning prior to hospital discharge in the acute post birth stage were excluded. We deliberately did not limit the publication date or context in which tube weaning may occur to be able to broadly scope the different tube weaning approaches described to date. Hence, studies describing tube weaning programs in any medical/school/home setting, any country and led by any discipline were included. Two researchers (EL and SD) independently screened all titles and abstracts and then reached consensus on differing exclusion/inclusion decisions. The same two researchers then independently reviewed the full texts for inclusion.

Key Concepts

The key concepts underpinning this review were:

1. Collate and summarise the outcome measures used in research to date to document tube weaning success. In order to be able to capture a variety of definitions used and described by the included studies, we were not guided by an *a priori* definition of 'success'.

2. Identify and describe the principles and/or evidence that were drawn upon in the design of intervention programs, commonalities and differences, and how this related to outcome measures used.

Search Strategy

A search was designed to be as exhaustive as possible with a view to capturing all relevant literature, therefore no restriction of the start date was applied. Key health databases were included (Medline, Ovid and CINHAL), databases that index a broad range of scientific literature (Scopus and Web of Science), a hand search (described below) as well as a search of the grey literature using Google advanced search (see Appendix 1). We employed a comprehensive four-phase search strategy as recommended by the Joanna Briggs Institute (2017):

i. We identified a preliminary list of key words from initial limited search of one data base (Medline);
ii. From the above list and clinical experience, we identified a comprehensive list of keywords (Appendix 1) and ran database searches (Medline, Scopus, Web of Science and CINAHL);
iii. We located articles not identified by our database search but referred to in the studies/reference lists found through the database search;
iv. We completed a grey literature search using Google Advanced Search engine and the list of key words in Appendix 1.

Data Extraction and Analysis

Data extraction and analysis approaches were underpinned by qualitative research approaches to rigour, to manage any influence through the unconscious biases held by the authors (Nicholls, 2009a). This included all three authors, only one of whom has specific experience in paediatric tube weaning (EL) collectively deciding on the data to be extracted and developing a data charting form (Appendix 2). Data extraction design was finalised after several cycles that included two researchers (EL and SD) independently extracting the initially agreed-upon data for the first 10 studies and resolving any differences. Similarly, the identification of commonalities and differences between intervention approaches and a decision regarding an appropriate classification of these approaches was finalised after several cycles of discussion and refinement between all three members of the research team.

Results

Our findings are presented in two sub-sections. First, we summarised the general characteristics of the included studies (Appendix 2) and identified commonalities between tube weaning approaches. Second, we explored and documented the outcome variables presented in each study (Table 1) and any overarching themes identified between the type of approach and outcome measures reported.

Themes	Outcome measures reported: Behavioral approach	Child- and family-centered approach	Biomedical approach
Mealtime environment and behaviors	Average length of mealtime[21] Percent adverse events experienced[28] Total inappropriate behaviours[21] Generalizing to home and classroom[40] Change in scores on "Infant Feeding Behavior," parent, and rater checklist[9] Change in questionnaire on positive mealtime environment[20] Caregivers can be taught to implement behavior therapy within home environment[38] Adult establishing and maintaining instructional control[40] Adult initiating IPC[21]	Maintenance of oral eating in the home setting following discharge[13] Normal feeding behavior[19] Change in mealtime behaviors[22] Feeding behavior improved[5] Children becoming competent eaters who are able to read their bodies' cues and act on them[42] Increased development of normal-for-age eating behavior[42]	No data reported in these studies
Impact on caregiver	Change in Parenting Stress Index (rating scale)[20,38] Change in treatment satisfaction and acceptability survey[38] Change in questionnaire on parent aversion to mealtime[20] Change in questionnaire on interaction between child and caregiver[20]	Change in parental behavior with sustained changes in interaction patterns[19] Reported parental stress [23]	No data reported in these studies
Oral skill/ acceptance/ refusal	Swallows/oral feeding session[8] Frequency of tongue thrust swallow[7] Incidence of severe food refusal[34] Frequency of gagging and vomiting[12,34] Mouth clean[7,38] Initiating eating readiness[40] Establishing eating skills[40] Gags[7] Percentage of bites expelled[21] Percentage of bites accepted[21] Texture/flavor of foods consumed[40]	Decrease in refusal to eat[42] Change in oral skill development[22] Established oral feeding[5] Change in ability to self-feed finger foods[36] Number and variety of new foods[23]	Change in swallowing function[39] Reintroduction of oral feeding without refusal or discomfort[41]
Oral consumption	Grams taken per meal[21] Volume of food consumed[40] Ounces per day consumed orally[8] Energy intake (as percentage of goal)[20] Daily oral energy and fluid intake goals[28] Volume food targets reached[34] Percentage of daily energy/nutrition requirement consumed orally[9,10,12] Food acceptance and oral intake (measure over time)[40]	Percentage of goal energy orally[13] Eating adequately[14,15]	Oral intake[39]

Themes	Outcome measures reported: Behavioral approach	Child- and family-centered approach	Biomedical approach
Tube use	Successfully weaned[40] Discontinuation/elimination of tube feeding[7,20,34] Weaned from G-tube[28] Reduction in G-tube supplementation[10] Tube feeds decreased by >50%[35] Energy intake—oral and G-tube[11] Tube intake (measured over time)[38]	GT weaning[13] Decrease in or discontinuation of tube feeding[36] Timeframe for/pace of feed reduction[16,23] Successful cessation of both tube feeding and high-energy sip feeds[16] Increase in oral intake with subsequent decrease in PEG amounts[37] Level of weaning: Totally/partially/weaning trial without success/interruption of program[24] Overall reduction in tube feeding volumes[22] Complete tube weaning to sufficient self-regulated oral intake[24] Percent tube weaning post program[23] Complete discontinuation of tube feeding with sufficient oral feeding after treatment (3 weeks) with sustained stable body weight due to self-motivated oral feeding[18,26] Successful weaning defined as complete and definite cessation of NGT or GT use within 3 months of discharge with concomitant absence of a slowing growth rate and rapid resumption of an ascending and regular weight gain as well as a return to a normal social lifestyle[25]	
Anthropometrics	Weight[11] Weight loss[12,20] Weight (mean, SD, percent change)[28] Weight and height[21,34] Percentage of ideal body weight[9] Body weight (measured over time)[38]	Percent weight change[13] Gaining weight[14] Change in BMI *z*-scores[13,16,17] Weight-for-age *z*-scores (over time)[27] Constant growth velocity (weight, length, BMI)[5,22] Gaining weight at 3 and 6 months post program[15] Changes in height and weight over 3-month period[19] Stabilization of body weight established with increased body weight after 18 months[19]	BMI percentage decrease[17]
Other	Cost-effectiveness[35]	No data reported in these studies	Change in quality of life (pain)[17]

BMI, body mass index; G-tube; GT, gastrostomy tube; IPC, instructions, prompts, consequences; NGT, nasogastric tube; PEG, percutaneous endoscopic gastrostomy.

Table 1: Outcomes measured as per Therapy Approach

Included Studies

As per Figure 23, the initial full search resulted in a total of 1270 matches. Eight additional studies were located from references in related articles (n=7) and grey literature (n=1) and were included in the review. Following de-duplication and hand searching, 1272 studies progressed to title and abstract screening, of which 1224 were excluded due to being irrelevant to the research questions. The full texts of the remaining

48 studies were assessed for eligibility, of which 16 were excluded due to incorrect patient population or intervention or the paper presented a survey/review rather than description of a program or protocol. As a result, a total of 32 studies from 12 countries were included in the final data extraction and analysis process. Outcomes measured by each program varied and are summarised in Table 2. Publication dates ranged from 1985 to 2019 as per Table 2.

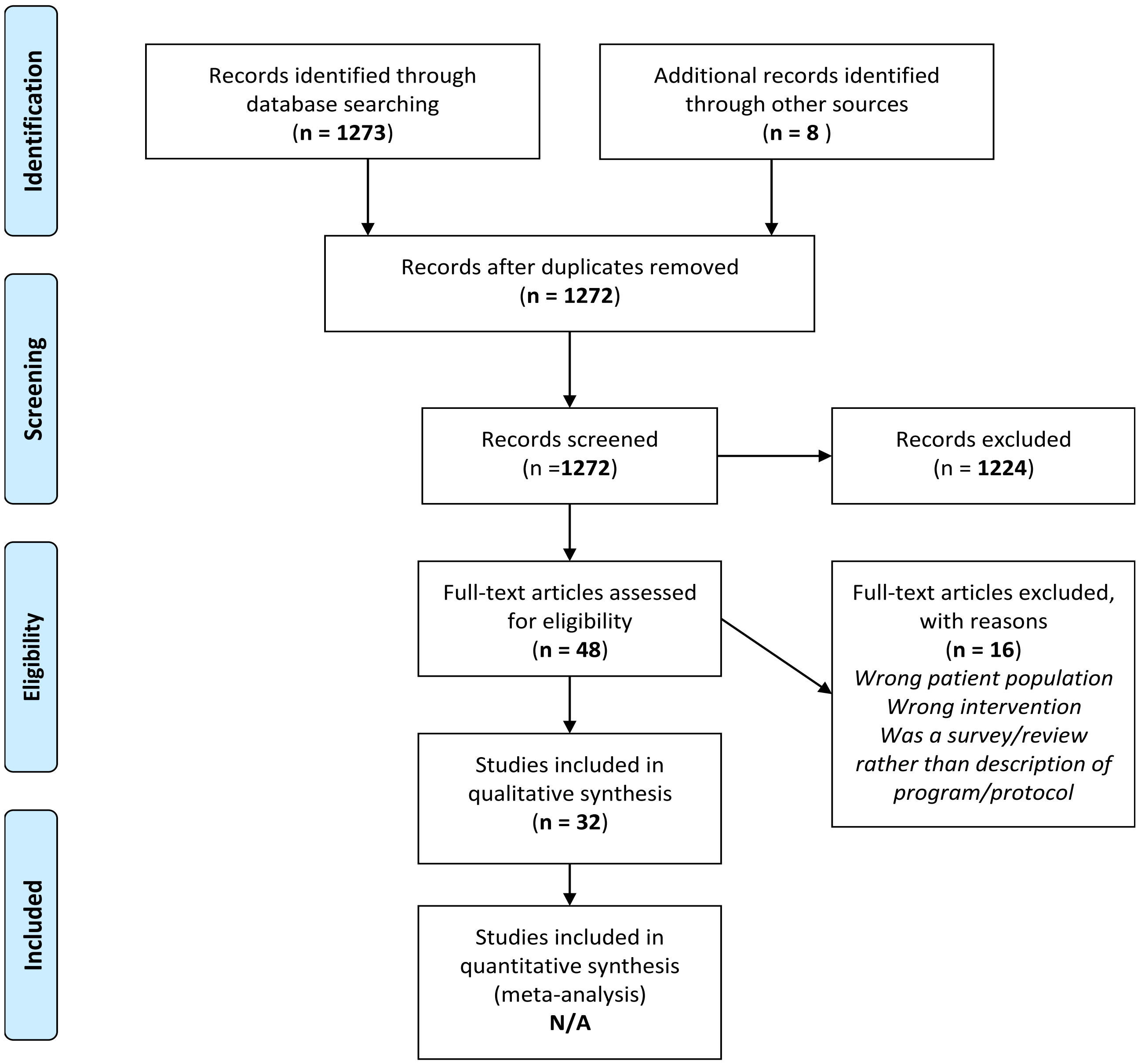


Figure 23: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) flow diagram for literature review search

Country	No. of published research articles	Reference (as per reference list)	Year of Publication	Type of Weaning approach	Research study design (JBI)
United States	14	Blackman & Nelson Lamm & Greer Tarbell & Allaire Byars et al. Clawson et al. Gibbons et al. Williams et al. McKirdy et al. Cornwell et al. Huppert Silverman et al. Brown et al. Davis et al. Pollow et al.	1985 1988 2002 2003 2006 2007 2007 2008 2010 2011 2013 2014 2016 2017	Behavioural Behavioural Child/Family Behavioural Behavioural Behavioural Behavioural Behavioural Behavioural Child/Family Behavioural Child/Family Biomedical Behavioural	Case series Case series Cohort Observational Case study Case study Cohort Case series Cohort Case study Cohort Cohort RCT Cohort
Canada	1	Benoit et al.	2000	Behavioural	RCT
Netherlands	3	De Moor et al. Kindermann et al. Hartdorff et al.	2007 2008 2015	Behavioural Child/Family Child/Family	Case series Cohort RCT
Japan	2	Munakata et al. Ishizaki et al.	2008 2013	Biomedical Child/Family	Cohort Cohort
France	2	Senez et al. Mirete et al.	1996 2018	Biomedical Child/Family	Cohort Cohort
Austria	3	Burmucic et al. Trabi et al. Marinschek	2006 2010 2014	Child/Family Child/Family Child/Family	Case series Cohort Cohort
United Kingdom	2	Harding et al. Wright et al.	2010 2011	Child/Family Child/Family	Cohort Case series
Israel	1	Shalem et al.	2016	Child/Family	Cohort
Germany	1	Wilken et al.	2013	Child/Family	Cohort
Australia	1	Lively et al.	2019	Child/Family	Cohort
Ireland	1	Shine et al.	2018	Biomedical	Cohort
New Zealand	1	Taylor et al.	2019	Behavioural	Case series

Table 2: Summary of included articles

Tube-Weaning Approaches

Across the included studies, we identified three distinct approaches to intervention with the ultimate aim of tube weaning. (1) Those being grounded in behavioural strategies (Benoit et al., 2000; Blackman & Nelson, 1985; Byars et al., 2003; Clawson et al., 2006; Cornwell et al., 2010; de Moor et al., 2007; Gibbons et al., 2007; Ishizaki et al., 2013; Lamm & Greer, 1988; Pollow et al., 2018; Silverman et al., 2013; Williams et al., 2017), (2) those with a biomedical or other treatment focus (Davis et al., 2016; Harding et al., 2010; Munakata et al., 2008; Shine et al., 2018) and (3) those which followed a child- and family- centred approach (Brown et al., 2014; Burmucic et al., 2006; Hartdorff et al., 2015; Huppert, 2011; Kindermann et al., 2008; Lively et al., 2019; Marinschek et al., 2014; McKirdy, Sheppard, Osborne & Payne, 2008; Mirete et al., 2018; Senez et al., 1996; Shalem et al., 2016; Tarbell & Allaire, 2002; Trabi et al., 2010; Wilken et al., 2013; Wright et al., 2011). We acknowledge that clinically there may be overlap between how components of each approach are utilised, however, within the published literature, weaning programs were clearly identified to follow one of these three specific approaches.

Behavioural approaches to changing behaviour are grounded in Skinner's established principles of operant conditioning namely the antecedents, behaviours and consequences that influence operant conditioning (Skinner, 1938). It assumes that paediatric feeding disorders are in part sustained through caregiver response to the child's learned behaviours when being offered food and/or drinks. Treatment, therefore, aims to (i) address the antecedents (i.e., manipulate a part of the mealtime environment to reduce adverse behaviour from the child) and/or (ii) provide or remove a consequence for a behaviour, also known as reinforcement or extinction) (Piazza et al., 2003) often in a de-contextualised environment (i.e., clinic/hospital). Biomedical approaches that describe a specific treatment (i.e., medication, sensory stimulation, direct tube feed manipulation) which is performed *on* the child in a prescribed manner without therapeutic intervention from the parents or therapists. Child- and family-focused approaches engage caregivers as a central part of the weaning process and support the child to initiate feeding behaviours and acceptance of food/fluids without reward or pressure but based on an awareness of internal state regulation. This method is grounded in a socio-relatedness model of learning as described, for example, by Louis Sander (Sander, 1987). Treatment therefore addresses the interactions between infant/child and caregiver to provide the organisation for shaping the developmental, biological and reconstructive therapeutic process across the life span.

Within each of these approaches, we explored the environments in which the tube weaning process took place, the team members involved, the use of tube-feed reduction/hunger induction and gross geographical areas where the treatments are used. See Appendix 2 for an in-depth overview of the characteristics of all included studies.

Behavioural Approaches

In total, 13 papers described a behavioural approach to weaning tube-fed children. Most (n=11), but not all behavioural approaches used a combination of hunger induction and tube-feed reduction only once oral intake reached a pre-determined level. This approach to feeding therapy was most frequently reported by studies describing programs in North America (eleven programs) (Benoit et al., 2000; Blackman & Nelson, 1985; Byars et al., 2003; Clawson et al., 2006; Cornwell et al., 2010; Gibbons et al., 2007; Ishizaki et al., 2013; Lamm & Greer, 1988; Pollow et al., 2018; Silverman et al., 2013; Williams et al., 2017), by one paper from the Netherlands (de Moor et al., 2007) and one from New Zealand (Taylor et al., 2019). Behavioural approaches represent the earliest published modes of teaching tube-dependent children to eat (Blackman & Nelson, 1985) and continue to be used (Taylor et al., 2019). Study designs include five case series, one randomised control trial, four cohort studies, one observational and two case studies. In general, behavioural approaches are carried out by a Psychologist or Behavioural Therapist. Additional medical (Paediatrician/Gastroenterologist) and allied health practitioners may support (Dietitian, Speech-Language Pathologist) if available at their facility or when required. Parent/carer involvement is generally limited to once the child has begun to make gains with oral intake and previous undesirable mealtime behaviours are diminished.

Biomedical Approaches

Four papers described what we have categorised as biomedical-interventions to transition children from enteral to oral feeding, in which a specific treatment is performed *on* the child. This group of research studies included (1) the use of appetite stimulate in conjunction with pain reduction medications (Davis et al., 2016) and reduction in tube-feed volume after 10 weeks of medication; (2) appetite stimulation via the olfactory system (Taylor et al., 2019) with periods of 'starving', (3) sensory stimulation of the oropharyngeal cavity accompanied by intermittent tube feeding (Munakata et al., 2008), and (4) direct tube volume manipulation in the absence of other specified treatments (Shine et al., 2018). These studies were carried out in the USA, Japan, France and Ireland and comprised one randomised control design (Davis et al., 2016) and three cohort studies (Munakata et al., 2008; Shine et al., 2018; Taylor et al., 2019). These treatments are provided by a research team member in one study (Davis et al., 2016), Dietitians (Shine et al., 2018) or were not specified in the other two studies (Munakata et al., 2008; Senez et al., 1996).

Child- and Family-Centred Approaches

Fifteen studies described an approach to weaning that we have categorised as a child- and family-centred model. In this model the caregivers are a central part of the weaning process and the child is supported to initiate mealtime behaviours and acceptance of food/fluids without reward or pressure. The reported child/family approaches all utilised a degree of enteral tube-feed reduction (appetite manipulation) either prior to or within the first few days of the intervention commencing. Three studies from the USA and twelve from Europe and Australasia utilised child-directed therapy with parents being integrated into the therapy either early or later in the program. Eleven of these studies followed a cohort design, one a randomised control trial and three are reported case series. The intervention teams providing child and family-based weaning therapy comprised a range of medical and allied health professionals including paediatrician, gastroenterologist, speech-language pathologist, dietitian, nurses, occupational therapist, music therapist, medical clown, horticulture therapist, psychosocial therapist, and preschool teachers. Parent or carer involvement was more frequently incorporated from the beginning of or soon after treatment commenced.

Outcome Measures Reported

In response to our second research question we identified that a breadth of outcome measures have been reported by individual programs with much variability across these (Table 1). These outcome measures can be categorised as:

1. Child's mealtime behaviours—e.g., length of mealtime, inappropriate behaviours, transference of mealtime behaviours to new environments.
2. Parental stress/behaviours.
3. Oral skill - the child's ability to bite, chew, manipulate and swallow food. This is a highly complex skill which requires not only precise motor coordination but also motor stamina and a regulated sensory system.
4. Oral consumption—a measure of how much was swallowed per meal offering recorded as grams/millilitres/ounces.
5. Tube use—volume/amount of tube feeding required throughout the weaning process.
6. Anthropometrics - behavioural programs mostly reported figures of weight (static and over time for two programs) with one reporting weight and height and one considering the percentage ideal body weight. Child/family approaches frequently identified weight changes over time (up to 18 months post-therapy) and considered the growth velocity across height, weight and BMI over time.
7. Other - cost of therapy, child's level of pain.

Discussion

We undertook a systematic and comprehensive Scoping Review of the internationally published tube weaning literature and identified three main approaches to weaning and seven categories of outcome measures. Each of the described approaches to tube-weaning conceptualises the 'problem' of the tube fed infant/child differently and, therefore, the principles that guide each approach and the outcome measures applied also differed.

General Principles of Weaning

We broadly grouped tube weaning approaches into three different ways of conceptualising the problem of weaning the tube fed infant or child:

Tube feeding is being maintained through individually learned responses by the child to the task of eating and drinking. This includes the impact of parents on their child's behaviour, and therefore need to be addressed through behavioural psychological approaches.

The problem is biomedical and consequently, a biomedical intervention is performed on the child; and the parent or caregiver are not mentioned.

The third approach attempts to consider elements related to child and parent stress and the interactional nature of eating and drinking. Child- and family- centred approaches conceptualise the problem as an interaction between individual behavioural responses, the context, child development and relational aspects of eating. In doing so they aim to ameliorate grief and loss and develop healthy parent–child dyads. This is based on the assumption that this will improve social-emotional outcomes for the family and promote ongoing health development for the child.

Further analysis of the characteristics of the three approaches to tube weaning showed that there were two main differences between them, primarily relating to the use of hunger provocation and the role of parents or caregivers, as discussed below.

The Role of Hunger Provocation Across Different Approaches

One of the key differences between weaning approaches was the way in which hunger provocation was used. In general, programs which adhered to a behavioural approach to weaning often taught the specific desired feeding behaviours with the child's usual volume of tube feeds provided. Until such time as acceptance of food and fluids reached a pre-determined level, tube-feed volumes remained at or close to their usual levels and were then slowly reduced commensurate with the amount of foods/fluids swallowed. As a result, children are likely to be taught the skills for eating and drinking without the intrinsic feeling of hunger.

Conversely, direct appetite manipulation and hunger provocation formed the foundation of one of the biomedical approaches. Specifically, one study described a program, which utilised medications to increase the child's hunger and consequently promote their engagement with oral food and fluids. Tube-feed volumes were reduced 11 weeks after commencing the first medication (Davis et al., 2016). In another program, tube-feed volumes were manipulated to provoke hunger in a specific group of children with congenital heart disease once children were clinically assessed by their program protocol as suitable to begin the tube weaning treatment (Shine et al., 2018). Factors for suitability included medical and nutritional stability, appropriate oral skills as assessed by Speech and Language therapist and completion of specific cardiac surgeries.

Hunger provocation also played an important role in the child- and family-centred approaches to tube weaning. One of the underlying principles of this approach was that a child needs to experience the interoceptive feeling of hunger and then learns through copying, exploring and intrinsic reward how to self-regulate this feeling (Trabi et al., 2010). As such, child- and family- centred approaches generally implemented tube volume reduction from the beginning of the weaning process. Tube feeding volume was then further reduced once oral intake increased.

The Role of Parents/Carers Across Different Weaning Approaches

The second main characteristic that differed across the three tube weaning approaches was the role of the parent or caregiver. Behavioural theorists suggest that children learn to respond to food or drink in the presence of their parents, families and mealtime environments (Cornwell et al., 2010). Tube-fed children are thought to have developed behaviours specific to their particular situation, for example food avoidance, oral aversion, reflexive vomiting and protective gagging. Consequently, interventions based on behavioural philosophies taught children to 'unlearn' these behaviours. This is required to be able to relearn appropriate behaviours without the influence of historic, tube-feeding-related responses from both the child and the parent (Cornwell et al., 2010). As such, parents were initially excluded from interventions using a behavioural approach and introduced only when the identified desired behaviours reach a pre-determined level. At this point, parents were then coached to achieve the same level of success with their child's acceptance of food and drink. The impact of a behavioural approach on being able to generalise eating to less structured and less directed environments is unclear as the therapies and outcomes achieved are predominantly described within a well-supported and tightly controlled clinic setting. Two programs however described the transfer of learnt skills to the classroom and home environment (Harding, Faiman & Wright, 2010; Williams et al., 2017).

Parental involvement (if required) in biomedical approaches was of a practical nature such as administering medication in the absence of medical, nursing or allied health staff performing or administering the protocol to patients. As such, parents took on the role of 'care provider', with the mealtime process being predominantly driven by the medical intervention.

Child- and family-centred approaches aimed to address the disruption to the parent–child relationship, which was often created through tube feeding. They aimed to establish enjoyable mealtime and parent–child interactions, facilitated by training desirable caregiver skills, to support longer-term maintenance of the child's eating skills in a variety of settings. This was founded on the understanding that feeding is relationally embedded (Rosenblum, 2004) and infants develop not as an isolated being, but as a result of the caregiver-infant dyad (Sander, 2000; Stern, 1985). Tube feeding was seen to be able to 'over-ride' a parent's natural instinct and role to be able to feed their child. This often displaces the '*moment of meeting*' (Sander, 2002, p. 24), in which the intention of the parent (nurturing) and the need of the child (nutrition) usually 'fit together' in a unique manner (Stern et al., 1998). The underlying philosophy of child autonomy and parental inclusion within child- and family- centred approaches may nurture the healing of this displacement (Segal et al., 2014).

In summary, the role of hunger provocation and of the parents or caregivers varied across the different tube weaning approaches. It is worthy to mention that the literature speaks mostly to mothers (Byars et al., 2003; Clawson et al., 2006; Dunitz et al., 1996; Gibbons et al., 2007; Lamm & Greer, 1988; Nijs & Cahill, 2010), with very little mention of fathers and the impact tube feeding has on them (Wilken, 2012). We propose that it is important for future research to evaluate the impact of tube feeding on *all* care givers involved in the child's life, because all of a child's relationships contribute to their growth and development (Wilken, 2012).

Outcome Measures Reported

Outcome measures reported varied across the three tube weaning approaches and appear to be driven by how the 'problem' of tube feeding is conceptualised and, therefore, the type of intervention that was delivered and how success is measured (Table 1).

Programs that follow behavioural principles specifically measured 'deficits' or undesirable responses from the child, including adverse and inappropriate behaviours such as vomiting, gagging, expulsion of food and tongue thrust swallow. They also assessed the child's ability to follow the behavioural principles being taught during structured sessions to 'undo' these responses. Some of these programs have reported on the capacity of these skills to be transferred to the home setting with a predominant focus on quantity of food consumed and number of undesirable responses displayed by the child. Two of the programs measured the change in parental stress from commencement to completion of the weaning program (Benoit et al., 2000; Silverman et al., 2013). This is in keeping with the now recognised importance of the parent–child relationship (Dunitz et al., 1996; Susz, Kalish, Kushilevitz, Orenstein & Raviv, 2009), but unique given that, generally, behavioural approaches consider the 'problem' to lie within the child and their learnt responses to food.

Biomedical interventions conceptualised the problem of prolonged tube feeding as biological and, therefore, assessed very specific and quantifiable outcomes that relate to anthropometrics or change in pain and swallow function.

Child- and family-centred approaches considered 'normalising' the child's interactions and behaviours within the mealtime environment without specific emphasis on monitoring the characteristics of the non-preferred behaviours or recording precise amounts of oral food consumed. The focus was placed on the quality of the mealtime experience, including establishing oral feeding, increasing the variety and texture of new foods explored and self-feeding both within a clinic and home setting over time. With an emphasis on improving the parent–child relationship as a maintaining factor for successful mealtimes, two programs incorporated formal parental stress measures pre- and post-therapy (Burmucic et al., 2006; Williams et al., 2017).

We also observed some regional differences, with behavioural approaches more often reported in studies originating in North America, with one published program from the Netherlands and one from New Zealand. Programs utilising a child- and family-centred approach were more frequently identified across Europe, the United Kingdom and Australia, with three programs originating in the United States of America. This suggests that there are regional differences in what constitutes best practice in tube-weaning. Development of a consensus on core principles that govern weaning practices and relevant outcome measures will be important for strengthening the evidence base on what works, rather than accepted practice.

Recommendations

The future development of optimal tube weaning programs relies, at least in part, on collating the best evidence for the success of existing approaches. However, to be able to systematically compare the outcomes of different tube weaning approaches, consistency across outcome measures is required. Dovey and colleagues proposed a set of assessment and measurement principles by which tube weaning should be undertaken in order to allow comparison between programs internationally (Dovey et al., 2018). Five core principles were put forward, which, if adopted internationally, would allow for the consistent comparisons of outcomes. In short, these include (i). a focus on caloric intake and weight status, (ii). a focus on the role of food in the social environment of mealtimes, (iii). a focus on individually tailored interventions, (iv). assessment of weaning suitability and readiness (Schauster & Dwyer, 1996) and (v). a focus on generalisability of new learned behaviours. This framework attends to outcomes beyond gaining weight such as ensuring that the child can engage with the family diet, supporting their social participation and developmental outcomes.

The findings of this scoping review support the suggestions by Dovey et al. (2018) as we have identified that these outcome measures are relevant to the variety of ways in which tube weaning is conceptualised across the three major approaches identified. Some behavioural and all child- and family-centred approaches also included broader social and relational influences or outcomes. However, it was striking that only four of the thirty-two research papers described above did investigate parental stress, behaviours and a positive parent–child relationship (Burmucic et al., 2006; de Moor et al., 2007; Silverman et al., 2013; Williams et al., 2017).

This suggests first that a clearly explained and evidence-based rationale for intervention designs should be provided along with outcome measures that are directly linked to the rationale. Second, it may be useful to broaden Dovey et al.’s (2018) consideration of the impact of tube weaning on the child’s ability to engage in family meals to include other outcomes related to the social and familial context e.g., to identify whether, and in which ways, parents/caregivers are key to successful weaning outcomes. Furthermore, the impact of tube weaning on other factors that are key to facilitatingchild development such as establishing a positive parent–child relationship should be considered.

Limitations

We employed a rigorous search strategy to review the available literature on paediatric tube weaning. This showed a high level of variability between study designs, detail of program protocols reported and measures of weaning success. We only considered those weaning programs published in English and do not claim to comment on any approaches not reported on or not published in English. Further, the level of detail provided regarding weaning protocols varied across included studies and our analysis of the literature needs to be considered in this context.

Whilst most programs can predominantly be classified into one of the described underlying approaches, evidence of overlap of strategies and principles was evident in some, which in turn influenced the outcomes measured. For these papers, we categorised them based on the majority of their principles and through consensus discussion within the research team.

Conclusions

Although great variability exists between tube weaning approaches and outcome measures internationally, three main categories emerged: 1) behavioural; 2) biomedical and 3) child- and family-focused approaches. The majority of studies describing behavioural programs originated in North America and tube feeds were often reduced only when a level of oral intake was achieved following specific behaviour–consequence teaching. Outcomes measured focused on specific oral skill, extinguishing undesirable behaviours and immediate/short-term weight changes. Biomedical approaches were reported in Ireland, France, Japan and the United States of America and varied from administration of appetite inducing medications to the introduction of sensory olfactory stimulation. Success with these approaches was measured in terms of anthropometric changes over the duration of the treatment, change in swallow function and change in pain. Child- and family- centred approaches were frequently adopted in Europe and Australasia and promoted eating skills through the use of provoking hunger via reducing tube-feed volumes early to allow for an intrinsic hunger response. Less emphasis was placed on measuring precise quantities of food consumed orally in favour of considering growth velocity over time in the context of generalisable and sustainable functional mealtime behaviours.

There is yet to be developed a set of internationally recognised and adopted outcome measures, which would allow all tube weaning programs to assess and report against a set of standard measures. Of note, the role of parents and caregivers within the tube weaning process varied among programs. Further research is required to explore the role of parents in the weaning process and how the transition from tube to oral feeding impacts on the child, the parent or caregiver, and their relationships and mealtime experiences.

CHAPTER 5: UPDATED SCOPING LITERATURE REVIEW – JANUARY 2023

Introduction

The purpose of this chapter is to provide an update on the scoping review presented in Chapter 4, including any additional tube-weaning philosophies that may have come to light in the three years since its original publication. A review of the recently published literature was undertaken using the same search terms and parameters as those used in the original review. Over the last three years, the topic of tube weaning has experienced increased international interest and awareness (Clouzeau et al., 2021; Syrmis et al., 2020). As such, published data relating to philosophies, processes, and outcomes on tube-weaning methods are becoming more readily available. With increased interest, new ideas may have been published that add additional support to the original approaches identified in the original review or describe entirely novel approaches. Therefore, an updated review is presented in this chapter to identify any new approaches reported in the literature or additional published weaning outcomes from programs using one of the approaches reported in Chapter 4.

Methods

A detailed description of the methods is provided in Chapter 4. The updated search presented in this chapter summarises the search results from 1 July 2019 to 24 January 2023. The new studies were reviewed by the author of this thesis, guided by the same rigour for data extraction and analysis followed in the original literature search, including completion of the data extraction form (see Appendix 1 and 2).

Results

The search returned 136 articles, of which 118 were excluded following title and abstract screening. The remaining 18 full-text articles were reviewed and, of these, another 11 were excluded because they did not meet the inclusion criteria (see Figure 24). Upon further review of these 11 excluded studies, 6 of these studies described the incorrect patient population or intervention. For five of these studies, reasons regarding their exclusion are provided below because, on first reading, they may have been considered to meet the criteria. However, upon further review, they related to weaning programs that have either been described in the original review or did not provide enough detail on the program design.

The following three studies were excluded following the full-text review because they were described in the original review. One of the identified papers (Krom et al., 2020) described long-term follow-up data from two studies captured in the original published literature review (Hartdorff et al., 2015; Kindermann et al., 2008). Therefore, it was excluded because it did not describe an additional weaning program or a new approach to weaning that was not already captured in the original review. Similarly, my own published paper (see Chapter 9) was excluded from the final list of articles because it related to a program previously described and included in the original review (see Chapter 4). An additional paper published by Sharp, Volkert & Raol (2022) was excluded because it did not add new tube-weaning program information. Instead, it provided further analysis of the characteristics associated with tube-weaning success based on the program presented in Sharp et al. (2020) and described below.

Two studies were excluded because limited details were provided on the design of the tube-weaning program (Cipolla et al., 2022). Cipolla and colleagues reported on mothers' experiences in a multidisciplinary tube-weaning program. However, insufficient detail regarding the program design and weaning outcomes was provided; therefore, it was excluded from the search (Cipolla et al., 2022). Dipasquale's team explored tube-weaning practices frequently used by French gastroenterologists involved with tube weaning. This paper was excluded because it did not provide detailed information on outcomes from tube-weaning approaches (Dipasquale et al., 2021).

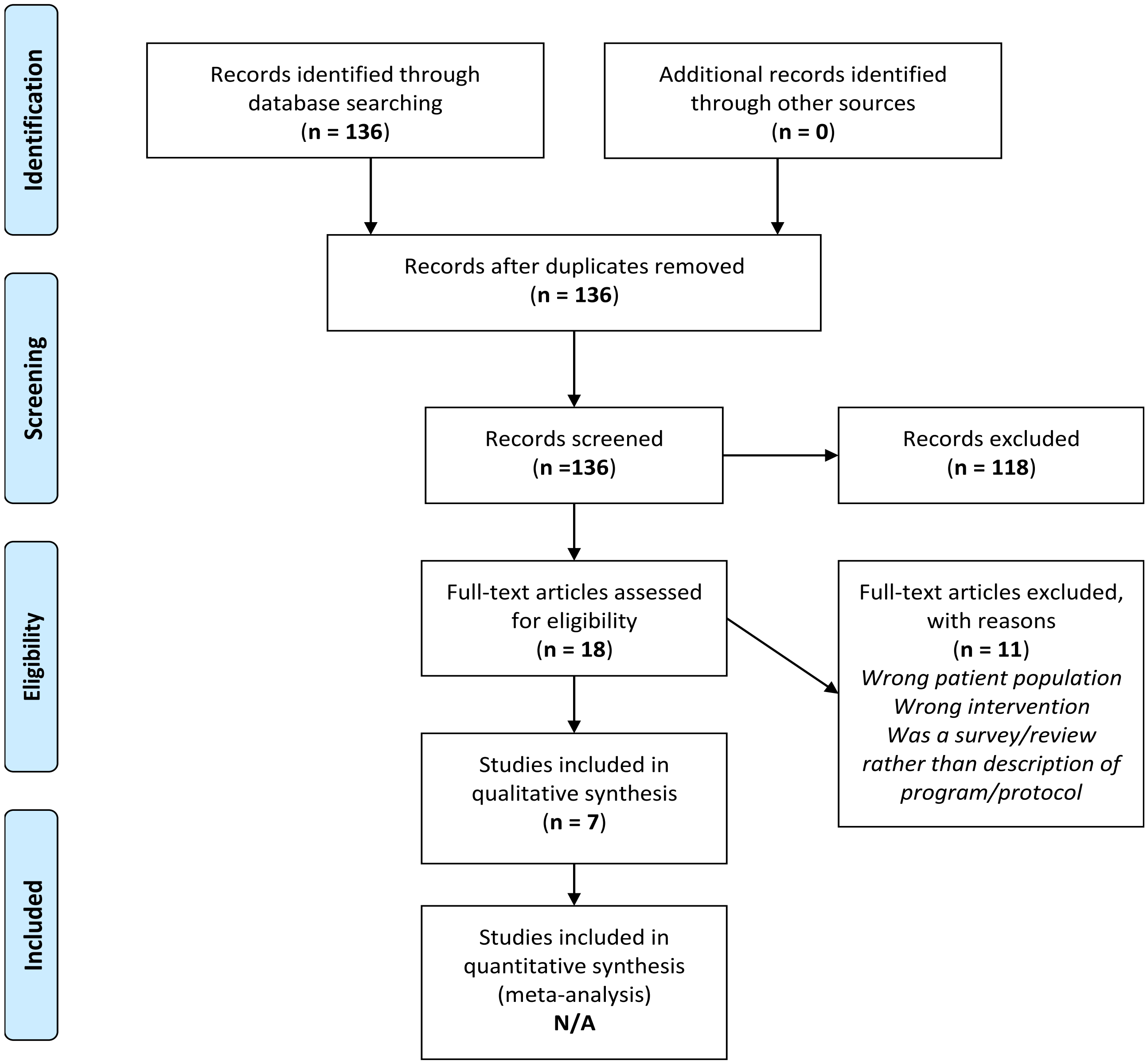


Figure 24: PRISMA flow diagram for the updated literature review search, July 2019 to January 2023

The remaining seven papers as identified in red in Table 3 were included and are presented below in accordance with the type of weaning approach (behavioural, biomedical, child- and family-centred) they align with.

Country	No. of published research articles	Reference (as per reference list)	Year of Publication	Type of weaning approach	Research study design (JBI)
United States	14 + 4	Blackman & Nelson Lamm & Greer Tarbell & Allaire Byars et al. Clawson et al. Gibbons et al. Williams et al. McKirdy et al. Cornwell et al. Huppert Silverman et al. Brown et al. Davis et al. Pollow et al. Sharp et al. Edwards et al. Grentz et al. Horsley et al.	1985 1988 2002 2003 2006 2007 2007 2008 2010 2011 2013 2014 2016 2017 2020 2021 2022 2022	Behavioural Behavioural Child/Family Behavioural Behavioural Behavioural Behavioural Behavioural Behavioural Child/Family Behavioural Child/Family Biomedical Behavioural Behavioural Biomedical Child/Family Child/Family	Case series Case series Cohort Observational Case study Case study Cohort Case series Cohort Case study Cohort Cohort RCT Cohort Cohort RCT Cohort Cohort
Canada	1	Benoit et al.	2000 2022	Behavioural	RCT
Netherlands	3	De Moor et al. Kindermann et al. Hartdorff et al.	2007 2008 2015	Behavioural Child/Family Child/Family	Case series Cohort RCT
Japan	2	Munakata et al. Ishizaki et al.	2008 2013	Biomedical Child/Family	Cohort Cohort
France	2 + 2	Senez et al. Mirete et al. Dipasquale et al.	1996 2018 2021	Biomedical Child/Family Child/Family	Cohort Cohort Cohort
Austria	3 + 1	Burmucic et al. Trabi et al. Marinschek Marinschek et al.	2006 2010 2014 2020	Child/Family Child/Family Child/Family Child/Family	Case series Cohort Cohort Cohort
United Kingdom	2	Harding et al. Wright et al.	2010 2011	Child/Family Child/Family	Cohort Case series
Israel	1 + 1	Shalem et al. Sadeh-Kon et al.	2016 2020	Child/Family Child/Family	Cohort Cohort
Germany	1	Wilken et al.	2013	Child/Family	Cohort
Australia	1	Lively et al.	2019	Child/Family	Cohort
Ireland	1	Shine et al.	2018	Biomedical	Cohort
New Zealand	1	Taylor et al.	2019	Behavioural	Case series

Table 3: Summary of published research articles from original literature review (Chapter 4 in black) and updated literature review January 2023 (red)

Additional Studies Reporting on Behavioural Approaches

One paper (Sharp et al., 2020) detailed a retrospective audit of an outpatient behavioural weaning program whose approach was previously detailed in Sharp et al. (2017). Behavioural intervention during this tube-weaning approach included positive reinforcement of preferred behaviours, bite persistence, and stimulus fading (Sharp et al., 2017). In line with other behavioural approaches presented in Chapter 4, this approach perceives that tube feeding is maintained due to conditioned food aversion resulting in disruptive mealtime behaviours and limited opportunities to develop the oral motor skills required for eating and drinking (Sharp et al., 2020). This differs from other behavioural approaches in that health professionals from different disciplines, such as occupational therapy, speech-language pathology, and social work more regularly provide assessment and advice if indicated, compared with traditional behavioural approaches that only include a psychologist (Blackman & Nelson, 1985; Pollow et al., 2018; Silverman et al., 2013).

Additional Studies Reporting on Biomedical Approaches

One program proposes a protocol for a medical treatment (Megestrol), for which the recruitment of participants is anticipated to be completed in January 2023. (Edwards et al., 2021). This is the same research team that previously reported on a similar randomised control trial of tube-weaning using a different medication, which was included in the review presented in Chapter 4. No further outcomes regarding the program are available at this stage.

Additional Studies Reporting on Child- and Family-Centred Approaches

Five tube-weaning therapy programs published since 2019 followed a child- and family-centred approach (Dipasquale et al., 2021; Grentz, Furfari, Keifer & Potter, 2022; Horsley et al., 2022; Marinschek et al., 2020; Sadeh-Kon et al., 2020). These programs consisted of outpatient approaches (n=2; Dipasquale et al., 2021; Sadeh-Kon et al., 2020), an online home-based approach (n=2; Grentz et al., 2022; Horsley et al., 2022), and a combined approach of an inpatient or outpatient program paired with online follow-up in the home environment (n=1; Marinschek et al., 2020). In the last three years, the number of online 'telehealth' weaning options has increased, as reflected by over half (n=3, 60%) of these newly published child- and family-centred programs being based in the child's home with online weaning support. This is compared with 7% (1 of 14) via online modality prior to 2019 (Lively et al., 2019).

Discussion

In total, seven additional research papers have been identified in the updated search presented in this chapter. While no new treatment approaches to tube weaning could be identified, over the last three years, more publications have described child- and family-centred approaches than behavioural or biomedical approaches. Of the 39 programs that have published tube-weaning program outcomes up until January 2023 (i.e., including the original and updated literature search results), 14 used behavioural methods, 5 were undertaken using biomedical treatment, and the remaining 20 programs incorporated child- and family-centred principles. Over the last three years, this reflects one additional behavioural program and one biomedical program publishing outcome data, in contrast to five child- and family-centred programs communicating their therapy outcomes. It is uncertain whether this is related to an increase in the awareness and incorporation of child and family philosophies into therapy approaches or whether it is a result of child- and family-based therapy programs now increasingly collating, interpreting, and disseminating their outcome results.

Of the recently published child- and family-centred programs, outpatient and online therapy is more prevalent than inpatient programs. This may reflect the greater awareness of the need for tube weaning and the resulting increase in published data supporting more cost-effective and practical methods for tube weaning. Additionally, the COVID-19 pandemic is likely to have affected accessibility for hospital-based treatment for tube dependency. This may reflect reduced access to outpatient appointments or that healthcare providers are more astute in offering online support. In addition, families may be more versed in online telehealth or find it more accessible and therefore are more open to accepting therapy in an online format.

Not only is technology developing to allow healthcare services to be provided via online platforms, but interest is also growing in the use of artificial intelligence (AI) assisted internet searching. Historically, families may have used the internet as part of their decision-making to research tube-weaning options and then compare various approaches to determine what may be most appropriate for their family. As AI becomes more sophisticated, dialogues with programs such as ChatGPT (Open AI, 2022) allows parents to ask questions relating to tube weaning and receive AI-generated content reflecting previously analysed and synthesised data. This means that internet-based searches will change rapidly and information sharing will become easier, hence the importance of reliable evidence-based research to identify and better define what information needs to be available for AI to share.

Summary – Chapter 5

The updated literature review presented in this chapter from data searched between 2019 and 2023 using the same search engines and terms from the original review published in Chapter 4 has shown no new approaches to tube weaning in this period. Of the new research papers identified, 72% represent child- and family-centred weaning approaches compared with behavioural and biomedical philosophies, with each representing 14% of tube-weaning approaches. Interestingly, home-based online telehealth-based weaning programs have become more prevalent over the last three years. This may be a result of hospital limitations imposed by the COVID-19 crisis or the expansion of tube-weaning practices to more cost-effective, functional, and accessible formats. Further research in this emerging area of healthcare would be beneficial to explore the efficacy of telehealth for tube weaning. AI has progressed as a future tool for information sharing, which may revolutionise how families access healthcare and information regarding tube-weaning options.

To maximise the family's efficacy in participating in a tube-weaning program and the resources provided by the health system, it is important to understand which children are suitable to begin the tube-weaning process. This may be guided by clear knowledge of any predictive variables that may influence weaning outcomes and determine suitable timing for transitioning from tube feeding to oral eating and drinking. To contribute to the researched-based literature on variables affecting the time it takes for children to tube wean, an audit of an Australian child- and family-centred tube-weaning program was undertaken and is described in Chapters 6 and 7.

CHAPTER 6: DESCRIBING A CHILD- AND FAMILY-CENTRED INTENSIVE FEEDING THERAPY PROGRAM

The results of the scoping literature review (see Chapters 4 and 5) show that there are many variables to consider in the design of tube-weaning programs. These include program logistics (e.g., location, duration, and frequency of therapy); the team members involved, including the role of parents; and clinical program design based on the perceived locus of the 'problem' (e.g., goal setting, outcomes measured, transfer of skill to different settings). There is limited research evidence to determine which variables are pertinent to tube-weaning success and how each contributes to the overall weaning outcome. It is critical to understand and consider the effect of the above variables on tube-weaning program design to be able to propose evidence-based guidelines regarding the most efficacious way of overcoming tube dependency.

A significant contributor underpinning therapy design is the focus on the causation or maintenance of the problem. Each of the three approaches described in Chapter 4 takes a different stance on the cause of food refusal in tube-fed children. Behaviour-based approaches assume that ongoing refusal of oral food and drink is partly maintained by the caregiver's response to the child each time they offer them something to eat or drink. As such, in behavioural-based weaning programs, parents are removed from the equation and the child is taught a new response to their refusal of food or drink. Once they display the 'correct' response to this offering (i.e., accepting and swallowing the food or drink on offer), parents are reintroduced to the therapy setting (e.g., Brown et al., 2014; Hartdorff et al., 2015; Pollow et al., 2018). This contrasts with biomedical approaches, whereby program design is underpinned by the idea that learning to eat and drink is a medical procedure that will be supported by pharmaceutical or medical intervention.

Biomedical interventions follow a structured medication provision or tube-feed reduction regimen without any additional behavioural or developmental support, including from parents. Therefore, these approaches assume that neither the child nor the parents play an active role in changing their behaviour or reactions to the food and drink being offered. Instead, a 'watch and wait' response to external therapy (e.g., medications, sensory stimulation, tube-feed reduction), administered by parents on a prescribed regimen, is adopted and assumes a medical interaction rather than a 'care' model.

The behavioural and biomedical models of weaning focus on an external contributor to weaning success rather than parents playing a pivotal role. For some parents, having an external cause to attribute to unsuccessful tube weaning may help reduce self-inflicted pressure to 'be successful'. However, biomedical models may be perceived as devaluing the parents' role in their child's progression from tube to oral intake because reflective and responsive parenting remains at the core of childhood development (Hong & Park, 2012). In particular, the development of feeding from birth in a healthy infant is the first environment within which feelings of reciprocity, closeness, and emotional support become established (Ainsworth, 1978; Bowlby, 1978). This means that for some parents, their inability to teach their child the perceived 'basic' skill of satiety may lead to feelings of self-worthlessness. As such, valuing parents' role in childhood development is fundamental to the child- and family-centred approaches described in Chapter 4.

Weaning programs based on family-centred care view the family unit as central to a child's learning and development within that environment. They acknowledge that learning does not occur in isolation but within a caregiver–child dyad (Sander, 1987; Stern, 1985). Learning takes place from birth, with an infant observing and processing nonverbal communication such as facial expressions, body posture, and gestures. In reaction to an adult's response, an infant adapts their behaviour; thus, their learning is shaped through events and responses (Braten, 1998; Stern, 1985). With repeated and varied experiences and exposure, an infant's internal sense of 'self' is moulded by previous memories of sensory inputs, thought, and action (Ernde, 1983; Schore, 1994). Some of these experiences will have fundamentally desirableor undesirableeffects on the child's psychological and physiological states—the results of which may last years (Mares, Newman & Warren, 2011). Undesirable early feeding and medical experiences may affect the child's ability to trust that a response to a specific experience has the capacity to change. A child who fears a previous adverse experience (e.g., aspirating or loss of breath control when feeding) may continue to refuse oral intake to safeguard themselves. Until they can gain trust in a previously adverse experience, ongoing fear of adverse mealtime experiences can affect their ability to transition from tube feeding.

However, the mapping of new neural pathways and memories (i.e., new learning) is possible because of the plasticity of the child's brain during childhood and adolescence (Hensch, 2004). With repetition and consistency of different behaviours and responses, children can (re)build their trust in new experiences.

This is particularly pertinent in developing mealtime confidence and success for tube-fed children with previous adverse experiences. The mechanisms by which the brain can shape and form new memories are known as neuroplasticity, which is described below.

Neuroplasticity

Neuroplasticity refers to the ability of the nervous system responses to change because of either intrinsic or extrinsic influences. These changes may be reorganising the structure, function, or synaptic connections of the nervous system. In particular, synapses play a critical role in memory formation and retrieval, learning, thoughts, feelings, behaviour, sensory integration, and brain development or recovery (Citri & Malenka, 2008; Mateos-Aparicio & Rodríguez-Moreno, 2019).

The mechanisms for change within synapses continue to be studied, and new models of neuronal plasticity continue to expand our understanding of how the brain can be reorganised (Citri & Malenka, 2008). While genetics are responsible for the basic structure of the nervous system and how synaptic changes respond to intrinsic and extrinsic stimuli, the environment into which a child is born moulds neuronal pathways into more permanent routes of behaviour, thoughts, and feelings (Hensch, 2004).

Learning to eat depends on the consistency and predictability of the mealtime environment, because this allows the child to build trust based on reliable expectations and adult responses. Implementing typical mealtime routines for tube-fed children as early as possible will support the development of neuronal synapses at specific time-dependent (critical) developmental windows as per feeding development in oral children. In these crucial phases, certain clusters of neurons are more susceptible to being influenced by environmental experiences (Hensch, 2004); as such, neuronal pathway development is age- *and* experience-dependent. If neural input is not provided, or if it is insufficiently or inconsistently provided, certain pathways may remain unmapped until repeat consistent neural information is provided. Once a path is mapped, the critical period for the next stage may commence (Pawlak et al., 2010). Unmapped neural pathways may explain why a tube-fed child's oral acceptance may appear 'stagnant' if a child continues to experience the same adverseresponse to their attempts at eating or drinking (e.g., choking, fear). As such, the child's same reaction to food and fluid offerings will persist until pathways and synaptic connections are reinforced that represent more desirable mealtime behaviours. The process of parents learning to offer different mealtime experiences and build their child's trust in new responses forms the basis of the parents' role in the child- and family-centred program discussed below and in Chapter 7. The next section explores how neuroplasticity can be harnessed to support the tube-weaning process by modifying parent–child interactions at mealtimes.

The Importance of Neuroplasticity for the Development of Mealtime Skills

Based on neuroplastic principles, the parent–child dyad can create new memories and associations of previously noxious events, such as tube reinsertions (Shore, 1997). (Re)insertion of an NGT requires a child to be held down by their parent (or any adult) on repeat occasions. The child learns that when an adult comes towards their face with an object, it is likely to result in discomfort. In anticipation of pain, they may enter a physiological state of stress when an adult approaches their mouth with a spoon loaded with food or a straw to drink from. Their resulting responses may vary from physical (e.g., kicking, throwing, biting) to emotional (e.g., crying, screaming), or dissociation (e.g., falling asleep, engaging in repetitive behaviours) in their attempt to avoid what they believe will happen next.

However, new neural associations can be created relating to enjoyable mealtime experiences by consistently changing the actions and behaviours of the adult. In the above example, it may help the child to maintain trust in their parent if an external adult (e.g., nurse) re-sites the NGT to remove this negative association between the parent and the child. In the mealtime environment, parents could refrain from frequent attempts to offer a spoon of food or place a bottle in the child's mouth. This promotes non-invasive adult interaction around food and drinks and allows the child autonomy for exploration. The child can build confidence and trust in a new reaction with repeated exposure and a consistently positive outcome. Each new mealtime goal is introduced from this foundation, and the child is afforded autonomy and control to promote their self-determination and success. Over time, these positive mealtime interactions may facilitate neuroplastic reorganisation of previously traumatic memories associated with mealtimes. In addition, the child's increased autonomy and control at mealtimes are likely to promote their self-determination, as outlined in Chapter 1.

As per the principles of SDT described in Chapter 2 (p. 97), the child's reaction and response to autonomous and self-directed learning further reinforce enjoyable and successful mealtimes. The result is that they are more likely to repeat these eating and drinking behaviours. Thus, autonomy and self-determination become the foundation that underpins the child's role in child- and family-centred approaches to tube weaning.

With any aspect of family functioning, parents and children often find themselves completing activities in a particular way. This may be related to how the food shopping is undertaken, where breakfast is eaten, and bath time and teeth brushing routines. Regarding tube feeding, parents have reported providing tube feeds in the same manner as prescribed by health professionals [Lively, McAllister & Doeltgen, 2022; P2, P3, P7] or in ways that best allow them to undertake the many other household caregiving responsibilities (Hopwood et al., 2020). To this end, parents complete daily family routines with their children (e.g., teeth brushing, getting dressed, and mealtimes) based on previous responses and experience. A challenge for parents becomes their ability to change responses and reactions to regular routines such as tube feeds, mealtimes, or oral offerings. For example, to offer food to their child, a parent may consistently ask, '*would you like some?*' or move a spoon loaded with food towards their child's mouth. Previous experience of objects coming towards their face may heighten the child's state of alertness and result in the child verbally refusing, turning their head, or pushing the spoon away. Coaching adults to present mealtime opportunities differently (e.g., the adult puts the spoon in front of the child but does not ask or attempt to feed them) gives the child autonomy to respond in that scenario as they wish. As described in Chapter 1 ('Emotional Regulation', p. 33), this facilitates the co-regulation of the emotional state between the adult and child and reduces the previously heightened reactions to specific stimuli (e.g., immediate refusal of the adult request). Scaffolding change in parents' actions and communication with their child to foster the child's autonomy and self-determination with oral eating and drinking form the basis of the Lively Eaters weaning program. It is through the context of this program that the research presented in Chapters 7 and 9 has been conducted. Therefore, an understanding of the principles and program structure aids the reader's understanding and gives context to the results of research projects 2 and 3. This child- and family-centred program is described further in Chapter 7; however, an outline is given below.

Lively Eaters Feeding Therapy Program

Learning to eat is a developmental skill affected by the emotional and physical environment surrounding the child (Dunn Klein, 2019). Lively Eaters Feeding Therapy was developed in 2010 to provide allied health feeding therapy support to children and their families. The program reflects all areas of development that must be considered for a child to learn to eat and drink successfully. As such, multiple disciplines provide assessment and advice across areas of physical, cognitive, and emotional development related to a child weaning from tube feeding. Team members include professionals from dietetics, speech pathology, occupational therapy, infant mental health, and paediatrics working collaboratively within an interdisciplinary approach. The team approach aligns with other published literature that describes child- and family-centred tube-weaning programs (Lively et al., 2021).

Families can access Lively Eaters Feeding Therapy via self-referral or referral from other health professionals. This intervention is available for families Australia-wide and internationally on a fee-for-service basis. Following acceptance of a referral, the assessment and phases of intervention for tube weaning are described below.

Lively Eaters Feeding and Mealtime Assessment

The importance of feeding and mealtime assessment is described in Chapter 1 (Part 1— Instrumental and Clinical Swallow Assessment, pp. 18-23). Clinical assessment commences with a parent interview to gather background information, including medical and developmental history (face-to-face or telehealth) and analysis of video footage provided by families of their child eating, drinking, or tube feeding. To reflect the child's oral interest and capacity across various environments and settings, mealtime assessment takes place through a range of platforms, including video observations, face-to-face interactions with the child in a therapeutic setting, and observations at their care or education setting. Children are referred for an instrumental assessment if it is available and if observational assessment indicates it is warranted.

The assessment outcomes provide a framework for developing appropriate and realistic mealtime goals for the child. Parent coaching is used to facilitate parents to implement strategies for these goals within the home environment.

Goal Setting with the Home Environment

Goal setting promotes developing and mastering new skills in achievable incremental stages through redirecting focus and momentum to new behaviours (Riopel, 2019). This is particularly important during tube weaning, because the endpoint of oral eating and drinking may feel far away for parents struggling with their child's profuse vomiting and oral aversion.

Specific short- and long-term goals that reflect the desired change are jointly discussed with the therapist and decided upon by the parents. Some parents report needing clarification on what is achievable for their child and may rely on the experience and feedback of the therapist to help determine appropriate goals (Lively et al., 2022). Parents are more likely to remain motivated to achieve agreed-upon tasks and outcomes when they set attainable mealtime goals for their family or child (Locke & Latham, 2006; Ogbeiwi, 2017). These goals are reviewed regularly in therapy sessions, and new goals are set as previous ones are achieved.

Therapy sessions may be provided in person at the Lively Eaters centre in Adelaide, South Australia, within the family home, or via telehealth. For all environments, parents are coached and supported to implement meaningful and functional changes within the home mealtime environment, because research shows that incorporating valuable and purposeful healthcare goals into engaging everyday activities is more likely to bring about sustainable and long-term change (Michie et al., 2015).

When the child and family have plateaued with mealtime goals within the home environment, an intensive week of child- and family-centred feeding therapy may be deemed clinically appropriate as the next phase from tube feeding to oral eating. This is provided by a team of health professionals as identified above and promotes a child's oral intake while reducing their reliance on tube feeding. During the week of intensive therapy, in collaboration with the parents, new mealtime goals are set to encourage a child's oral intake and therapy to support these goals, as described in the next section.

Intensive Feeding Program Structure, Philosophy, and Goals

The intensive feeding therapy program is facilitated within the paediatric ward of a small private hospital. It runs for five or six nights depending on the child's progress and the parents' confidence. The program is coordinated by a speech pathologist but implemented by a team comprising an experienced occupational therapist, dietitian, speech pathologist, infant mental health therapist, and paediatrician. Parental goals that have been predetermined with the lead therapist are communicated to the therapy team before the commencement of the intensive feeding therapy program. The intervention incorporates concepts from many of the learning theories described in Chapter 2, including Sensory Integration Theory, emotional and state regulation, parent–child relationship (Attachment Theory), and oral motor skill development, to progress the identified goals. As explained in Chapters 1 and 2, these theories and concepts are foundational to learning to eat and drink. In addition, the intensive program incorporates appetite stimulation via tube-feed volume reduction and regulation to provide the child with an intrinsic motivation to eat and drink (Dunitz-Scheer & Scheer, 2022).

The concepts of the theories outlined in Chapter 2 and the associated strategies are individualised and profiled to each family's needs. Strategies utilised in the shared family mealtime context include nonchalance, allowing the child autonomy to engage with foods/fluids at their pace, the division of responsibility, sensory food chaining, emotional regulation, specific oral motor support if the child requires it and is open to the level of direct attention oral motor activities require, and parent coaching (Appendix 4).

The therapists introduce relevant strategies within the family mealtime context at a pace that is appropriate to each child and family. The family's ability to observe, understand, react, and incorporate new strategies determines the pace. As described in Chapter 1, parents are educated, among other things, about the many sensory, regulatory, and motor skills required for successful eating and drinking. Examples of some of the key foundational goals and their significance are described in Table 4.

Non-preferred behaviour	*Therapeutic goal*	*Clinical relevance of this goal*
Parent/child interaction and behaviour		
A child stays at the table until they have finished their preferred food and then attempts to leave. Parent allows them to leave because	Parent learns strategies to support their child to remain at the table and manage any protest.	Implementation of boundaries supports child engagement. To increase their variety and volume of oral intake, children need to

they are keen to avoid 'upset' about mealtimes.	Child remains engaged at the meal table for increasing periods.	remain regulated in the mealtime environment for longer than a few minutes. However, many parents are unable to manage their child's protests.
A child's upset around food may escalate and only resolve with reliance on distraction (e.g., iPads), removal from the environment (avoidance), or counterproductive strategies (e.g., dummy).	Parent learns how to facilitate their child's emotional regulation without external options. Child learns to maintain emotional regulation within the mealtime environment.	To proceed with a meal, children need to learn ways of calming themselves at the table when upset/dysregulated rather than relying on external strategies.
A parent constantly offers food on a spoon or holds a cup to the child's lips and uses phrases such as '*would you like to try some?*' or '*yummy yummy this is delicious*'. A parent ignores a child's communication cues.	Parent allows their child a level of control and autonomy at the table, even if it does not align with the parents' ideal (i.e., even if the child does not eat). Parent learns to observe and interpret their child's mealtime behaviours and cues.	Although well meaning, parental intrusiveness can limit a child's self-determination and motivation to engage. To develop independence, children require choice, control, and respect at mealtimes, without their behaviour being demanding, controlling, or misinterpreted.
Sensory		
A child may refuse to engage in the meal when seeing an unfamiliar brand or variety of food on the table.	Child tolerates being near unfamiliar or non-preferred food and drink.	Children with food aversion may actively reject and avoid being around food. Avoidance is not conducive to learning to eat.
A child may gag or remove themselves from the environment if they cannot tolerate food odours.	Child tolerates the smell of food.	Children with sensory-processing challenges may struggle to tolerate the smell of foods and therefore are less likely to engage with them.
A child may refuse to touch/smell/taste food on their own accord or only does so with a direct request from another person.	Child shows spontaneous intent to engage with foods in an exploratory manner.	To promote a child's intrinsic motivation to learn more about food by touching/squishing/smelling/ licking, or manipulating it without direction from an adult.
A child may show emotional signals (e.g., 'hangry', frustration) but may only taste or swallow small volumes of food or fluid, if any at all.	Child learns to experience and respond appropriately to their interoceptive signals of hunger and appetite (internal 'pain').	Many tube-fed children are fed on a time and volume schedule and therefore have limited experience with hunger and how to resolve it themselves.
A parent presents too many food options or only their favourite food options.	Parent learns to manage food choices (variety and volume) provided to the child.	Visual overload (too many food choices) can disengage a child.

		Over-provision of preferred foods reduces motivation to engage with new foods.
Oral motor		
A child attempts to drink fluids, resulting in coughing, fluid loss from the mouth, and possible subsequent refusal.	Child learns to coordinate sucking and swallowing for single and then consecutive sips of fluid.	A child may not persist with an action if a skill remains difficult, unsuccessful, or painful.
A child may refuse puree (due to texture preferences or other foods looking visually different) but not yet have the oral skills for more textured foods.	Graded exposure to more textured foods in the context of the family meal, so the child sees everyone eating the same food.	Development of oral skill strength, stamina, and precision allows greater opportunity and motivation for food variety with reduced risk of choking or aspiration.

Table 4: Common behaviours and examples of key foundation mealtime goals implemented with families during the Lively Eaters intensive tube-weaning program

It is essential that parents understand the significance of these (often small) foundational steps rather than focusing solely on the end goal of their child chewing and swallowing textured foods of nutritional value and sufficient quantity. Without the foundational building blocks to eating and drinking, children will not develop the internal drive for lifelong maintenance of their newly acquired skills (i.e., eating and drinking) (Dunitz-Scheer & Scheer, 2022).

Although it is paramount to use both the child's and parents' self-determination to develop mealtime success, the contribution of a child's physiological disposition must also be considered. The literature review presented in Chapter 4 illustrates that there is a limited international consensus on gold standard tube-weaning therapy. This may result, in part, from uncertainty on which factors are pertinent to weaning outcomes. More recently, an extensive position paper was published that proposed 30 recommendations to streamline tube-weaning program design (Clouzeau et al., 2021). The recommendations have a strong focus on health professionals' consideration of factors that may inhibit tube-weaning success, including physiological factors such as weight, tube feed tolerance, digestion, oral skills, and medication use. In addition, they report on clinical aspects relating to weaning program design, such as using a multidisciplinary team and the therapeutic settings recommended for tube weaning based on the child's risk factors. Only 2 of the 30 recommendations include considerations for parents. Preparing parents for the potential longer-term consequences of tube feeding on oral skills and ensuring family 'readiness and availability' for weaning are listed (Clouzeau et al., 2021). No further elaboration on what readiness and availability relate to is provided. If parents are considered valuable and critical contributors to a child learning to eat and drink, a deeper understanding of how tube feeding may affect parents and what is required of them during weaning is needed. These considerations are discussed in detail in Chapters 9–11.

Summary – Chapter 6

Three main approaches to tube weaning were identified in Chapter 4, namely behavioural, biomedical, and child- and family- centred. Within the framework of each approach, parents assume a different role based on the underlying belief of the cause of oral food and fluid refusal. However, in published tube-weaning outcome papers, the role of the parents is superseded mainly by the measurement and reporting of qualitative outcome variables. These include recording anthropometric changes, oral feeding maintenance over time, and the volume of food and fluid consumed. One specific child- and family-centred program, Lively Eaters Feeding Therapy, was described to provide the background context of the weaning program audited in the following chapter because it was unable to be included in the published paper. Chapter 7 describes the outcomes of the audit, which explored some of the variables hypothesised to contribute to tube-weaning success.

A selection of variables thought to impact the time it may take children to wean to oral intake was audited in the context of the above-described Lively Eaters tube-weaning program (Lively et al., 2019). These variables were considered and identified by the authors prior to Clouzeau et al. (2021) publishing their tube-weaning position paper, which identified similar factors for consideration when tube weaning. Variables include those that may affect learning to eat, such as the severity of a child's medical condition, whether they eat or drink small amounts to begin with, and how interested and excited they are to join their family at the dinner table. An evidence-based understanding of the effect of these factors on weaning outcomes is essential if they are to be determining factors for weaning readiness and success.

CHAPTER 7: EXPLORING FACTORS THOUGHT TO INFLUENCE WEANING

Published as: Lively, E. J., McAllister, S., & Doeltgen, S. H. (2019). Variables impacting the time taken to wean children from enteral tube feeding to oral intake. *Journal of Pediatric Gastroenterology and Nutrition*, *68*, 880–886. https://doi.org/10.1097/MPG.0000000000002330

This chapter was peer-reviewed and published in the *Journal of Paediatric Gastroenterology and Nutrition* in 2019. The aim of this study was to audit the outcomes of an intensive tube-weaning program to determine whether any outcome variables could be used clinically to predict the time it would take for children to wean from tube feeding.

The published article was originally prepared with the American Medical Association (AMA) referencing format as per the journal specifications. References in this chapter have been reformatted in line with the requirements of this thesis.

This paper was co-authored with the contribution of each author being as follows:

Ms Emily Lively—60% concept development and project design; 70% data collection, statistical analysis, and interpretation; 60% drafted and finalised manuscript, submitted for publication.

Professor Sue McAllister—20% concept development and project design; 20% edited manuscript.

Associate Professor Sebastian Doeltgen—20% concept development and project design; 30% statistical analysis and interpretation; 20% edited manuscript.

Introduction

Infants born with chronic medical conditions are surviving in greater numbers due to improved medical treatment and technology (Hack et al., 2005). Subsequently, the use of enteral tube feeding has increased in children experiencing prematurity, physical, anatomical, or neurological anomalies, metabolic diseases, conditioned dysphagia, severe paediatric disorders, and non-organic failure to thrive (Daveluy et al., 2006; Miller, 2009; Rudolph & Link, 2002). Tube feeding frequently persists beyond medical stability due to behavioural and stress responses (Babbitt et al., 1994; Burklow, Phelps, Schultz, McConnell & Rudolph, 1998; Crist & Napier-Phillips, 2001). Internationally, approximately 4/100,000 children require enteral tube feeding (Harding et al., 2010) which is costly, impacts social, psychological, medical, and general development and causes high levels of parental emotional and psychological stress (Heyman et al., 2004; Wilken, 2012).

Weaning a child from tube feeding is complex and stressful due to multiple variables which may influence the delicate process of transitioning from tube to oral intake. Internationally tube weaning practices comprise behavioural (Benoit et al., 2000; Silverman et al., 2013), multidisciplinary child initiated (Cornwell et al., 2010; Dunitz-Scheer, Scheer & Tappauf, 2007; Harding et al., 2010; Tarbell & Allaire, 2002; Trabi et al., 2010) or online coaching approaches (Marinschek et al., 2014). Following publication of the research presented in this chapter, further analysis of international tube weaning approaches indicated behavioural, biomedical and child- and family- centred therapy as the three approaches tube weaning programs utilise (Chapter 2; Lively et al., 2021). Most involve hunger provocation through varying enteral feed volumes and are implemented in a variety of settings including community clinics, hospital (inpatient and outpatient) and home (Kindermann et al., 2008; Marinschek et al., 2014; Silverman et al., 2013; Trabi et al., 2010; Wilken et al., 2013).

Variables that influence weaning include the child's medical complexity, type of tube used for feeding and age (Bazyk, 1990; Ishizaki et al., 2013). Therapists may also consider weaning success to be influenced by the child's pre-weaning ability to accept and swallow food/fluid, sensory and regulatory capacity, and oral motor skills.

This study investigated biological variables which may impact the time taken to wean children participating in an intensive inter-disciplinary inpatient tube weaning program.

Methods

Research Design

A retrospective audit was conducted on the clinical files of 62 children who accessed an intensive weaning program from November 2010 until August 2016.

Inclusion/Exclusion Criteria

Data were included from all children from birth to eight years of age who commenced Phases 1 and 2 of the intensive tube weaning program within the audit time frame. The demographics of the children included are presented in Table 5.

Participant characteristics	
Sex	28 Female, 34 male
Age at commencement of prewean, y	Mean 2.4 (SD 1.71) range 0.6–7.7
Level of prematurity (WHO preterm birth categories)	Group 1, extremely preterm (<28 wk): n = 13 (21%) Group 2, very preterm (28–32 wk): n = 5 (8%) Group 3, moderate to late preterm (32–37 wk): n = 9 (15%) Group 4, term (>37 weeks): n = 35 (n = 56%)
Type of enteral tube feeding	32 NG, 30 PEG
Length of time tube fed before weaning, y	Mean 2.1 (SD 1.75) range 0.21–7.5
BMI *z* score at prewean	Mean −0.47 (SD 1.03)
Weight (kg) at prewean	Mean 10.45 (SD 2.98)
Percentage of required calories provided via tube feeding at prewean	93% (SD 21.12)
Coexisting medical factors	54 Children (87%) had coexisting medical factors in isolation or conjunction comprising: Neurological disorder: n = 10 (16%) Chromosomal disorder: n = 24 (39%) Malformation or disease of oral/GI tract complications: n = 15 (24%) Congenital metabolic conditions: n = 5 (8%) Congenital heart disease: n = 25 (40%) Respiratory complications: n = 27 (44%) Food allergies: n = 7 (11%) Cancer: n = 1 (1%)

BMI = body mass index; GI = gastrointestinal; NG = nasogastric; PEG = percutaneous endoscopic gastrostomy; SD = standard deviation.

Table 5: Overview of participants' characteristics

Description of the Intervention Program

The intensive intervention program was conducted in close collaboration with the families. It was supported by an interdisciplinary team led by a speech-language pathologist (SLP) and included a Dietitian, infant mental health specialist (IMH), paediatrician, occupational therapist (OT) and nurses. The underlying principles used to guide all stages of the weaning program were family-focused mealtimes, child autonomy, appetite stimulation and educating parents/carers to facilitate successful mealtimes by exploring and supporting the parent/child relationship. The intervention comprised three main phases: (i) assessment and development of weaning readiness; (ii) intensive weaning; and (iii) maintenance.

Once the child's medical practitioner consented to tube weaning, a comprehensive assessment was undertaken by a SLP, Dietitian and OT. Assessment explored medical and developmental background, historical and current tube feeding practices, current feeding regimen, calories and growth, oral acceptance of food and/or fluids, mealtime behaviour, sensory processing, and seating. Oral skill, pre-cursors to oral acceptance (self-initiating interaction with food, exploring food, eye gaze), swallowing safety, sensory tolerance and parental engagement were directly assessed by the appropriate discipline using a combination of standardised (e.g., Winnie Dunn Sensory Profile (Dunn, 1999)), observation, questionnaire (Weiss & Marmar, 1997) and clinical assessments (oral motor, video fluoroscopy swallow study where clinically indicated). Assessment findings were used to develop strategies in the home environment prior to intensive therapy. Families met with the IMH therapist (Occupational Therapist, Diploma in Infant Mental Health, and 25 years of mental health experience). The IMH therapist's role in the weaning process is to support parents in establishing and restoring the relational foundation of successful mealtime interactions and behaviours.

Readiness for the next intensive weaning phase was based on the following factors: medical stability defined as no acute medical complications or pending investigations or surgery and health had remained stable over at least the last 2–3 months; safe swallowing characterised by the absence of aspiration or other adverse events on the food and fluid consistencies offered; weight maintenance; plateau of mealtime skill through outpatient treatment; and parental capacity/readiness and overall family context to support the transfer of skills to the home environment (e.g., moving house, new job).

When deemed by the team as ready to wean, the Dietitian developed a three-day pre-wean gradual reduction to 40% of the child's typical daily calories with overall fluid volumes being maintained via electrolyte solution. This commenced within the child's home and facilitated maintenance of fluid and electrolyte balance while reducing overall calories (see Appendix 3, which outlines the hunger provocation, therapy and follow-up program). The child was then admitted to a paediatric ward and reviewed medically by nursing staff and a Paediatrician. Medical review by the paediatrician continued with daily monitoring of hydration status (physical), glucose (via glucometer), weight, stooling pattern (parental report), urine output (fluid balance chart) and the overall health of the patient.

Hunger provocation via graded reduced tube-feed volumes continued over the subsequent 7 days of admission to assist with motivation to eat by experiencing the consequence of hunger and the fulfilment of oral intake. Additional tube feeds were administered overnight (if required) at an amount and rate calculated as suitable for hydration, to manage extensive weight loss and maintain blood glucose levels based on their oral intake that day. Weight loss of up to 10% from the start of the pre-wean weight was accepted (19, 24). NG tubes were physically removed when glycaemic levels and hydration were stable. Daily bare weight pre-breakfast was recorded by nursing staff and parents/therapists recorded daily food/fluid intake and urine/stool output.

All mealtimes and snacks were provided in a family mealtime environment (including siblings) with a team member supporting and coaching. No force-feeding was allowed. Mealtimes lasted 10–15 minutes initially, extending to 20–25 minutes by program completion. The child was offered textured food that they would be able to self-feed, matching their level of oral motor skill and their sensory preferences. Food was offered on five structured occasions each day in a range of venues (hospital, café, playground, restaurant) with fluids offered via milk, bottle or breast as required. Parents met with a team member for a debriefing after each meal.

Children were discharged from the intensive component of the program after 7 days with their tube feeds either removed or reduced/eliminated, with weight loss plateauing, blood glucose levels stable following overnight fasting, and hydration deemed medically adequate. Medical care was transferred back to the child’s medical practitioner.

All children were reviewed (via Skype or in clinic pending proximity to the clinic) weekly and then fortnightly for 3 months post-completion of the intensive part of the program, with further support, advice and tube-feed reduction provided once established back in the home environment. The child’s weight, height, oral and mealtime behaviours, urine and stool output, general development, sleep and behaviour were monitored. Ongoing strategies around mealtime and food and drink behaviours, specific food suggestions, and tube-feed volumes (if required) were given as well as emotional support to parents. Children in this study were deemed as weaned when they no longer required any food or fluid via their tube and could maintain their growth and nutrition on oral intake alone.

Audit Methodology

Ethics approval was obtained from the appropriate local human research ethics committee (Appendix 5). Variables of interest were extracted from clinical files from the pre-wean assessment and the 3-month review. Variables were selected based on research evidence regarding the impact on weaning outcomes (Dunitz-Scheer et al., 2009; Wilken et al., 2013) as well as those commonly thought clinically to influence and included age, gender, level of prematurity, weight, type of enteral tube, length of time tube fed, medical conditions, mealtime and oral behaviours/skill and time taken to wean.

Classification of Variables for Analysis

Oral skills, mealtime/food interaction behaviours and medical complexity were classified to allow the grouping of children into descriptive categories for analysis. The rating charts for oral skills and mealtime and food interaction were developed by two Speech Pathologists with a minimum of ten years of paediatric feeding experience. Each child's information was extrapolated from clinical files and rated. Medical complexity classifications were completed independently by three experienced allied health professionals with a minimum of ten years of paediatric feeding experience. The majority consensus for the medical classification was accepted.

Oral skills were classified into ten ordinal categories to reflect the typical development and clinical judgement of the specificity, complexity and functionality of oral movements required for swallowing different textures, liquids, or combinations of these (Table 6).

Oral skills	**Rated 1–10 where 1 indicates best performance and 10 indicates poorest** 1. Manipulates and swallows soft chew diet and thin fluids 2. Manipulates and swallows mashed diet, dissolvable finger foods and thin fluids 3. Manipulates and swallows puree diet, dissolvable finger foods and thin fluids 4. Manipulates and swallows soft chew diet plus thickened fluids 5. Manipulates and swallows mashed diet, dissolvable finger foods, and thickened fluids 6. Manipulates and swallows puree diet, dissolvable finger foods, and thickened fluids 7. Swallows liquids (thin) 8. Swallows liquids (thickened) 9. Mouths and tastes foods/fluids but doesn't swallow 10. Complete refusal of all foods/fluids
Mealtime feeding/food interaction behaviours	**Rated 1–5 where 1 indicates best performance and 5 indicates poorest performance** 1. Participates in oral food and drink experiences and allows adult involvement 2. Accepts self-feeding (spoon, cup/bottle, or finger foods) but refuses adult attempts to assist with or encourage feeding 3. Happily explores food/drinks by self, in a sensory manner but minimal amount ingested 4. Minimal spontaneous interest/awareness in oral food/drink; passive acceptance; high level of distraction required 5. Upset at food/drink offerings (including obstructive feeding behaviours such as gagging, vomiting at sight of food, throwing food, screaming in highchair)
Impact of medical complexity on weaning (rating scale)	0. No diagnosed medical condition but requiring a tube due to faltering growth 1. Least impact on weaning (ie, predicted easiest to wean) 2. Moderate impact on weaning 3. Severe impact on weaning (predicted hardest to wean).

Table 6: Rating system used to categorise variables into oral experiences, mealtime feeding/food interaction behaviours, and medical complexity

Mealtime feeding and food interaction behaviour variables were classed into 5 categories (Table 6) which clinically represented different stages of food interaction commonly observed in the children seen in this program.

The type of medical condition(s) is likely to impact differently on feeding abilities and behaviours, therefore summing the raw number of medical challenges was not considered meaningful. A four-point rating scale was developed to represent the anticipated impact of each child's medical condition(s) on the weaning process (Table 6). The professionals' ratings for each child were summed, creating a weighted score. As the participant sample was small, these resulting groups were collapsed into 2 categories for regression analysis as 'mild impact' (0 and 1) and 'moderate to severe impact' (2 and 3) on weaning (see Appendix 6 for development of classification for medical conditions).

Level of prematurity was classified against WHO preterm birth categories of (Group 1) extremely preterm (< 28 weeks), (Group 2) very preterm (28 to 32 weeks), (Group 3) moderate to late preterm (32 to 37 weeks) and (Group 4) term (WHO, 2018b). These categories were collapsed into two groups for analysis with categories 1 and 2 in one group and categories 3 and 4 in the other.

Data Analysis

Data were analysed using SPSS for Windows, version 23 (IBMSLPSS, Chicago, IL). Individual variables expected to influence the weaning process were analysed using univariate Cox regressions first to decide which variables to include in subsequent logistic regression analysis. Variables that had a significant impact on the time taken to wean were the type of feeding tube; medical complexity; age; and length of time tube fed (all $p<0.05$; Table 7). In order to avoid the effects of multi-collinearity, non-parametric analyses of the relationships between age and duration of tube feeding were then undertaken which showed a high correlation between these variables (Spearman's $r=0.89$, $p<0.001$). Therefore, only the length of time tube-fed was included in the final regression model as this variable was deemed a potential predictive variable that is clinically easily assessed, and the sample size did not allow for a larger number of variables to be included.

Variables that individually did not impact on the time taken to wean in the preliminary Cox regressions were excluded from further analyses (summarised in Appendix 7).

Prematurity level was investigated to identify if it interacted with the level of medical complexity; however, this was not found to be the case ($B = -0.60$; $SE = 0.65$; $p=0.362$; Exp (B) = 0.55; 95%CI for Exp (B) = 0.15/1.99; $X^2 = 0.41$). Therefore, the prematurity level was not considered in subsequent analyses.

Descriptive statistics explored the number of children weaned through the program and their growth post-weaning.

Finally, a three-step logistic regression model was developed that incorporated the variables of time tube-fed prior to weaning, medical complexity, and type of tube to determine the strongest predictors of time taken to wean. The logistic regression analysis was followed by an evaluation with survival analyses of the two different types of tubes and levels of medical complexity to quantify the effects of tube type and medical complexity on the time taken to wean (Table 7).

Variable	Model 0 Univariate analyses n = 62					Model 1 (time tube-fed, medical conditions) n = 62					Model 2 (time tube-fed, medical conditions, type of tube) n = 62				
	B	SE	*P*	Exp (*B*)	95% CI for Exp (*B*) Lower/ Upper	*B*	SE	*P*	Exp (*B*)	95% CI for Exp (*B*) Lower/ Upper	*B*	SE	*P*	Exp (*B*)	95% CI for Exp (*B*) Lower/ Upper
Time tube-fed prior	−0.041	0.011	<0.001	0.96	0.94/0.98	−0.039	0.011	<0.001	0.96	0.94/0.98	−0.025	0.011	0.023	0.98	0.96 / 0.99
Medical complexity	0.71	0.29	0.015	2.03	1.15/3.60	0.62	0.3	0.037	1.86	1.04/3.34	0.7	0.31	0.023	2.01	1.1 / 3.67
Type of enteral tube at time of wean	1.47	0.32	<0.001	4.34	2.31/8.17						1.23	0.37	0.001	3.42	1.65 / 7.08
X^2 change from previous step						4.39					11.3				
Significance (*P*) of X^2 change						0.036					0.001				

B = beta value; CI = confidence interval; Exp(B) = odds ratio; *P* = value of probability; SE = standard error for beta; X^2 = Chi square value.

Table 7: Multiple regression model of variables identified in preliminary analyses to have a significant effect on time taken to wean

Results

Data from 62 children were available (mean age 2.4 years, SD 1.71, age range 6 months to 7 years, 7 months; 28 female; 32 fed via NG tube, 30 fed via PEG). All children were initially highly dependent on tube feeding with 93% (SD 21.12) of calories being provided via the tube for a mean time of 2.1 years (SD 1.75; range 0.2–7.5 years). Fifty-four children (87%) had at least one diagnosed medical condition. The mean weight at the time of weaning was 10.54kg (SD 2.98) and the mean BMI z-score was −0.47 (SD 1.03). Mean score for pre-wean mealtime behaviours was 2.63 (SD 1.32) and 5.66 (SD 2.6) for oral experiences.

By the completion of the 7-day intensive program 37 children (60%) were fully weaned with this number increasing to 45 children (73%) by 3 months and 50 children (81%) within 10 months of commencing the weaning process. By 3 months post-discharge, 97% of weaned children remained on exclusive oral intake. 31 children (69%) had exceeded or remained within 100g of their pre-wean weight and the remaining 14 children were within 10% of their pre-wean weight. The mean weight loss during the 7-day intensive period was 2.75% (SD 2.19) of the child's pre-wean weight and by 3 months post-discharge the mean weight was a 3% gain from pre-wean weight (SD 1.84).

Children with NG tubes (Mean 13.8, SD 11.14) had been tube fed for a significantly shorter time (p = <0.001) than children with PEGs (Mean 38.30, SD 22.42).

The first regression model indicated that the time tube fed and perceived level of medical complexity predict the time taken to wean. However, adding the type of tube to the regression created the strongest predictive model of time taken to wean (Table 7).

Finally, survival analyses comparing the time taken to wean between nasogastric versus PEG tubes and between the two levels of perceived medical complexity revealed shorter weaning times for children with nasogastric tubes ($X^2 = 23.19$, $p < 0.001$) and children who were deemed medically to be less complex ($X^2 = 5.99$, $p = 0.014$) (Figure 25). However, medical complexity did not differ between children who were fed via an NG or a PEG tube ($X^2=1.60$, $p = 0.207$).

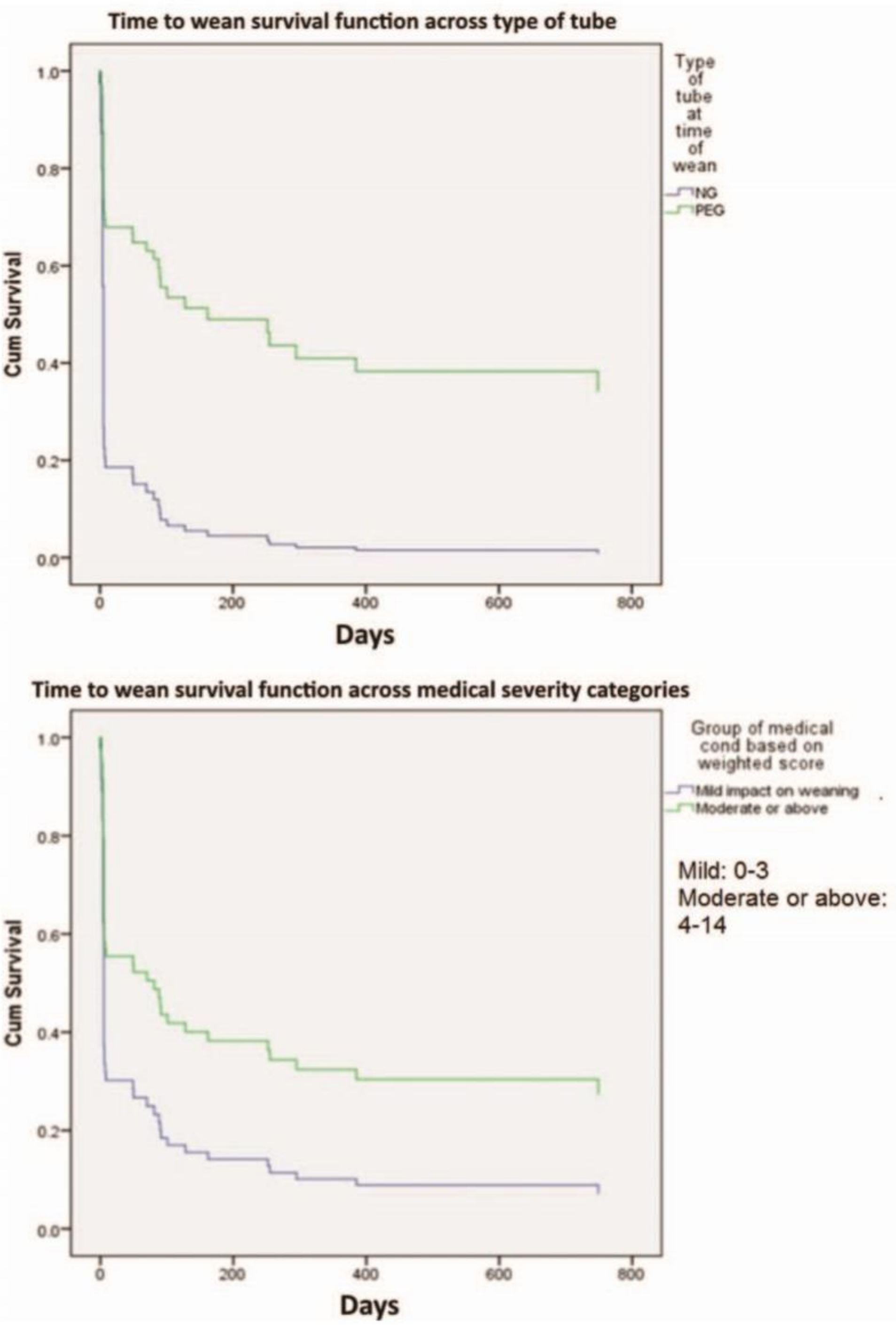


Figure 25: Survival analysis graph

Discussion

Tube weaning children is a delicate process that is influenced by many individual, social and psychological variables. A file audit of 62 children weaned through an intensive interdisciplinary, family-centred program showed that biological/physical factors such as the type of feeding tube, complexity of medical conditions, age and length of time tube fed were all significantly correlated with the time taken to wean. However, a logistic regression model including the length of time tube fed, type of feeding tube and degree of medical complexity was the strongest predictor of time taken to wean.

Factors Correlating with the Time Taken to Wean

We explored several biological factors generally assumed to be correlated with the time taken to wean. For example, a child's age and time tube fed prior to the weaning period positively correlated with the time taken to wean. This suggests that younger children wean more quickly, perhaps because they are less psychologically dependent on the tube having been tube fed for shorter periods of time. We investigated the relationship between a child's degree of medical complexity and the time taken to wean as it was anticipated that a more medically fragile child may be more difficult to wean because lifesaving treatments took precedence over learning to eat. Those children deemed as medically 'more complex' did indeed take longer to wean, a finding that remained significant in the strongest predictive model in the regression analysis. However, we also note that even the children in the more complex group successfully weaned over the course of the intensive weaning program, albeit taking about 9 times as long as the children in the less complex group.

These findings have two important implications. First, a higher degree of medical complexity does not prevent children from successfully weaning from tube feeding. Our finding of a longer time taken to wean should not preclude more medically complex children from attempting to wean in a supported environment. Second, parents of more medically complex children may require specifically tailored assistance that enables them to support their child through a longer weaning process.

Children with nasogastric tubes transitioned 3.6 times faster from enteral to oral feeding and had an overall shorter duration of tube feeding prior to admission than children with PEG tubes. It is likely that the shorter period of reliance on tube feeding contributed to the shorter duration of the weaning process. In addition, it may be that greater oral invasiveness and the more overt visual appearance of the NGT provided greater motivation to transition faster to oral intake, although this was not formally evaluated in this study. Of note, children with an NG tube were not significantly less likely to have a medical complexity rating of 'moderate-severe'.

Factors Not Correlating with the Time Taken to Wean

In preliminary analyses, we explored several variables usually assumed to potentially influence the time taken to wean and used by health professionals as indicators for readiness to wean. For example, a child's prior oral experiences or mealtime behaviours. In Australia, parents have anecdotally reported that they have been refused weaning programs by some teams based on the parameter of not yet eating or drinking 'enough'. Our analyses demonstrated that a child's oral experiences or the way they engage at mealtimes did not predict the weaning time and therefore these variables alone should not be the basis for deciding whether a child is ready to wean. Similarly, BMI z-scores did not predict the time taken to wean, suggesting that solely relying on this measure to clinically determine readiness to wean may also be insufficient.

Limitations

We believe the following limitations apply. First, the sample size of 62 children limited some of the analyses that could be conducted, in particular the size of the multiple regression model. For this reason, we conducted preliminary analyses on individual variables in order to identify those most appropriate to include in the final regression model. However, we note that our sample size compares well with international tube weaning literature where participant numbers vary from single case studies (Gibbons et al., 2007) to 10 (Hartdorff et al., 2015) and 221 participants (Trabi et al., 2010). In these studies, children were medically healthy (i.e., non-organic reasons for tube feeding) or experienced a variety of medical conditions and had been tube fed on average for more than ¾ of their lifetime. This is comparable with the current study in which 87% presented with comorbid medical conditions and tube feeding for a mean of 2.1 years. We also note that our findings are based on data obtained retrospectively and relate to this specific program only; however, they provide a basis for comparison and consideration by other programs as well as future research.

Second, while a rigorous process was undertaken to standardise the clinical judgements being made about oral skill, mealtime behaviour and weaning-related medical complexity, further validation of these rating scales are warranted and our findings relating to these variables should be interpreted in this context.

However, those categorised as less medically complex did wean significantly faster than the more medically complex, suggesting clinical classification represented a meaningful grouping.

Conclusion

This retrospective case audit investigated biological factors thought to influence the time taken for children to transition from enteral feeding to full oral intake. Our analyses suggest that of the variables presumed to impact time to weaning, time tube fed, and type of feeding tube combined with the degree of medical complexity were the strongest predictors of time taken to wean in this cohort. Variables such as the volume of oral food and drink a child consumes prior to weaning, and the ability to chew textured foods or gain additional weight before weaning, were not predictive of time taken to wean. These variables, therefore, should not be the main criteria when deciding to initiate weaning.

The intervention approach audited assumes that weaning success relies on the child and caregiver engaging in a relationship that involves mutual trust and respect for feeding cues and behaviours. Our findings suggest further research should consider investigating whether psychological variables can mitigate the impact of physical variables with a view to developing a biopsychosocial model for tube weaning.

This research project explored child-based factors relating to tube weaning. The intrinsic, biological factors described above were unable to account for why some children wean in a quicker timeframe than others. As indicated by the title of ‘child- and family-centred’ weaning programs, both the child and the family play a role in tube weaning. To this end, further exploration of parent-based factors that may impact a child’s ability to learn to eat and drink was undertaken. Further information regarding the parental capacity for tube weaning may contribute to the differences in the time it takes some children to tube wean. The outcomes of the research exploring the role and experiences of parents during tube weaning are thus presented in the following chapters.

CHAPTER 8: EXPLORING PHYSIOLOGICAL AND PSYCHOSOCIAL FACTORS INFLUENCING TUBE WEANING

The outcomes described in the audit research of the child- and family-centred tube-weaning program outlined in Chapter 7 suggest that physiological factors alone are not sole predictors of the time it may take a child to learn to eat and drink (Lively et al., 2019). Specifically, the complexity of medical diagnoses, the length of time a child has been tube fed, the child's BMI, and the level of tube dependency (i.e., how many calories are provided via the tube) do not appear to inhibit a child from learning to eat and drink. However, these factors also do not guarantee that a child will learn to eat and drink.

Therefore, this poses questions about children who are not medically complex or have not required the tube from birth. What factors are interacting if these children take longer to wean than a child with a greater number of, or more severe, comorbidities? Perhaps other potential influences contribute to children successfully learning to eat and drink.

As described in Chapter 2, children's learning is thought to occur from the interplay between each child's cognition and their environment. This encapsulates the people, places, and experiences that influence the child and provide opportunities for observation and self-initiated imitation if desired (Bandura, 1977). Understanding the influence of these environmental factors on a child's learning capacity regarding mealtimes and satiation may provide a valuable context within which to view the process of tube-dependent children learning to eat and drink orally.

The results outlined in Chapter 7 (Lively et al., 2019) indicate that a child can progress with their oral intake following intensive feeding therapy and subsequently reduce or eliminate tube dependency upon completion of the program. Conversely, some children maintain a lower level of tube dependency during and immediately after the intensive therapy; however, they require increased supplementation in the following months (Sadeh-Kon et al., 2020). This may be because of continued weight loss and energy deficits resulting from a lack of improvement in oral skills and mealtime interest. Understanding the factors that result in some children excelling and others regressing with oral intake is critical in providing effective support to target those who are most likely to have the most significant effect on weaning outcomes. For example, if responsive feeding (as described in Chapter 1, p. 29) remains challenging for a parent, the resultant effect may be an increase in the child's food refusal behaviours and maintenance of, or reinstating, tube feeding. Specifically, working with parents to understand and implement responsive feeding principles may need to become a key therapy goal.

The factors influencing a child learning to eat and drink may have a physiological or anatomical foundation or stem from environmental factors. Both considerations are discussed in the next section in the context of potentially contributing to tube-weaning outcomes.

Physiological Variables That May Affect Successful Tube Weaning

Until food and fluid are regularly consumed by a child or consumed in greater quantities, it may be challenging to detect altered anatomical or physiological pathways. As tube-weaning progresses and a child's intake increases in volume and frequency, oral or pharyngeal motor fatigue or incoordination may lead to identifying previously undetected swallowing challenges (Dunitz-Scheer & Scheer, 2022). In addition, an unforeseeable and unpreventable change in medical status, such as the onset of seizures or post-viral complications, may affect the swallowing function or safety and result in reinstating tube feeding. For some children, a worsening of their underlying medical condition over time may warrant the return to tube feeding. This was evidenced at a 12-month follow-up of children attending a child- and family-centred weaning program (Sadeh-Kon et al., 2020). Over one-third of the children who were fully weaned upon completion of the three-week intensive program had reverted to partial tube feeding resulting from regression of their underlying medical status. Ongoing weight loss in the presence of prolonged oral skills progression was also seen in this group of children as a reason for recommencing tube feeding (Sadeh-Kon et al., 2020).

Many tube-fed children have immature gastrointestinal systems (as discussed in Chapter 1, p. 37), which may be a result of one or more of at least 22 paediatric gastrointestinal conditions that are known to possibly require tube-feeding support (Rivera-Nieves et al., 2019). Gastrointestinal complications may be revealed only once regular oral intake commences and food variety is introduced (e.g., inflammatory bowel disease, chronic diarrhoea). For these children, gastric intolerances can be minimised by using commercial formulas that have an exact and ‘controlled’ composition of ingredients. These children may be able to tolerate small tastes of foods; however, as the volume of ‘uncontrolled’ foods they ingest increases, gastric intolerance may become more problematic. This may result in gastric discomfort and, in turn, some children may revert to tube feeding as a more comfortable form of nutrition. This is supported by long-term tube-weaning follow-up data whereby 66% of children who reverted to tube feeding had gastrointestinal disorders (Krom et al., 2020).

In addition to sudden-onset medical conditions, regression of an underlying medical condition, and gastrointestinal complications, genetic disorders may also affect the need for long-term tube feeding. Children with genetic conditions account for one-third of those who experienced ongoing tube dependency at long-term follow-up of participants who had attended a child- and family-centred clinical hunger provocation program (Krom et al., 2020).

It may take weeks or months of oral eating and drinking for physiological symptoms to appear or worsen. At this point, the resumption of tube feeding may be clinically indicated. As reported by some of the parents in the research presented in Chapter 9, witnessing their child’s regression of oral intake can be frustrating and devastating for them (Lively et al., 2022). The unknown reasons why their child is regressing may influence their confidence in their child’s ability to eat and drink, as well as their ability to facilitate their child’s oral development (Cipolla et al., 2022). While it may be a physiological variable that contributes to a child’s oral intake reduction, the psychological effects on the child and the parents may perpetuate the situation. The potential psychosocial and psychological factors that may result in reinstating tube feeding are discussed below.

Psychosocial Variables That May Affect Successful Weaning

Chapter 2 highlighted the importance of the environment and significant caregivers in developing successful mealtime skills. In particular, Ecological Systems Theory (Bronfenbrenner, 1977), SCT (Bandura, 1977), Attachment Theory (Bowlby, 1969), and SDT (Deci & Ryan, 1985) emphasise the influence of the greater community and environment around a child. For example, SCT (Bandura, 1977) and Ecological Systems Theory (Bronfenbrenner, 1977) suggest that a child may observe others in their environment (i.e., at mealtimes) and choose whether to imitate the mealtime behaviours they witness. In the absence of this, it may be reasonable to reflect that the greater environment and community may also contribute to a child's regression in oral intake.

Although the theories mentioned above all influence child learning, the child- and family-centred weaning program described as part of this research program focuses on the parents' influence on their child's learning (see Chapter 9). Therefore, the role of parents in developing their child's independence at mealtimes is of particular interest when exploring factors—beyond biological—that contribute to or interrupt the maintenance of newly acquired oral and mealtime skills as identified in Research Project 2 (see Chapter 3). As described in Chapter 2 (p. 96-99), SDT will be used to explore the role of parents in teaching their tube-fed child to eat and drink. The principles of SDT can be applied to both the child and the parent because they both strive towards healthy psychological, social, cognitive, and skill development within the context of mealtimes. Although other theories described in Chapter 2 (e.g., Social Cognitive, Ecological Systems, Attachment, Sensory Integration) are highly relevant in explaining the development of a child's mealtime skills, SDT reflects both the parent and child's internal growth. Both the parent and child's inner growth across new oral and mealtime skills reinforces further development. Therefore, SDT will be used to support a deeper exploration into both the possible experiences of the child and the role of the parents (an aspect indicated by this research program as a key influencing factor in tube-weaning success) at mealtimes.

A Child's Self-Determination as a Facilitator of Mealtime Skill Development

Although the three fundamental needs of SDT were described in Chapter 2 (i.e., autonomy, competence, and relatedness), this section will outline the differences between a tube-fed child learning to eat and drink due to internal motivation (i.e., self-determination) compared with those who rely on external motivation. Self-motivated children are more likely to persist with a task even in the face of hard-to-master skills (Ryan et al., 2008), and in the presence of an internal motivator (i.e., hunger), a child is frequently motivated to seek food or drink to relieve their hunger pain. Subsequently, they are more likely to repeat the behaviour of reaching for food or drink each time they feel hungry. The internal physiological motivation of hunger drives the repeated pattern of seeking food and independent eating. When internal motivation is high, eating and drinking occur despite the environment they are in. For example, a child with sensory-processing challenges who cannot tolerate loud environments may still be motivated to eat at childcare because they are hungry and see others eating, despite being in a noisy environment.

However, children who are taught to eat and drink based on an external motivator (e.g., tangible rewards) are more likely to require that motivator in their environment to be successful with eating or drinking, and are less likely to recognise and respond to their internal hunger cues (Field, 2020). In fact, research has shown that external rewards for task completion undermine a child's intrinsic motivation (Deci et al., 1999). For example, in the context of learning mealtime skills, a child who only eats sitting on the lounge with an iPad while being spoon-fed by their parent may not accept food offered by their parent when seated at a table with no iPad. Without a specific motivator (e.g., tech device or favourite toy), the child may refuse to eat, thus affecting the transferability of mealtime skills to different environments. The child appears to lack intrinsic motivation (self-determination) to improve their mealtime skills and respond appropriately to their internal hunger cues unless an external reward is available. This is despite a person's natural internal drive to endeavour to master developmental skills, develop socially as part of their community, and strive for excellence without requiring external rewards (Csikszentmihalyi & Rathunde, 1993; Harter, 1978).

SDT may also explain why some children may strive to achieve new skills; however, these may not be achieved without them experiencing internal conflict and dialogue to manage what they perceive as opposing demands to make a decision, answer a question or solve a problem. For example, a tube-fed child may observe their family or peers eating and drinking daily. However, whenever their parent brings a spoon, food pouch, or straw towards the child's face, they reject it by pushing it away or turning their head. Although they may have the internal desire to eat and drink orally, they refuse the adult-directed environment within which this is offered because prior experiences of their parents approaching their face have resulted in pain or discomfort (e.g., NGT changes, medication administration). It may be difficult for the child to build trust and confidence with oral eating, which is unhelpful for tube weaning. Consequently, food refusal may not be a result of their lack of self-determination but a reflection of the barriers inhibiting them from acting on their self-determination. To support their self-determination, a child or parent may alter the environment and thus support them to become more open to new learning experiences.

To resolve their internal conflict of mistrusting the mealtime environment despite the desire to eat, the *child* can alter the environment and provide themselves with the opportunity to explore and experiment with a new skill without direction or input from adults. For example, the child may reach for a sibling's spoon when no one is watching, mouth the rim of a food pouch while in the stroller, or sip from a drink bottle left lying at childcare while people are occupied with other tasks. By doing so, they practice the motor, sensory, and social skills required for more successful oral eating.

A Parent's Self-Determination as a Facilitator of Mealtime Skill Development

To support their child's resolution of internal conflict and promote trust in mealtimes, a *parent* can facilitate 'self-learning' environments for their child by providing the developmentally appropriate opportunity and then allowing autonomy for the child's self-motivation to ensue. Coaching and supporting parents in providing such an environment is one of the goals of the tube-weaning program described in Chapter 9 and forms the basis of the child- and family-centred approach to tube weaning as described in Chapters 4 and 7.

As outlined in Chapter 1 (p. 26), the development of children's mealtime skills depends upon many motor, cognitive, and emotional elements, including the child's ability to sit in supported seating, maintain emotional regulation, and observe what is happening at the meal table. The ability of the parent in facilitating this 'calm and alert' state will allow the child to initiate and imitate patterns of behaviour observed in others, such as dipping their finger in a sauce or bringing a biscuit towards their face. The development of these foundational skills is required before a child is likely to bring food or drink to their mouth. Once they have the confidence to bring food or drink to their mouth, they may begin to explore and develop the oral motor and sensory skills required for eating and drinking, as described in Chapter 1.

Coaching parents to understand each of these stages of skill progression facilitates within them a sense of progress and improvement as their child works towards the ultimate goal of eating and drinking. A parent's confidence in their child's ability can build as they observe their child's self-learning and motivation to improve their mealtime skills. Witnessing a change in their child's skills can provide valuable reinforcement for parents that their role in facilitating new strategies and environments is supporting their child to flourish (D'Arrigo, Copley, Poulsen & Ziviani, 2020).

Based on Ecological Systems Theory and SCT, parents' successful implementation of a new approach is likely to lead to changes in their child's external mealtime behaviours (i.e., responses you observe your child doing). The intensive program presented and audited in Chapters 7 and 9 of this research program is centred on this theory. This means that health professionals provide the initial structure and guidance to parents to support the environment and strategies known to support children's learning and self-determination (as per SDT, Chapter 2, p. 96-99). Health professionals can play an important role in drawing parents' attention to subtle changes in observable mealtime behaviour, because these may not be immediately obvious to parents. For example, a child may actively touch and engage with food instead of throwing it each time it is placed in front of them. A parent may reflect that '*they are still not eating*'; however, the child's self-determination of more functional engagement with food is their driving factor for continued and expanding change. Within the mealtime context, when a child spontaneously strives to develop the three fundamental psychological needs at the core of their self-determination and mental wellbeing (i.e., autonomy, competence, and relatedness) (Ryan & Deci, 2000), a parent's behaviour is positively reinforced as per the principles of operant conditioning (Skinner, 1938).

In turn, positive reinforcement increases the likelihood of a repeat presentation of the behaviour, and this cyclical pattern facilitates positive feedback (Skinner, 1938). For parents, this may include allowing their child autonomy at mealtime or reducing their stress level around food offerings by changing the event's focus from calories consumed to an enjoyable experience. When a change in a parent's behaviour leads to a observable desired outcome within their child, parents may develop a sense of competence with decision-making and parenting confidence away from the medical model of tube feeding to which they have frequently become accustomed. Not only is their child's self-determination bolstered by the change in the mealtime environment, but so is the parent's self-determination of being responsible and capable of teaching their child to transition from tube feeding.

However, at times, the family cannot uphold the principles and strategies established and practiced together during family-centred therapy. The effects and sequalae of tube dependency on the child and parents (as discussed in Chapter 1 (p. 64-69) may contribute to ongoing adverse associations with tube feeding. However, trauma theory may be used to explain how post-traumatic stress may affect the responsivity and behaviours of both the child and the parents at mealtimes. The ongoing effects of trauma (as described in Chapter 2, p. 101) form one of the psychosocial reasons why tube feeding may need to be reinstated or maintained in children who are learning to eat and drink. These effects are discussed below.

The Role of Trauma in Maintaining the Need to Tube Feed

Medical trauma among children and parents of tube-fed children is common because these children have complex medical needs and may require multiple interventions. Trauma can affect daily life, social capacity, and the mental health of children and parents (Edwards et al., 2016; Hopwood et al., 2020; Krom et al., 2017). Although children play a significant role in their mastery of oral intake, I propose that a parent's ability to incorporate new strategies at mealtimes to support their child in learning to eat and drink depends on their ability to regulate their emotional state at mealtimes (see Chapter 1, p. 34). The act of offering food and watching their child refuse these offerings may cause increased stress and anxiety for them (as discussed in Chapter 1). Chapter 9 of this research program explores parents' experiences during tube weaning. The extensive tube-feeding experiences shared by the parents interviewed for this research highlighted the lasting memories of the traumatic events their child had experienced or that they had witnessed (Lively et al., 2022). The physiological effects of trauma are described below to understand how this trauma may be relevant to a child and their parents during tube weaning.

Physiology of Trauma

Childhood trauma results when a child experiences an emotionally painful or distressing event or multiple events that may have ongoing physiological or psychological responses (NCTSN, n.d.). Children are likely to display the effects that trauma has on them through a change in behaviour and emotion. For example, the child may be clingy, easily frightened, difficult to console, have sleep difficulties, impulsive, or experience regression in previously acquired developmental skills (NCTSN, n.d.; De Bellis & Zisk, 2014). Additionally, as with adults who experience traumatic stress, these children may experience low appetite, poor growth, and digestive problems (NCTSN, n.d.; Roer et al., 2021).

As described in Chapter 1 (p. 38), tube-fed children often experience medical invasiveness, repeat surgeries, serious illness, discomfort, and pain (Wilken, 2012). In addition to repeated invasive NGT placement, examples of potentially trauma-inflicting events for tube-fed children include breathing difficulties caused by aspiration or other respiratory or cardiac complications, frequent acid reflux or vomiting resulting in throat pain, and repeat attempts at being orally fed against their will (Blumenstein, Shastri & Stein, 2014; Krom et al., 2017). Similarly, parents are often traumatised at having witnessed these, at times lifesaving, events or in response to their child's diagnosis or prognosis (Muscara et al., 2015). Therefore, during tube weaning, potential trauma responses from the child and the parent may influence the progression of a child's oral skill and intake.

Being a part of, or witnessing, traumatic events can result in physiological changes in children and their parents. For example, they may experience a persistent state of 'fight or flight', wherein they remain hyper-aroused and scared that the same traumatic event may be repeated. Hyper-arousal results in physiological responses such as increased heart rate, difficulty concentrating, irritability, hyper-vigilance, and challenges with emotional regulation and aggression (DSM-5). Therefore, hyper-arousal in either a child or their parent may interfere with their responsiveness and engagement at mealtimes. To illustrate, a hyper-aroused *child* may be agitated, unable to calm and regulate themselves, and therefore show limited interest in the mealtime occurring within their environment. A hyper-aroused *parent* may not feel physiologically hungry because of heightened stress levels resulting in high adrenaline levels. Within the context of family mealtimes, parents are encouraged to eat their meal and thus provide an environment for their child to observe and imitate from. Rather than eating their meal, a hyper-aroused parent may intently watch their child's every move at mealtimes, adding perceived pressure to the child to eat. A child's oral acceptance or even exploration may be reduced if we consider the above example of a hyper-aroused child and parent within the same mealtime context.

The effects of trauma on the physiology of the developing brain are not fully understood but are likely to be multifactorial and are suggested to be dependent upon the child's age and the extent and type of trauma experienced (De Bellis & Zisk, 2014; McCrory et al., 2011). However, it has been shown that the size of the prefrontal cortex of children who have experienced childhood trauma is reduced, suggesting dramatic effects on the neurophysiological architecture of the developing nervous system (McLaughlin, Sheridan & Lambert, 2014). The prefrontal cortex is responsible for cognitive processes such as thought, language, planning, and memory, as well as behavioural responses such as emotional and social interpretation, regulation, and response inhibition (De Brito et al., 2013). As discussed in Chapters 1 and 2, emotional regulation, intentional imitation, and motor planning are all foundational mealtime skills required for a tube-fed child to transition to oral intake.

To support a traumatised child to regulate their emotions, reduce arousal levels, manage stress, and develop their cognitive skills and resilience following traumatic events, parents need to be reliable, responsive, and protective (Pears et al., 2013; Samuelson, Krueger & Wilson, 2012). However, parents who have witnessed their child receive lifesaving interventions may themselves be traumatised and experience the cognitive and emotional effects of trauma. This may include challenges related to memory, attention, thinking, language, and emotional regulation (Gioia, Isquith, Retzlaff & Espy, 2002; Muscara et al., 2015). This, in turn, may affect their emotional availability to interact with and interpret their child's cues at mealtimes and their ability to provide the responsive environment and reassurance they require. The parents' ability to learn how to facilitate successful tube weaning is paramount to child- and family-centred approaches. Yet, is it possible to mitigate the physiological responses to trauma by supporting parents (and children) to understand and manage the psychological effects of trauma?

Psychology of Trauma

The psychological effects of trauma may be experienced by children and adults involved in the original traumatic event or the care following the event. As previously discussed, the tube-weaning approach at the centre of this research program relies on active learning from the child and the parent. However, because the subjective experience of a traumatic event is often longer-lived than the objective effects, the effects may be felt months or years after the actual event (Toof et al., 2020). This is because, psychologically, children and parents may re-experience traumatic events in the form of nightmares, flashbacks, or memories triggered by situations such as interactions with people, places, or activities associated with the traumatic event (NCTSN, n.d.). For example, parents of children who experienced a significant burn reported ongoing feelings of depression, anxiety, and post-traumatic stress because they witnessed the burn event and felt helpless at the time (McGarry et al., 2013). These feelings were exacerbated if they had previously experienced traumatic events.

For children having to endure invasive medical procedures—at times performed by their parents (e.g., NGT changes)—their cries for help may be perceived to go unheard as the parent persists with the necessary procedure. At other times, a parent may be responsive and reactive to the child's upset. The unpredictability of whether the parent will comfort or dismiss the child's request for help may influence the child's attachment to their parent (as per 'Attachment Theory', Chapter 2, p. 89). To manage their trauma, a child may attempt to escape and avoid the situations they know to cause pain (Shear, 2012). This may include avoiding connection with their parent, which can influence the parents' sense of worth and subsequent interactions with their child. This dynamic becomes particularly challenging at mealtimes when mutual trust and interaction are paramount, as discussed in Chapter 1 ('Development of Mealtime Skills', p. 29).

In addition to witnessing medical interventions, parents may experience trauma through their feelings of grief, self-blame, shock, sadness, and loss associated with learning that their child requires tube feeding and any diagnoses that may be related to this (Bingham, Correa & Huber, 2012; Sher-Censor, Dan Ram-On, Rudstein-Sabbag, Watemberg & Oppenheim, 2020). As described in Chapter 1 ('Development of Mealtime Skills', p. 33), the ability of a parent to regulate their emotions and those of their child is a necessary precursor for successful mealtimes. However, grief and shock may leave parents overwhelmed and unable to regulate their emotional state. Instead, they may choose to escape and avoid situations that remind them of the traumatic event (Shear, 2012). An emotionally unavailable parent is likely to be less responsive to their child's needs, which may result in an insecure attachment, as described in Chapter 2 ('Attachment Theory', p. 91) (Bowlby, 1969). As described throughout this research program, tube weaning relies on teaching parents how to provide consistent, predictable, and reliable mealtime environments. However, undertaking this may be too challenging for some parents who are still working through processing their trauma and stages of grief.

To successfully parent a child with additional medical or developmental needs with a secure parent–child attachment, parents must be able to resolve the grief and loss they have experienced (Marvin & Pianta, 1996; Sher-Censor et al., 2020). This involves working through the four stages of grief identified as (i) shock and numbness, (ii) yearning and searching, (iii) despair and disorganisation, and (iv) reorganisation and recovery (Williams & Haley, 2017). Resolution of their child's challenges is reached when parents can accept and manage the painful emotions of their child's diagnosis. This allows them to move forward with thoughts of the future rather than remaining in the past with anger, extreme emotion, denial, and unrealistic expectations for their child (Marvin & Pianta, 1996). With resolution comes the ability for parents to acknowledge and respect their child's cues, which contributes to the foundation of a secure parent–child attachment and sensitive, responsive caregiving (Marvin & Pianta, 1996). Some parents have reported that providing appropriately responsive caregiving at mealtimes is challenging because of the longstanding medical experiences they have endured with their child (Lively et al., 2022). Some parents are overly attentive to compensate for the undesirableexperiences their child has endured, which may inhibit a child's autonomy and competence (Ryan & Deci, 2000). Others may be less responsive or nonresponsive as a result of the trauma or grief responses highlighted above. This affects parent–child attachment and may have implications for the quality of the mealtime environment within which a tube-fed child learns to eat and drink.

Summary – Chapter 8

Many measurable factors may contribute to 'if' and 'how easily' a child weans (Lively et al., 2019). It is pertinent to understand the relationship between the child and their parents because the outcome of the audit of the weaning program presented in Chapter 7 suggests that factors beyond biology may contribute to weaning success. These outcomes led me to consider other possible factors, such as the parent–child relationship, which may contribute to how quickly tube-fed children learn to eat and drink. A mealtime environment that facilitates a child's self-determination to improve their oral skills can be facilitated upon the foundation of a secure parent–child attachment that supports responsive parenting. This relationship reflects (i) the contributing factors within their environment (as per Ecological Systems Theory and SCT; see Chapter 2), (ii) the parent's emotional and mental state (Christie et al., 2019), (iii) the child's emotional and mental state (De Bellis & Zisk, 2014), and (iv) the parent's previous life experience (Hong & Park, 2012). In addition to the physiological reasons why a child may maintain tube feeding, psychological reasons that may interfere with the transition from tube to oral feeding were discussed. These factors may affect a parent's ability to parent, to allow their child autonomy, and to allow their child to be exposed and attempt new experiences, even if it means their child does not succeed initially.

To improve tube-weaning services, it is imperative to understand the lived experiences of parents at various timepoints throughout their child's tube-weaning journey. Parents' self-determination and experience of trauma at different timepoints of tube feeding may influence their child's oral eating and drinking outcomes and the development of successful mealtimes. Identifying parents' barriers, in addition to their high and low points, can provide clinical direction for targeted support. To address the current gap in the literature regarding parents' experience of tube weaning their child, the next chapter describes a qualitative research project that was undertaken to explore parents' tube-weaning journeys.

CHAPTER 9: EXPLORING TUBE WEANING FROM THE PARENTS' PERSPECTIVE

This chapter was peer-reviewed and published online in the journal *Child: Care, Health and Development* in December 2022. It is not yet published in print. The aim of this study was to provide insights into the experience of parents from the time of tube insertion to tube removal to inform and improve clinical tube-weaning practice.

The published article was originally prepared with the SAGE Harvard referencing format as per the journal specifications. References in this chapter have been reformatted in line with the requirements of this thesis.

This paper was co-authored with the contribution of each author being as follows:

Ms Emily Lively—60% concept development, project design and ethics approval, 60% data collation, data analysis and interpretation; 60% drafted and finalised manuscript, submitted for publication.

Professor Sue McAllister—20% concept development and project design; 20% data interpretation; 20% edited manuscript.

Associate Professor Sebastian Doeltgen—20% concept development and project design, 20% coordination of data collection to maintain anonymity and data interpretation, 20% edited manuscript.

Introduction

Children who depend on enteral feeding for their growth and nutrition can experience a range of longer-term physiological, developmental and psychosocial challenges, which are often not anticipated by their family (Brotherton et al., 2007). Whilst tube feeding can be lifesaving, it may also create challenges such as tube dependence, poor tolerance of feeds and inability for the child to learn appetite regulation. In addition, feeding disorders (Goday et al., 2019) can distort the parent–child relationship and consequently interfere with the child's psychosocial development. For example, tube dependency increases parental medical responsibilities, such as administering tube feeds and medication, maintaining tube sites, and attending medical review appointments. It can also create an extreme degree of stress, which may impact parenting capacity (Krom et al., 2019; Pederson et al., 2004; Wilken, 2012). Continued tube feeding is a source of psychological stress and trauma for many mothers and adversely impacts their emotional capacity parenting (Pederson et al., 2004) and identity as a caregiver and provider (Wilken, 2012). In addition, parents have reported challenges bonding with their child through the lack of typical feeding routines and the broader impacts of sleep disturbance, restricted family activities and outings, altered family relationships as well as challenges associated with public perceptions of them and their child (Brotherton et al., 2007; Hopwood et al., 2020; Tarbell & Allaire, 2002). This increasing awareness of the impact of tube feeding on the child and family has stimulated research on best care practices for children who may be suitable for weaning (Clouzeau et al., 2021; Hopwood et al., 2020, 2021).

However, tube weaning is complex and associated with significant challenges for the child and their parents/caregivers, as both parties transition through complex learning processes, in which: (i) the child learns to recognise hunger/thirst, trust the mealtime process, develop oral skills required for chewing and swallowing and desensitise themselves to previously negative stimuli (i.e. food or fluids); and (ii) the parents learn how to recognise and respond to their child's mealtime cues (Satter, 1990) rather than relying on medical methods alone to provide nutrition (Hopwood et al., 2020), to trust their child's abilities and allow them time to learn the new skills required to transition to family mealtimes.

Tube weaning is undertaken in a variety of settings (hospital, home, telehealth, clinic) and is informed by one of three main perspectives—namely behavioural, biomedical or child- and family- centred (Lively et al., 2021). Tube weaning programs are mostly reported with regard to protocols and criteria; physiological outcomes such as weight, oral skills, oral consumption; changes in mealtime environment; and longer-term maintenance of outcomes (Lively et al., 2021). Some studies report the impact on caregivers before and after but not during weaning (Silverman et al., 2013; Taylor et al., 2019). Tube weaning positively impacts family life over time as mealtimes become normal, time is no longer spent on tube feeding and complications, vomiting is reduced, the child is more included with siblings (i.e., at mealtimes, family outings) and parental stress is reduced (Brown et al., 2014; Marinschek et al., 2019; Silverman et al., 2013; Taylor et al., 2019; Wilken et al., 2013). Therefore, it is pertinent to understand how to best support parents to enable their child to achieve and maintain oral eating and drinking. However, there is very limited research on the actual weaning process as experienced by the child or their parents. Mother's experience and perceptions while undertaking tube weaning has been investigated and key themes identified were maternal emotional stress, collaboration with the team and resumption of a more typical family life (Cipolla et al., 2022). Whilst the high levels of maternal responsibility and expertise in tube feeding has become increasingly acknowledged (Clouzeau et al., 2021; Hopwood et al., 2020, 2021; Tarbell & Allaire, 2002), we are yet to understand the barriers, facilitators and emotional journey mothers and fathers experience during the tube weaning process. This understanding will help facilitate targeted and timely healthcare and is key to improving the experiences and outcomes for the child and family. Therefore, this study investigates parents' thoughts, experiences and reflections as they made the decision to, and then participated in, an intensive tube weaning program.

Methods

Ethics

This research was approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Appendix 8) and written informed consent was obtained from parents prior to participation.

Participants

Out of 82 families who had previously participated in an intensive multi-disciplinary tube weaning program based in Adelaide, Australia (Lively et al., 2019) between 2011 and 2019, 14 families (9 mothers, 2 fathers and 3 mother & father dyads) agreed to participate in semi-structured interviews (average 60 minutes). All children had complex medical conditions including prematurity, extended hospital admissions and tube feeding at or soon after birth. The main components of the intensive weaning program are summarised in Table 8 and have previously been described elsewhere (Lively et al., 2019). The program includes assessment and intervention prior to and after families attending a five-night inpatient feeding therapy program with a team of feeding therapists (Speech Pathologist, Dietitian, Infant Mental Health therapist, Nurse, Occupational Therapist and Paediatrician) to promote their child's oral intake and reduce tube-feed volumes. The individualised child- and family-centred approach (Lively et al., 2021) occurred in the context of family mealtimes and supported parent–child emotional engagement, behaviour and state regulation, oral motor and sensory integration therapy, in conjunction with appetite stimulation and satiation.

Phases of the weaning program	Key components of each phase
Assessment and development of weaning readiness	
Referral to intensive weaning program by medical practitioner or family	▪ Referral received for tube weaning ▪ Intake forms sent to family for completion
Initial Assessment undertaken by either a Speech Pathologist (SP), Dietitian (DT) or Occupational Therapist (OT) with subsequent assessment by the other disciplines as required Assessment undertaken in person or via telehealth and video analysis	▪ Medical and developmental history ▪ Historical and current tube feeding practices ▪ Current feeding regimen ▪ Previous and current growth, calories, nutrition ▪ Oral acceptance of food/fluids, oral motor skills, swallowing safety ▪ Mealtime behaviour ▪ Sensory processing, sensory tolerance ▪ Seating ▪ Parental experience of mealtimes
Development and implementation of strategies within the home environment prior to intensive weaning program	▪ Parents meet with Infant Mental Health (IMH) specialist—commence establishing/restoring the relational foundation of mealtime interactions ▪ Fortnightly or monthly review with SP/DT/OT as deemed clinically appropriate

Phases of the weaning program	Key components of each phase
	▪ Ongoing review of feeding and mealtime goals
Ready for weaning	▪ Medically stable with no pending surgeries ▪ No diagnosed dysphagia ▪ Weight maintenance or gain ▪ Plateau of mealtime skill through outpatient therapy ▪ Parental commitment, stable home environment
Intensive weaning	
Commencement of pre-wean plan within home environment	▪ DT developed pre-wean gradual feed reduction to 40% of child's typical calories commencing 3 days prior to hospital admission
Intensive weaning program	▪ Admission to paediatric ward ▪ Daily nursing and medical (Paediatrician) review ▪ Continued reduction in tube-feed volumes as deemed medically safe ▪ Child- and family-centred therapy facilitated by hunger provocation ▪ Implementation of regulation, relational, oral motor, sensory and mealtime environment strategies within the mealtime context provided by a combination of DT, OT, SP and IMH, up to 7 hours/day ▪ Discharge from intensive component of therapy after 7 days with stable weight, blood glucose levels
Maintenance	
Regular review/therapy in clinic or via Skype	Alternating SP and DT review, weekly for 4 weeks then fortnightly, for at least 3 months (longer if clinically indicated) to support further tube-feed reduction (if tube not removed/ceased) and problem-solve challenges. Ongoing parental support as required via IMH therapist

Table 8: Outline of Feeding Program intervention

Interviews

We conducted semi-structured interviews in order to promote rich description and reflections from each family regarding their experiences, social and cultural impacts and changes (Nicholls, 2009b; O'Brien, Harris, Beckman, Reed & Cook, 2014; Tracy, 2010). Questions prompted parents to reflect on their experiences at critical time points within the intervention program. Questions followed the temporal sequence of the weaning process, from tube feeding to decisions regarding weaning, preparation for and commencing the 6-day intensive inpatient program, consolidating therapeutic goals into the home environment as well as their overall experience. Parents were prompted to explain their tube weaning journey with their child and identify key issues from their perspective, which the interviewer used to guide follow-up questions (see Appendix 9).

As the first author had led the weaning program for each child she was not involved in recruitment of participants and a research assistant conducted the interviews in person, over the phone or via video-link. The interviews were audio recorded, transcribed *verbatim* and de-identified. Data from the first 6 interviews were reviewed by the research team and interview questions revised with a view to facilitating the richness of the data (Nicholls, 2009a). Revisions made included specific timeframes for questions (e.g. Q5: '*in the first 4–6 weeks back at home*') and re-ordering the sequence of questions to assist with flow of parental responses. Data from the next three interviews were reviewed and was found to be very similar to previous interviews. Hence repetition of the initial six interviews was deemed unnecessary and the final 5 interviews were completed with the revised guide.

Rigour

First author (EL) is a Speech Pathologist, the founder and clinical therapy lead of the tube weaning program that the interviewed families participated in. Her clinical experience allowed in-depth understanding of the context and processes of tube weaning. Authors SMc and SD are both experienced Speech Pathologists and researchers who participated in study design and data analysis, facilitating transparency and ensuring EL's interpretation was not overly bound by personal perspective.

Data was entered in to NVivo v12 (QSR International Pty Ltd, 2018) and qualitatively analysed using Braun and Clark's (Braun & Clark, 2006) inductive thematic analysis to guide a theoretically flexible, transparent and creative method of analysis. Data were grouped into patterns of shared meaning rather than being deductively allocated to pre-determined codes. This facilitated preservation of the meanings expressed avoiding premature interpretation and allowed for the further development of themes.

Themes were initially developed by EL and were anchored to timepoints including decision-making, time prior to weaning, during weaning, post-weaning and reflection on the whole process. SM and SD coded randomly selected files to explore functionality of this theming process. The team then discussed how well this approach reflected the data resulting in consensus on more sophisticated themes that represented the emotional and learning journey described by parents in parenting a tube-fed child.

Findings

Figure 26 depicts the following commonalities as identified from the iterative coding process described above:

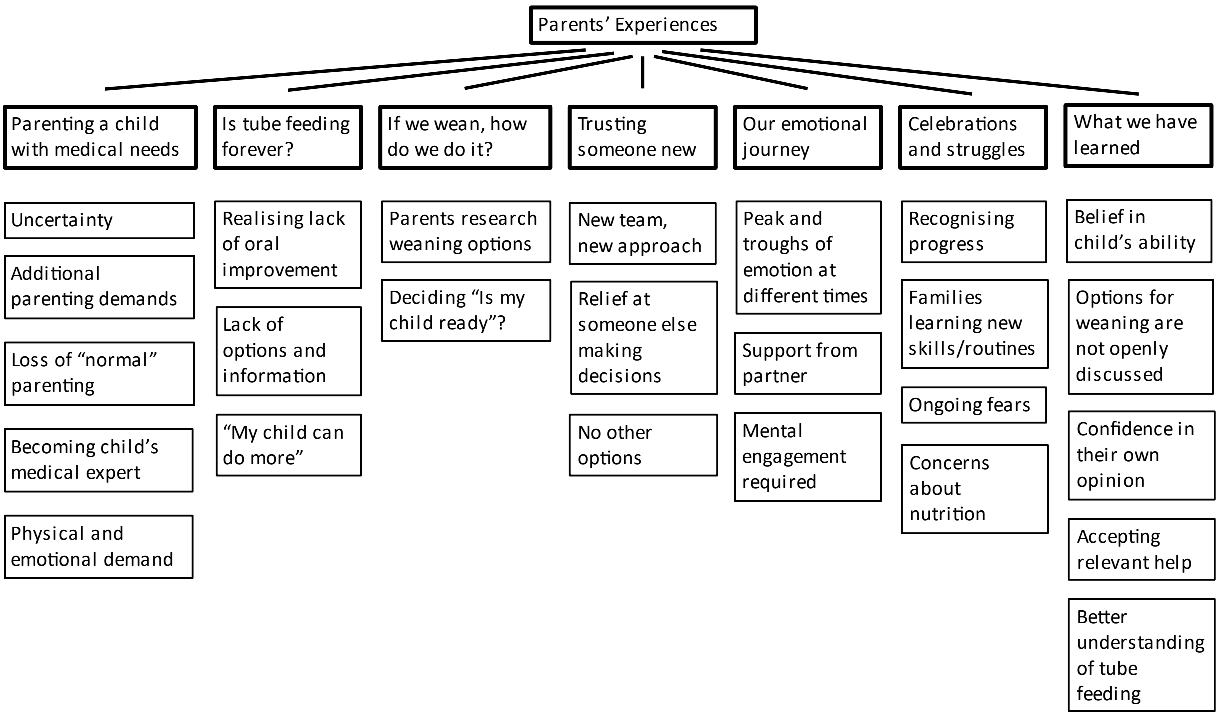


Figure 26: Overview of themes and sub-themes

Theme 1: Parenting a Child with Medical Needs

All parents interviewed reflected on the impact their parenting experience had on their decision to seek tube weaning for their child and subsequently their personal experience of that weaning process. They reflected that undertaking tube weaning was stressful because they had a limited sense of what parenting a non-tube-fed child is like, and their previous experiences of parenting a child with complex medical needs led to anxiety, guilt, shame and stress.

Parents highlighted that they began their journey being unaware of the medical or developmental challenges that lay ahead for their child as well as of the ongoing role of tube feeding. For example, parents commented that upon going home, they were unaware that the feeding tube would remain in place for the unforeseeable future [P05]. Parents highlighted how their atypical experience of early parenting continued to impact their confidence, in their child's ability to develop mealtime skills and the ways in which they facilitated their child's autonomy throughout the weaning process. One family described that their early parenting experience was shaped by their firstborn '*needing the doctors and needing the machines but not needing us*' unlike their experience of parenting their second child [P12]. Managing medical appointments and perfecting the medical and therapeutic interventions that they were required to undertake (such as tube reinsertion, medicine administration, allied health appointments) was described as a full-time role, leaving little emotional and physical energy for typical parenting. Parents described their parenting as '*following instructions from medical and allied health staff, making (lifesaving) decisions and just getting through*' instead of focusing on bonding with their newborn [P10] and building their confidence with 'trial and error' parenting. Parents spoke about missing out on the opportunity for common parenting activities, such as '*feeding my child, going to typical playgroups and having family time away*' [P01; P04; P10]. In turn, this influenced their capacity to allow their child autonomy when they were learning to eat, as up to this point their parenting experience was dictated by prescribed feeding regimens, regular weight monitoring and plotting growth [P01; P02; P05; P09]. Parents described the preceding, often traumatic, events and circumstances that shaped their emotional and psychological capacity to subsequently engage with the weaning process. For example, parents had to develop an understanding and acceptance of their child's unique circumstances and the need to become medical experts of their child's chronic health needs. For some, weaning wasn't initially a priority because '*the feeding tube became the least of our worries when faced with lifesaving surgeries*' [P11] or developmental impacts [P14]. Normal simple parenting tasks such as settling their child to sleep were stressful. For example, one family had to simultaneously manage complex medical interventions, such as a continuous positive airway pressure (CPAP) machine, a spinal brace and nasogastric tube [P03]. This family highlighted that it was their responsibility to integrate all of the interventions recommended by different health professionals and '*through trial and error on our* *behalf*' [P03] learn how to manage them as '*no doctor had a full appreciation and proper understanding as to what those interventions would do together*' [P03].

These challenges meant that weaning wasn't initially a high priority, but this changed once their child's medical needs stabilised and/or parents' expertise in meeting their child's medical needs was established. Parents reflected that their child's earlier fragility and their own dependence on professionals making decisions on their behalf impacted the weaning journey as unpleasant memories or doubt on their ability to make good decisions resurfaced; as well anxiety regarding their child's safety and potential to learn to eat.

Theme 2: Does My Child Have to be Tube Fed Forever?

Parents learned to live with the tube but then realised that, without making changes, this will be '*their life forever*' [P11, P04, P05, P10, P13]. Parents initially viewed the tube as lifesaving and necessary in the early weeks or months of their child's life. However, as their child's health improved without functional improvements in oral intake, parents wanted to find a way to teach their child to eat as they '*just didn't want this for my child, there just had to be another way that he would feed orally*' [P05]. Parents spoke of a sense of trust in their child's capacity and ability to eat, despite at times not showing the physical skill some teams deemed necessary before weaning. Parental aspirations that long-term tube feeding was not an option drove them to look for alternative options from those being offered by their local feeding, medical and/or allied health teams [P01, P02, P04, P05, P10, P11]. Parents spoke about forming their own therapy team as they became increasingly empowered by their belief in their child's potential and disillusioned with the lack of options offered by their local team [P01, P03, P11]. Some parents identified they had limited support or access to the specialist knowledge required for tube weaning and therefore explored tube weaning options independent of their treating team [P01, P02, P05, P09, P10, P13]. Others relied upon the professional opinion of their treating team to indicate when the child was ready to wean [P06, P08, P14] even if that team were unable to provide a weaning option and were '*going along with the journey and hoping it would turn out well*' [P14].

The shift in perception from the tube being absolutely required to the possibility that their child could be eating and drinking orally, facilitated parents' engagement with a multifaceted decision-making process.

This involved decisions around whether they should explore tube weaning and the options available for doing so.

Theme 3: If We Wean, How Do We Do It?

Parents described their investigation of tube weaning approaches and program options via internet searches, social media groups or speaking with other parents who had attended the program [P01, P02, P03, P05, P06, P07, P09, P10, P11, P13]. Parents considered several factors in their decision-making process including the level of support provided by the treating therapy team to manage both medical and emotional challenges [P02, P07], needing to travel interstate [P02, P05], costs involved [P04, P13] as well as considering '*what are our other options and what have we got to lose*' [P11]. Having the support of their child's local team was important to some parents, while others were frustrated by the lack of progress or direction offered by their local team, which further propelled parents to seek alternative options [P01, P02, P04, P05, P09, P10, P11, P13].

Whilst parents remained hopeful that by attending the weaning program their child would become tube-free, they also felt trepidation for '*the unknown*' [P08, also expressed by P12] and feared weight loss and '*failure*' [P09, P12, P14). When deciding whether weaning was the appropriate next step, one parent spoke about '*even a 1% improvement will be great*' [P09] and cautious excitement that their child '*might actually be able to do it*' [P09]. Another feared that attempting to tube wean may result in '*coming out with needing it permanently or another health issue or complication*' [P08].

Once the family had decided on weaning, explored the options and gathered information, parents described the next step as having to place trust in a program and in professionals—some of whom they had only met online.

Theme 4: 'Trusting Someone New'

Medical/health input had been a standard part of these families' lives. Parents described a range of different relationships with their local therapy team varying from wanting to dissociate from them due to lack of a tube removal plan or no progress over time [P01, P09, P11, P13], to close working relationships albeit with plateauing progress and no other options for improvement [P02]. Parents had to be open to building trust with a new team and different approach. For example, after a previous unsuccessful weaning attempt, it took one family 6–12 months of working via telehealth with the new team before they felt confident the team understood their son and family enough to attempt the intensive weaning program. Other parents felt that '*we have nothing to lose*' [P11]; '*there's no one in XX who can actually help us*' [P01]; and '*Well, let's do this. That gives us more options for kinder(garten) and then we don't have to have carers at kinder*' [P02]. As such, it appeared their desire for weaning options helped them overcome possible trepidation based on previous feeding therapy experiences. Parents also reported feeling '*relief at being in someone else's care who had worked with tube weaning and knowing that this would be ok*' [P05]. Whilst being supported alleviated some of their stress, it did not remove the roller-coaster of emotions that parents experienced at different time points through the tube weaning journey.

Theme 5: Our Emotional Journey

Many parents described a cyclic journey through the extremes of emotion experienced at different time points. Peaks of worry or joy were interspersed with troughs of calm before the next peak arrived. Peaks included worries about the future when there were no plans for teaching their child to eat; confusion with conflicting advice being given by a range of different professionals regarding the best strategies for oral aversion and oral intake; and frustration regarding understanding tube dependency and their child's behaviours [P2, P4, P9, P11, P13]. These worries were alleviated by the relief at finding a tube weaning option and having a different avenue to pursue.

On the other end of the spectrum of emotions, the excitement and delight at watching their child eat and drink more consistently and in larger volumes counter balanced anxieties experienced such as how to maintain new routines and oral intake in their everyday life, frustration when cooking efforts were refused by their child, or concern around weight fluctuations and nervousness that their child may stop eating at any time.

Parents reported tube weaning was often the first intervention they made the conscious decision to undertake with their child that hasn't been '*lifesaving and necessary*' [P12] and within which they were active facilitators. Whilst they mentally attempted to prepare themselves for how difficult it was going to be, '*it's different until you go through it, and I don't think I still would have believed how difficult it was*' [P10].

Theme 6: Our Celebrations and Struggles

Learning to eat takes many little steps and hurdles along the way. Parents vividly recalled the joy they experienced when they observed the '*look on her face when she realised that putting food in her mouth made her feel better*' [P01], or seeing their child acknowledge, ask for and enjoy food and drink [P01, P02, P03, P05, P07, P09] in a range of environments [P02, P03, P09].

Families whose children had their nasogastric tube removed during the intensive program were cautiously excited [P08, P11] but also concerned the tube could be reinserted anywhere from a month to 3 years post removal [P01, P09]. Parents reflected it took them some time to realise that new skill development doesn't happen immediately and a change in energy levels and/or weight will occur when children learn a new way of receiving calories [P01, P03, P06, P07, P09, P10]. This led to reported feelings of failure, frustration, devastation, doubt in their child and the program at the time [P01, P02, P03]. Many parents reported that their biggest anxiety after weaning was weight gain [P05, P07, P09] with one parent remaining anxious for 3 years post-weaning as their child's gastroenterologist had stated '*a lot of kids that are weaned off the tube, they could not use the tube for a year and then I've seen a lot of them need it again and get back on it. So, until she's off it for two years, we're not even going to consider taking it out*' [P09].

Theme 7: What We Have Learned

Many parents reflected that at some point they realised that there was no plan for tube removal [P01, P02, P05, P09, P10, P11, P13]. One parent likened this to '*you don't send the kid home in a wheelchair after they've had a broken leg without "Oh, by the way, here's your physio referral. This is what you'll do"*' [P02]. Another mother felt that without her '*pressuring and driving it, there didn't seem to be anybody else that was pushing that way and if I wasn't driving it, it wasn't going to happen*' [P10].

Both metropolitan and rural families identified that they lacked access to experienced tube weaning therapists, with many families told to '*keep doing what you're doing and we'll review in X months*' [P01, P03, P10, P11, P13]. Parents noticed the level of support changing as their child transitioned from the acute hospital setting into the community [P05] and although some families received a good level of early support from their community therapy teams [P02, P08, P14], others found this support to further exacerbate their child's challenges or be of no value to them and in time ceased it [P01, P03, P05, P09, P11]. Parents recalled that targeted and relevant support was vital and that not all support was helpful if it was not relevant to their experience at the time [P02, P03, P08, P12]. They developed confidence in their own opinion about what's best for their child and were able to identify which professionals had the expertise they were seeking to support their child [P01, P03, P04, P05, P06, P08, P09, P11].

The process of teaching their child to eat challenged many parents to recognise they needed to relax the control they had developed over the feeding process [P01, P03, P04, P14]. Parents learning to tube feed within a medical model expressed becoming obsessed with numbers, volumes and weights, which they automatically prioritised as indicators of progress when their child began to eat and drink, rather than how their child was indicating readiness to eat. Parents reflected on the change in their parenting as they were taught to facilitate skill development within their child by providing an emotionally supportive environment at mealtimes rather than '*specifically teaching our son*' [P03]. Together, parents became confident knowing 'the process of mealtimes' [P01] and both being '*on the same page*' [expressed by P01, P03, P04, P05, P14], which enabled them to continue with the weaning program [P03, P11, P12, P14].

Parents desired more focused support from their treating team at their local hospital [P01, P02, P09, P13], support to prepare mentally for the intensive phase of therapy [P09, P10] and earlier information about what tube feeding involved so that they could have been more proactive about developing a tube exit plan [P01, P04, P09, P10, P11].

Discussion

This research explored the experiences of parents as they taught their tube-fed child to eat and drink while participating in a family- and child-centred weaning program. In the following, we discuss how their experiences can inform services supporting parents of tube-fed children with regard to three key aspects: parents as team members, communication regarding tube removal options and parents as change agents.

Parents as Key Team Members

Our findings indicate that parents are often positioned as being outside the treating team and have to initiate tube weaning discussions with the team. Of note, this research gathered data individually from mothers, fathers, and parental teams (both mother and father) highlighting the importance placed by mothers and fathers on the opportunity to share their experiences and how they worked together through the process. Effective care is underpinned by principles that centralise parents in intervention processes. For example, the principles espoused in the International Parent and Family Centred Care model (IFPCC): respect, dignity, information sharing, participation, and collaboration (IPFCC, 2010). Partnerships between health professionals and families are built on explicit communication and facilitating parents to have an active role in decision-making, goal setting relevant for their circumstances, as well as accessibility to and implementation of, therapy strategies. Treating teams could draw on (IFPCC) principles to identify ways in which they could effectively engage families as they transition through each phase of their child's tube-feeding-related care including whether to initiate weaning. Instead of being external to the treating team, parents would be positioned as co-collaborators and central stakeholders. This would facilitate the weaning process through recruiting parent's developing expertise, considering their priorities and addressing their concerns. Other strategies such as Family as Faculty (FAF) (Graff, 2021), Parent and Child Therapy (PACT) (Chambers, Amos, Allison & Roeger, 2006) and Bowen Family systems theory (Erdem & Safi, 2018) have proven successful in supporting children with developmental or medical needs and could be adapted for services supporting tube-dependent children. These approaches also position parents as an integral part of their child's team, draw upon the intricate knowledge they have regarding their child and integrate this with therapists' clinical knowledge and the evidence base. In doing so, parents are empowered as agents of change not only for their child but for the broader team working with them (Graff, 2021; Heller & McKlindon, 1996).

Although these principles of quality care may appear obvious, the reality of implementing them can be challenging for health professionals. Professionals' views regarding best practice care may differ from the strategies parents find useful (Heller & McKlindon, 1996; Tarbell & Allaire, 2002). Some professionals may view family-centred care as requiring parents to take responsibility for decisions for which they are illequipped. However, family-centred care addresses parents' desire for a truly collaborative approach, whereby information and expertise are shared, discussed and a plan agreed upon (MacKean, Thurston & Scott, 2005). The resulting agreed goals and actions are more likely to fit within parents' capabilities and align with the needs of the family unit (Dennis, Baxter, Ploeg & Blatz, 2017), which in turn facilitates maintenance of new skills.

Our findings highlight that parents value being a part of their child's team and, to maintain their engagement with an intervention team/professional, services need to be transparent, relevant and functional. In addition, therapy should incorporate parental expertise and knowledge, which merit consideration even when they conflict with the opinions and goals of the professionals. Parents' desire for a partnership with professionals/intervention teams was strongly apparent through all stages of managing their child's needs but particularly in the context of decision-making regarding tube weaning options. This was highly emotive for parents, who felt that there was little clarity and that they had to drive the decision whether and how to wean.

Tube Exit Plans and Tube Weaning Options

Placing a tube may be one of many lifesaving interventions vital to managing the acute phase of a medically complex infant's needs (Blackman & Nelson, 1985; Trabi et al., 2010). However, a key finding in this research was that parents felt that tube feeding had become the normal state for their child and there appeared to be no clear plan for establishing oral eating and drinking. The support by care teams for trialling weaning varied from affirmative confirmation of readiness to explicit resistance but was often only expressed when this discussion was instigated by the family. A lack of tube exit plans for tube-fed children may contribute to ongoing tube use (Jones, Southwood, Cook & Nicholson, 2022). Symris and colleagues (2023) suggest that developing the awareness and training of health professionals who work with children with temporary feeding tubes may improve these children's transition to oral intake (Symris, Reilly, Frederiksen & Bell, 2023).

Tube weaning is a complex multi-disciplinary process that should be tailored to each child's unique needs and there are no guarantees of success (Sharp et al., 2017), which makes forward planning challenging.

However, parents in this research clearly expressed their need to better understand tube weaning and their options, as many reported this to be the first major intervention that *they* have been responsible for in the care of their child. This is in contrast to the many interventions which, to that point, had been led by health professionals (i.e., prescription of medication, recommendation of surgery or allied health therapy). Furthermore, they reflected that they became their child's expert as they learned to manage the demands of caring for a child with complex medical care requirements such as tube reinsertion, medication administration and oxygen monitoring, a finding consistent with the experiences of other parents raising medically complex children (Aldiss et al., 2021; Brotherton et al., 2007; Hopwood et al., 2020; Page et al., 2020; Pederson et al., 2004). This included making medical decisions on behalf of their child (Page et al., 2020), even if they felt this was beyond their expertise (Aldiss et al., 2021) and at times taking actions against the advice of their treating team.

This was clearly stressful for the parents who experienced frustration, isolation and, at times, anger towards their treating team. In turn, we anticipate that the treating team may be concerned as parental decisions might not always be understood; all of which impact on care (Tarbell & Allaire, 2002). Adapting patient and family-centred care models for services to tube-fed children would support and make clear the relevant therapeutic pathways to enhance outcomes for both the child and family (Constand, MacDermid, Bello-Haas & Law, 2014; Khayal & McGovern, 2021).

Parents as Change Agents

The parents interviewed in this study were proactive change agents who challenged the status quo and pursued options to enable their child to have more autonomous and competent mealtime experiences and opportunities despite significant challenges. These family's teams were unable to address parents' belief that '*there must be something more for my child*'. This could be due to constraints within which their service operates such as funding, weaning expertise or service models that prioritise professional expertise (Syrmis et al., 2020). However, parents' drive to find new opportunities for their child meant that these parents repositioned themselves as central to decision-making and took responsibility for determining the next steps in tube removal (Hopwood, Pointon, Dadich, Moraby & Elliot, 2022), even though they were anxious, feared failure and were concerned that they may inflict further pain upon their child.

Self-determination theory (SDT) provides a framework for understanding how parents moved into the role of expert and change agents for their tube-fed child and provides guidance for design of family-centred care models. SDT describes a cycle where humans strive to have their basic physiological needs of autonomy, competence and relatedness met by drawing from the social contexts surrounding them and, when change to health-related behaviours is successful, further confidence and competence is promoted (Ng et al., 2012; Ridgway et al., 2016; Ryan, Kuhl & Deci, 1997). Specifically, in the context of tube weaning, upon realising that weaning opportunities could not be provided by their local team, parents sought an alternative to provide their child an opportunity for typical mealtime and social experiences thus supporting their child's self-determination. Parents' competence and confidence in decision-making was bolstered and their self-determination reinforced when they engaged with a team that was able to support family goals and teach parents how to teach their child new skills (i.e., eating and drinking). This process may be influenced by the child and/or parents experiencing post-traumatic stress relating to past medical interventions (Page et al., 2020) with parents pre-emptively compensating for their child without allowing them the opportunity to initiate and sustain new mealtime behaviours themselves (Bowen, 1978; MacKay, 2017). Facilitating opportunity for the child's self-determination in striving to eat and drink independently through the frameworks provided by weaning programs which incorporate IPFCC principles (Lively et al., 2019; Tarbell & Allaire, 2002; Wilken et al., 2013) promotes parents' self-determination as they witness their child's autonomy and competence in learning to eat and drink flourish.

In summary, acknowledging that parents' and professionals' goals may not always align is an important step in family-centred care (Dadich et al., 2021). Respectful, honest conversations between parents and professionals regarding options may nurture parents' self-determination, facilitate partnerships to seek solutions together and find a middle ground whereby professionals support parental belief in their child and supporting children's self-determination to achieve their best.

Limitations

It is important to note the reflections expressed by parents in this study are unique to their experiences with their child and available services and therefore may not be generalisable to different contexts. In addition, the findings described in this study relate to parents who have participated in this specific intensive weaning program and therefore may differ to the experiences of parents who have accessed other programs. As parents' reflections were recorded retrospectively, perspectives on experiences may have changed since participation in the tube weaning program. Future studies could evaluate parents' experiences in real time. Research is also needed to develop consensus on optimal shared care pathways in which parents are key members of a care partnership with health professionals.

Conclusion

Although previous research has evaluated the significant impact of tube feeding on both the child and their family members (Hopwood et al., 2020; Krom et al., 2019; Pederson et al., 2004; Tarbell & Allaire, 2002; Wilken, 2012), there is only a very limited evidence base exploring parental experiences during the tube weaning process (Cipolla et al., 2022). This study contributes to this evidence base by demonstrating that initiating and engaging in tube weaning is an emotional process that is challenging, multi-factorial and individual to each family and is influenced by their experiences of parenting their medically complex child up to that point. This study also contributes pertinent information regarding the challenges parents experience with decision-making and undertaking tube weaning with their child. Parents expressed willingness to put trust in a process if provided with options, afforded autonomy, empowerment, acknowledgement and relevant support that is facilitated by a family-centred care model. Weaning teams have the power to enable collaboration with parents on family-specific therapeutic supports relevant to individual children. Establishing care partnerships will likely maintain parental engagement and achievement of parental goals, even if services are not able to offer the family's' choice and need to refer to other services. These insights can be utilised by teams to support not only the tube-fed child but also the parents' as key partners in this process.

CHAPTER 10: DISCUSSION

Families with lived experience of tube feeding and tube weaning have provided retrospective insights into their experiences, as documented in Chapter 9 (Lively et al., 2022). In combination with the outcomes from the other research projects presented in this thesis in Chapter 4 (Lively et al., 2021) and Chapter 7 (Lively et al., 2019), this body of research has contributed to a deeper understanding of the challenges experienced by tube-fed children, their families, and the health professional teams that support them. Specifically, I have identified the following areas for consideration by the health professional teams supporting tube feeding and weaning as areas for clinical consideration: (i) respecting parents as equals in team decision-making (Research Project 3), (ii) supporting parents with the emotional, psychological, and physical support they require to manage concerns arising at varying timepoints of tube dependency (Research Project 3), (iii) information sharing and planning at the time of tube insertion (Research Project 3), (iv) knowledge and understanding both by the treating team and parents of *when* to approach tube weaning and whose role this is (Research Project 2), and (v) knowledge and understanding both by the treating team and the parents of *how* to approach tube weaning (Research Project 1). These gaps in the tube feeding and weaning continuum have been distilled by integrating the findings of the three presented research studies with relevant evidence and theory. Specifically, they relate to improving clinical tube feeding and weaning experiences by setting expectations based on the evidence for tube-weaning readiness and success with increased certainty and transparency.

Extensive background information has been provided to illustrate the complexities of learning to swallow, eat, and drink, as well as child and parent factors that may interfere with the typical development of these skills (see Chapters 1 and 2). The insertion of a tube to nourish a child is often fraught with uncertainty and stress (Dadich et al., 2021). Decisions regarding what type of tube is required and what to feed the child may add to decision fatigue, yet they are a responsibility that parents feel they should shoulder (Lively et al., 2021; as per Chapter 1 p.50-55). A lack of explicit planning for tube weaning may leave some children dependent on tube feeding (Dunitz-Scheer & Scheer, 2022). As detailed in Chapter 1, this brings associated challenges for the child, the family, and the greater community. Using a framework of EBP to support parents and professionals in making informed and timely decisions regarding the most appropriate type of tube for their child may limit the possible side effects of ongoing tube feeding and dependency and support weaning success. Concurrently, explicit planning for tube weaning may help allay parents' fears regarding the permanency of tube feeding if weaning is appropriate and readiness is indicated (Clouzeau et al., 2021; Dadich et al., 2021).

Tube weaning may be undertaken in many ways in terms of the method and location of tube weaning. As noted in Chapter 5, online, telehealth weaning programs have become more prevalent in the last three years. This may be a result of reduced access to in-person health services because of the COVID-19 pandemic and presents a new avenue for research into the efficacy of this modality. In terms of the method of weaning, the synthesis of the published international tube-weaning literature presented in Chapter 4 (Lively et al., 2021) indicates three approaches used to teach tube-fed children to eat and drink. The findings from the research presented in Chapter 4 highlighted the differences in how each of the described approaches conceptualises the 'problem' that maintains tube feeding in some children. In turn, this influences the learning theories underlying each of these identified approaches. The framework for weaning differs depending on how a team views the 'locus' of the underlying reason maintaining the child's refusal to eat and drink orally; Therefore, parents would benefit from understanding explicitly how the treating team views the locus of the 'problem' and the subsequent management approach. This will support parents in making an informed evidence-based decision regarding the best weaning approach for their child. Health professionals and parents may use the categorisations outlined in Chapter 4 as a reference for tube-weaning options and explanations for the therapy approach (Lively et al., 2021).

In addition to describing the different theoretical underpinnings of tube-weaning programs, Research Project 2 explored a set of objective outcomes commonly measured pre- and post-tube-weaning. International consensus has yet to be reached on what measures should be reported; as such, significant variability in reported outcome measures is noted in the published literature (Lively et al., 2019). Seven categories of outcome measures were identified across areas of child oral skill and mealtime progression, the volume of oral intake and the resultant volume of tube feeding, anthropometrics (i.e., growth), parent stress, and other factors (e.g., cost of therapy, child's pain level). Not all programs measure all outcomes, which makes it difficult to compare and contrast ‘success’ across studies. The research outlined in Chapter 4 contributes information on the different eating or mealtime skills that weaning approaches emphasise, such as number of bites taken, amount of food consumed, mealtime behaviours, and pleasurable mealtime experiences. This information allows parents to align with a weaning approach that best corresponds with their beliefs and goals.

The published tube-weaning literature has grown over the last 35 years, with a strong focus on the process of tube weaning, the step-by-step protocols for acceptance into and participation in programs, and success rates. Research Project 2 in Chapter 7 advances the awareness that biological factors alone are not predictive of the time it will take children to wean (Lively et al., 2019). For example, gaining additional weight before commencing weaning may not be required because BMI z-scores were not predictive of the time it took children to wean (see Chapter 7). Likewise, children who had obstructive mealtime behaviours (e.g., dysregulated at the table or reliance on iPad to eat) before commencing the weaning program were able to wean in a similar timeframe to children who were able to sit at a table calmly and attend to the mealtime without requiring active distraction. In essence, these findings provide important information to both health professionals and families regarding any preconceived criteria that biological or behavioural benchmarks must be met before commencing weaning. This view aligns with Constructivism Learning Theory in that adaptations can be introduced into the mealtime environment with subsequent adjustment to parents’ interactions in response to observing the behaviour outcomes in their child. Together, the child and the parents are reacting and responding to new experiences and adjusting their responses with each incremental change. This is discussed further in the context of Principle 1 (see Chapter 11).

While most tube-weaning data describe individual programs and outcomes, the actual experiences of the participants throughout the process—child, family, and clinician—remain unclear. There is limited information relating to how participants experience tube weaning, and in the last decade, only three published tube-weaning programs have reported measured research outcomes of self-rated parental stress and parent–child interactions pre- and immediately post-weaning (Silverman et al., 2013; Taylor et al., 2019; Williams et al., 2017). It is unclear from these three research studies whether it was mothers, fathers, or both parents who reported these levels of stress and parent–child engagement. Instead of measuring and reporting on participants' experiences, much of the tube-weaning literature is focused on changes in children's skills and behaviours during a weaning program and whether the tube was removed. The effect of the actual process of tube weaning on parents—not just how they feel once it is complete—lacks awareness and evidence-based research. Cipolla et al. (2022) found that mothers' negative experiences of tube feeding their child (i.e., stress, fear, parent–child relationship) improved as tube weaning progressed. To my knowledge, Research Project 3 in Chapter 9 is the only published qualitative exploration of parents' (mothers' and fathers') experiences as they participated with their child in a tube-weaning program (Lively et al., 2022). As presented in Chapter 9, the findings of this research add new information to the tube-weaning literature, specifically retrospective insights and reflections on the uncertainty, decisions, challenges, and emotions parents experience *during* weaning. While exploring the experience from the child's perspective (pending age) may be challenging, an appreciation of this would also add valuable information to the current literature.

A clear overarching theme from Research Project 3 (Lively et al., 2022) highlighted the discrepancy that parents felt of having to advocate so strongly for their child in a system that perhaps worked predominantly alongside—or even in a directive 'we are the experts' way—rather than collaboratively with the family. The discord between the parents and the team could be illustrated in one of two ways. First, the parents and child work together while the health professionals consider the child their 'patient' to provide advice and therapy (see Figure 27).

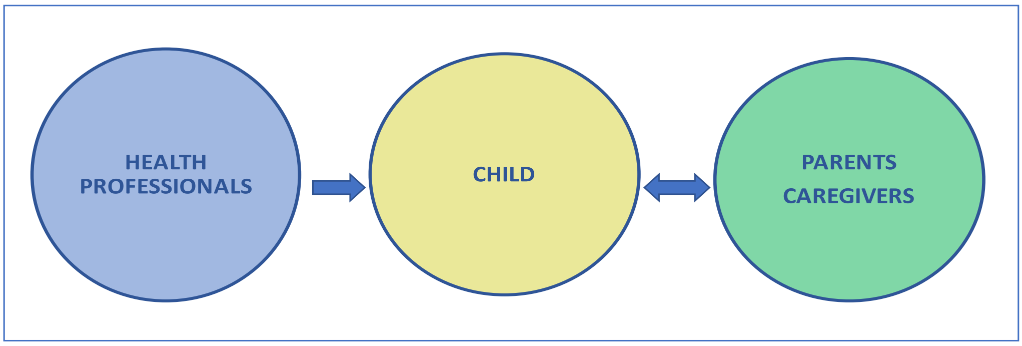


Figure 27: One representation of parents' reflections on their experience of healthcare services

Alternatively, parents may experience a small level of collaboration regarding options and decision-making between the health professionals and them and their child, while most of the partnership to improve feeding and mealtimes occurs between parents and their child (see Figure 28).

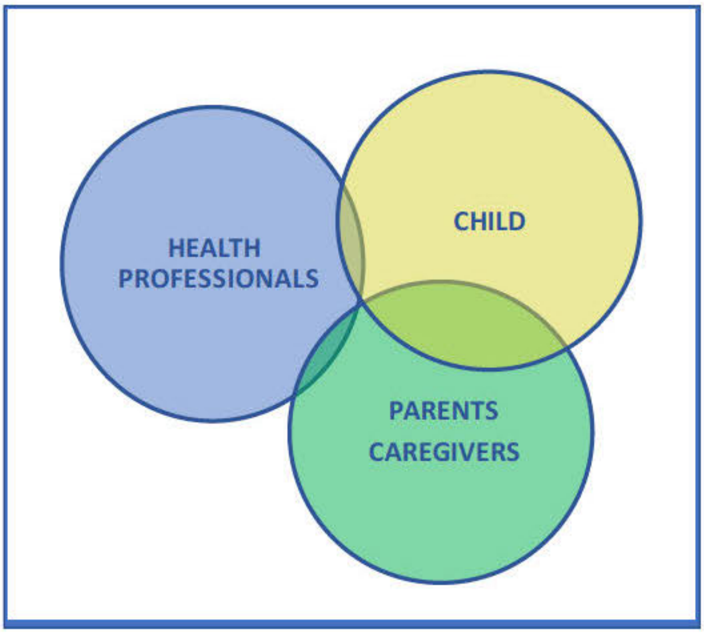


Figure 28: Alternative representation of parents' reflections on their experience of healthcare services

To facilitate a more even collaboration between all team members, parents should be carefully positioned as equal partners in the decision-making process, despite perhaps holding a different level of clinical knowledge than the professionals in the team. How parents may be included in the team is discussed further in Chapter 11 and Figure 30 (p.,208, Principle 1).

In positioning parents as equal partners, the role of each parent in their family may influence their perception of their role in their child's care and therefore the level of input they provide to the team. For example, a mother who provides full-time care while the father attends full-time work may feel more responsible for implementing care and therapy within the home (Adams et al., 2020). Equally, the father may feel uncomfortable or unfamiliar with how to offer and provide such care, which may influence how he participates within the team. In addition to the role of each parent within their family, the constitution of each family may differ, resulting in each family bringing their own unique dynamics to the weaning team.

In considering the term 'parents,' it is essential to acknowledge that this may take the form of mothers alone, fathers alone, mothers and fathers, mothers and mothers, fathers and fathers, foster carers, or any other combination of adults providing care for children. When working with families of varying cultural and religious backgrounds, consideration of norms and expectations may be required, because this may influence the engagement of the parents within the team and the uptake of therapeutic strategies (Latif, 2020). Cultural beliefs on what each parent contributes to the decision-making process and therapy plan must be reflected in the expectations that health professionals place on parents.

As the findings of this research program have demonstrated, tube weaning cannot be undertaken by following a strict set of steps, rules, or protocols because this does not follow best EBP of incorporating the family's goals and child's capabilities with clinical and research experience. This was highlighted in parents' reflections on the difficulty of weaning despite trying to prepare themselves for the process (see Chapter 9; Lively et al., 2022). Learning to eat is a developmental skill, and much like learning to walk and talk, it will not be acquired overnight (Morris & Klein, 2000). As mentioned by some of the parents interviewed in Chapter 9, and as supported by other literature, all medically stable children should be given the opportunity to develop mealtime skills in whatever capacity they can (Dunitz-Scheer & Scheer, 2022; Lively et al., 2022). If mealtime interest or oral intake does not improve with feeding therapy, health professionals and families should consider changing their approach. As per the underpinnings of Constructivism Learning Theory (explained in Chapter 11 p.210), learning is co-constructed between the child and their experiences in the context around them. If that experience remains constant, a different response cannot be expected from a child (i.e., the same therapy strategies). As such, weaning may be considered on a continuum of commencing with a change and allowing the child to learn and develop the skill over time rather than viewing weaning as a last resort or a 'pass or fail' procedure.

In summarising the stages of tube feeding from clinical exposure and the research projects presented in this thesis, I have identified the phases and challenges that families face along the continuum from tube placement to tube permanency or removal (whichever is applicable), which is similar to parents moving from surviving to thriving with tube feeding, as described by Hopwood et al. (2020). This continuum is illustrated in Figure 29 and provides suggestions of which team may be supporting the child and family at each phase.

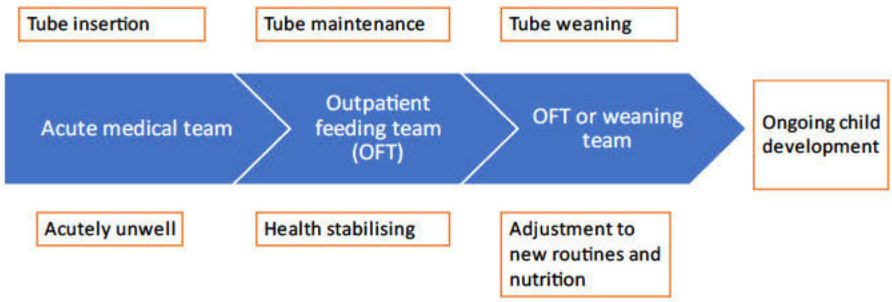


Figure 29: Phases of tube feeding and the teams that may be involved in each phase

Phase 1—Time of Tube Insertion in the Hospital Environment

At the time of tube placement, many children are critically unwell in a hospital where survival and health are paramount. The acute medical team—often comprising doctors, nurses, and allied health—is responsible for many of the intervention options at this time, including the placement of a feeding tube. Decisions may be made for a child by health professionals based on their best clinical judgement, experience, and research knowledge. Parents may feel no option but to consent to medical recommendations (Dadich et al., 2021). This is a time when the unknown and unexpected can cause a high level of stress for parents (Dadich et al., 2021; Thiele, Knierim & Mader, 2016), which has been referred to in one study as '*deconstruction—a journey of loss and disempowerment*' (Hewetson & Singh, 2009). Mothers have described the loss of their mother-dream as they come to realise that motherhood is different to how they imagined it to be and they feel disempowered from their role as a mother (Hewetson & Singh, 2009). Fathers are also affected; in the acute phase of their child's medical treatment, the father's role has been likened to being on the periphery and feeling out of place in the NICU despite having an essential role as the support person for their partner while their partner cares for their child (Serlachius et al., 2018). Fathers may be left feeling helpless and like a burden as a result of a disjointed partnership with the health professional team and limited resources to support their partner and child (Serlachius et al., 2018).

Parents' vulnerability during early intensive care experiences can constructively or disparagingly affect their ability to understand and nurture their babies (Shaker, 2013). To mitigate adverse parenting experiences during critical times, such as when establishing feeding, greater inclusion of parents in the intensive care phase could be considered. Parents and nurses have reported encouraging effects when parents have been supported to provide care and feeding experiences early in their child's intensive care rather than only once the child is medically stable. Nurses' trust in parents' capacity to provide more complex care evolved as they observed no adverse effects on infants (Toivonen, Lehtonen, Loyttyniemi, Ahlqvist-Bjorkroth & Axelin, 2020). Active and early care provision by parents during hospital admissions can support their confidence with tube feeding (and other medical care) when transitioning to the home environment.

Phase 2—Time of Tube Maintenance in the Home Environment

Tube feeding at home may not have been envisaged by parents and involves a period of adjustment, establishing routines, and developing confidence in troubleshooting the daily challenges of tube feeding (Hopwood et al., 2020). This stage of settling into the 'new normal' has been described by mothers of children with swallowing or chronic feeding difficulties as '*reconstruction: getting through the brokenness*' (Hewetson & Singh, 2009, p. 327). Over time, they come to accept the reality of their child's challenges and build their confidence with information gathering and decision-making to facilitate their child's journey (Hewetson & Singh, 2009). This is likened to Hopwood et al.'s (2020) transition of the family from 'surviving' to 'thriving' as a tube-feeding family. It aligns with the reported feelings of some of the parents interviewed in Chapter 9 who experienced a period when tube feeding became 'the norm' as they settled into life with tube feeding. It was the feeling of 'being settled' with tube feeding that agitated parents to find a way to support their child to learn to eat and drink because tube feeding felt far from 'normal' to them (Dadich et al., 2021).

In Australia, ongoing support regarding feeding development may be provided by the acute medical team that is already familiar with the child, the hospital outpatient 'feeding team', or a private health professional practice. The composition of feeding teams varies internationally with any combination of health professionals, including a dietitian, speech pathologist, or medical practitioner, as well as an occupational therapist or psychologist when indicated or available (Edwards et al., 2016). Health professionals within the feeding team review, among other variables, anthropometric status (weight, height, BMI), calories and nutrition provided via tube feeding, current oral intake, and strategies to improve oral motor skills and consumption (e.g., Kindermann et al., 2008; Lively et al., 2019; Marinschek et al., 2014; Wilken et al., 2013).

Phase 3—Time of Tube Weaning

As acceptance and maintenance of tube feeding progress, parents and health professionals may feel that movement along the continuum towards tube weaning is appropriate. Concurrent tube exit planning (i.e., tube weaning) should occur alongside supporting families to make tube feeding as 'normal' as oral feeding within the home environment. Tube weaning may be facilitated by the hospital feeding team or by referral to another program (e.g., private practice or online program).

The weaning team assumes responsibility for reducing enteral tube volumes and promoting oral intake via whichever approach their team uses, as described in Chapter 4. Learning to eat and drink orally is a dynamic process rather than a 'once-off' procedure. Constant developmental, cognitive, and skills-based changes continue to affect and influence a child well beyond the duration of a tube-weaning program. This highlights the importance of providing ongoing monitoring and guidance to families, because new challenges regarding food textures, weight gain, food selectivity, or hydration are sometimes faced months after tube weaning.

Summary – Chapter 10

In addition to understanding models of tube weaning and predictors of weaning success, improving the parent and child experience of tube weaning remains at the forefront of this research program; as such, the role of the child and family have been discussed thus far. This chapter summarised the key findings from each of the research projects and highlighted clinical areas of tube-weaning practice that may require further consideration. These areas include providing support to families at different stages along the continuum of tube feeding and weaning (see Figure 29), and consideration for minimising tube dependency by understanding which variables may support the tube-weaning success. Furthermore, this chapter described the role of each parent with the family unit as well as the role of the family within the weaning team and the emergence of new modalities for tube weaning via online programs. After identifying these as areas for clinical consideration, I have distilled five pertinent principles to support health professionals working with tube-fed children. I developed these principles after synthesising my findings across the three research studies in combination with relevant theory and evidence. Chapter 11 details these principles with recommendations of how they may be enacted by each of the teams identified above, in conjunction with the family. The team's responsibility for each identified principle is explored and described. To support the discussion of these developed principles, Chapter 11 will draw on additional data from those published in Chapter 9, which have not been reported in the published article.

CHAPTER 11: PROPOSED PRINCIPLES FOR TUBE-WEANING INTERVENTION AND RESEARCH

My learnings from this research have allowed me to reflect on how tube feeding 'comes about', as well as the journey that families embark upon in their quest to understand what tube feeding means and ways to support their child on the journey of learning how to 'take a bite'. The three presented research projects have contributed to my awareness of how weaning may occur, as well as the complex interactions between potential influencing factors—physiological, psychological, and psychosocial—for the child and the family. Team dynamics and knowledge also influence tube weaning. To clinically advance tube-weaning practices for the benefit of children and their families, I have developed five principles for consideration by the teams working with tube-fed children. The information in the principles draws on and integrates the findings of the presented research projects in combination with other relevant research evidence and theories. These principles should be considered dynamic and responsive to new research data, therapist experience, and client preferences as per the principles of EBP (Dollaghan, 2007). For each principle, recommendations are proposed that outline how each principle may be carried out in practice and how they can inform future research questions. I start with the principle of parents as key members of the therapy team, which builds the foundation of working with families and influences the other principles.

PRINCIPLE 1: Parents are key members of the therapy team

In line with the literature relating to parents as partners in care (e.g., Thiele et al., 2016) and parents in early intervention (e.g., Alexander & Dore, 1999), Research Project 3 (see Chapter 9) highlighted the importance that parents place on being active, valued, and a respected member of the therapy team. Supportive, respectful, collaborative, and nurturing relationships promote desirable and productive human functioning (Micalizzi, Dahlborg & Zhu, 2015). These values should hold firm for all team members—parents and professionals—to facilitate the best practice of family-centred care. The flow-on effect of inspiring family-centred care promotes child health and development, parent–child relationships, and the sense of achievement for both parents and professionals alike (Ammentorp, Mainz & Sabroe, 2005; Kleberg, Westrup & Stjernqvist, 2000).

As per the data reported in Chapter 9, parents seek open, honest information at all stages of their experience and want to have their views heard and considered within decision-making and therapy implementation. As recently as 2018, parents of infants in NICUs reported the disempowerment they felt when hospital staff assumed care of their infants (Serlachius et al., 2018). An educational intervention targeting intensive care nurses in Finland proved successful at increasing parental empowerment with decision-making by developing the nurses' listening, reflecting, and negotiating skills in the unit (Toivonen et al., 2020). In the absence of being respected as their child's 'expert' or being understood by the team members, parents are likely to be less active or may disengage from services (Aarthun, Oymar & Akerjordet, 2019; D'Arrigo et al., 2020; Lively et al., 2022).

For collaboration between professional teams and parents to work successfully, the professionals should reflect on their cohesion as a team and their knowledge of the individual child, the family, and their professional and weaning practices. The findings from a semi-structured qualitative interview study involving parents of children admitted to a Norwegian hospital suggested that care should be taken both between health professionals on the team and within individual professional disciplines to coordinate and convey consistent information to parents (Aarthun et al., 2019). This may include medical or therapeutic information, in addition to knowledge of each team member's skill set, personal challenges or strengths, and their scope of practice and experience (Walter, Arnold, Curley & Feudtner, 2019). For each new team that forms around a child, the parameters of the health professionals' clinical and personal abilities will differ. So that family inclusion is not hampered by a lack of clarity and indecisiveness, any of the health professional team members should be able to provide cohesive and consistent healthcare information (Walter et al., 2019). It has been proposed that for a team to present a cohesive front before engaging the parents on the team, three principles remain first and foremost to improve group functioning. These are (i) morale, (ii) mutual trust, and (iii) commitment to developing a shared model of team understanding of the family's goals, potential barriers, and realistic outcomes (Walter et al., 2019). In addition, the American Academy of Pediatrics proposed that paediatric care teams must incorporate clear roles, effective communication, and measurable processes and goals (Katkin et al., 2017). Understanding the components that hinder or improve group cohesion—particularly in the context of tube-weaning teams—may form the basis of future research. This knowledge could be used by teams to develop culture, morale, and trust.

Historically, while maintaining a pleasant working relationship with parents, professionals have been viewed as the authority on expertise and knowledge relating to specific conditions and interventions, with the parents' role being that of the receiver of the professionals' expertise (Alexander & Dore, 1999; Kennedy, 2003; Serlachius et al., 2018). This is despite the reality that parents are often the ever-present care provider of their child 24 hours a day. The evidence indicates improved care outcomes for children when true *care partnerships* are created *with* significant caregivers (Christian, 2016; Serlachius et al., 2018). To ensure that parents are on an *equal footing* with other team members (e.g., paediatrician, speech pathologist, dietitian, gastroenterologist, nurse) and remain engaged in collaborative decisions regarding the care of their child, the balance of authoritative power between the professional and the family must be levelled. Parents can provide expert information about their child—the way they learn best, their temperament, and the best ways to regulate them—and health professionals can provide knowledge about how children, in general, learn to eat, drink, and moderate their appetite.

Families should feel at the centre of their child's team, with shared decision-making, reciprocal learning and collaboration occurring *with them* rather than *around them* (Hopwood & Edwards, 2017; Katkin et al., 2017). The challenge for health professionals and parents is that parents depend on health professionals involving them in decision-making regarding their children (Aarthun et al., 2019). Constraints such as organisational culture, time, resources, and the value that health professionals place on the parental role potentially affect the level of parental involvement in decision-making (Aarthun et al., 2019). Negligible parental involvement in therapeutic planning was evident from a systematic review that explored therapy options to improve the parenting skills of families with a child with special healthcare needs and medical complexities (Bradshaw et al., 2019). With parents rarely contributing to the development of the therapy plan, the relevance, meaningfulness, and functionality of intervention goals were reduced. The outcomes of research into working with families has highlighted that best practice collaborative work with parents values their knowledge, incorporates their goals, and supports them in their role; however, translating this knowledge into practice remains challenging (Thiele et al., 2016; Toivonen et al., 2020). This has been attributed to the lack of the above factors that improve collaboration (Smith, Swallow & Coyne, 2015). Therefore, in working towards a true partnership in care, professionals must ensure that parents feel listened to and involved in decision-making, which in turn supports parents' coping capacity, balances their stress levels, and improves their feelings of competence (Serlachius et al., 2018; Tallon, Kendall & Snider, 2015). Future research may focus on developing the evidence required for effective education to change practice. An additional research project may trial and evaluate the effectiveness of a training package to develop or improve awareness of health professionals' active listening, reflecting, and negotiating skills to support equal care partnerships in the context of tube weaning.

One such example is the paediatric intensive care team at the Cincinnati Children's Hospital, which implemented a strategy to improve the parent–professional relationship and partnership. The strategy, which decreased harm to patients by two-thirds, was the following mantra that was instilled in all staff and families: '*we are the experts in healthcare, and you are the expert in the care of your child*' (Micalizzi et al., 2015). Reflecting upon this, I propose that parents may consider themselves the expert on their child's care *and* the expert in their child's healthcare. Individual nuances of each child and family create opportunities for parents to determine the best option for their circumstances. In doing so, advice or suggestions from professionals may not be best suited for individual children given the interaction of their unique presenting challenges. As parental confidence in decision-making grows, so does their expertise in their child's healthcare (Cipolla et al., 2022). This was highlighted in Chapter 9, with one parenting couple commenting that '*all of these interventions overlaid on top of each other that simply no doctor had a full appreciation and proper understanding as to what those interventions would do together. And it was really only trial and error on our behalf that we were learning*' [Lively et al., 2022). Experience with and confidence in making medical decisions has also been associated with parents with prior hospital/medical experience. Parents who have previously experienced hospitalisation of one of their children were more active in making medical decisions (University of Michigan Health System, 2007), suggesting that prior parental experience increases confidence in proactive questioning and information seeking.

Considerations for Weaning Team Composition

Engaging and maintaining parents on an equal footing within a group of professionals may be challenging and require clear information regarding everyone's roles from the onset. The question of whether it is the professionals' responsibility to provide information for the parents to consider, or whether it is the parents' role to drive change and discussion, brings to the forefront the fundamental definition of a healthcare team. I have considered four ways that parents may sit within the framework of a team (see Figure 30). The differences in these team-forming structures can be illustrated as follows and can have subtle but powerful differences in the power and influence that each team member holds.

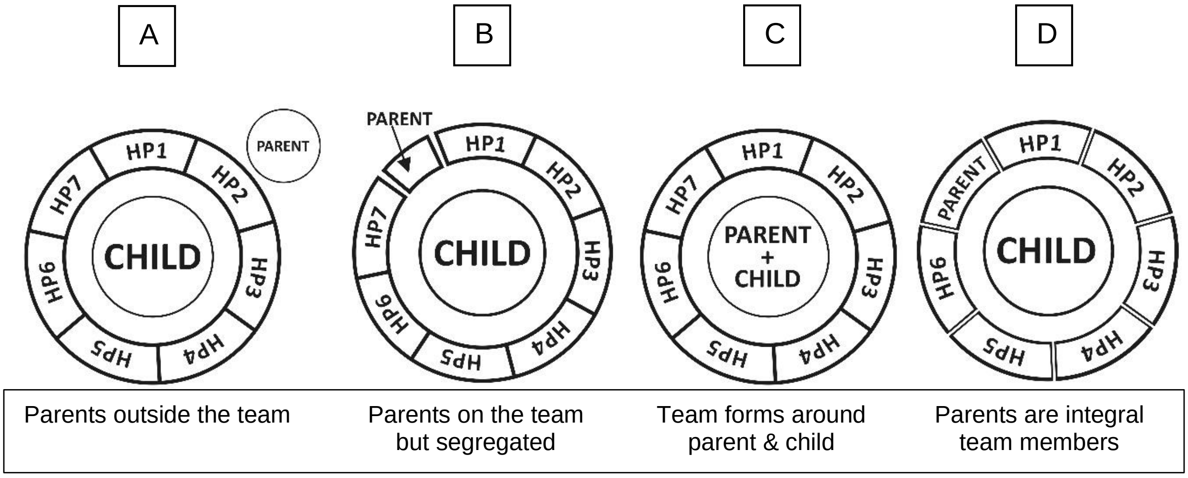


Figure 30: Models representing how parents may be incorporated as part of the team working with their child

Note: HP = Health professional

Figure 30 [A] depicts the team forming around the child with the parents at the outset of the team. Decisions may be made by the team and discussed with the parents; however, the parents may not feel that they are an integral part of the decision-making process. The second possible team composition may comprise the health professional team that is formed based on the individual child's health needs, with the parents then joining that team as invited members (see Figure 30 [B]). This model portrays that the health professionals form a cohesive team and the parent, although a part of the team, is still slightly segregated and not on an even decision-making level. Another potential view of team formation results when both the child and parents are considered equally as the patient, and therefore a team to meet the needs of both the child and parents is developed (see Figure 30 [C]). Support and advice are provided to both the parent and the child instead of discussions and outcomes being a collaborative process. The final model (see Figure

30 [D]) represents my view on developing a respectful and trusting foundation for working with families. In this model, the child is at the centre of the team, and all appropriate professionals and parents are invited onto the team from the outset so that each member holds an equal role. Decisions, questions, and treatment options are raised by any team member and are respectfully discussed, with everyone's opinion valued.

It is likely that the individuals within the team and their roles will evolve organically over time, and for each child, the roles of the team will differ. This builds flexibility and fluidity into the team culture, allowing anyone to join the team with their expertise levels and personal and professional background, ideas, and at times, challenges. Not only will parents develop expertise relating to their child over time, but other team members will also continue to increase their general knowledge of working in teams and therapy options, specifically regarding the family on the team. A true transdisciplinary team would embrace the views and advice of each team member, perhaps at times transcending their disciplinary margins. This would be for the benefit of sharing knowledge to determine the priorities for a child, rather than each team member putting forward their priorities to be actioned (Van Bewer, 2017). In this way, at any point that a team member requires some time away, other team members are aware of that person's role and can cover them in their absence. This relates to professionals who may need an intermission from the team and parents who may fluctuate between being a strong and stoic team member to one of fragility. For some parents, the traumatic experience of a medically fragile infant may limit their capacity for rational thought and reasoning beyond the immediate (Thiele et al., 2016) and may require health professionals to take the lead at times. At other times, the parent member of the team may be the driving force or the supporting member to others (Hopwood et al., 2022). To work collaboratively, teams must be mindful and respectful of the emotional and physical coping capacity of all team members (and that these may vary at different times), in addition to being aware of the additional exhaustion, self-doubt, anger, grief, guilt, and isolation that some parents may experience following a traumatic or pre-term birth (Thiele et al., 2016).

It is essential to recognise and respect that parents may make a decision that is not aligned with the rest of the team's view, and that individual team members also have personal opinions—neither of which may be the perfect or best option (Dadich et al., 2021). In considering the weighting of input from parents, some suggest that in the absence of clear evidence of one approach over another, parental choices should remain first and foremost (Wampold, Lichtenberg & Waehler, 2005). To support parents' decision-making, professionals on the team should continue to provide parents with emerging evidence and information that may be relevant to their circumstances, and allow them time to process this to support their decision-making autonomy. It is vital that team members do not attempt to 'protect' parents because that only serves to disempower them (D'Arrigo et al., 2020); instead, they should support their active engagement through problem-solving, collaboration, and transfer of therapy strategies into the home environment.

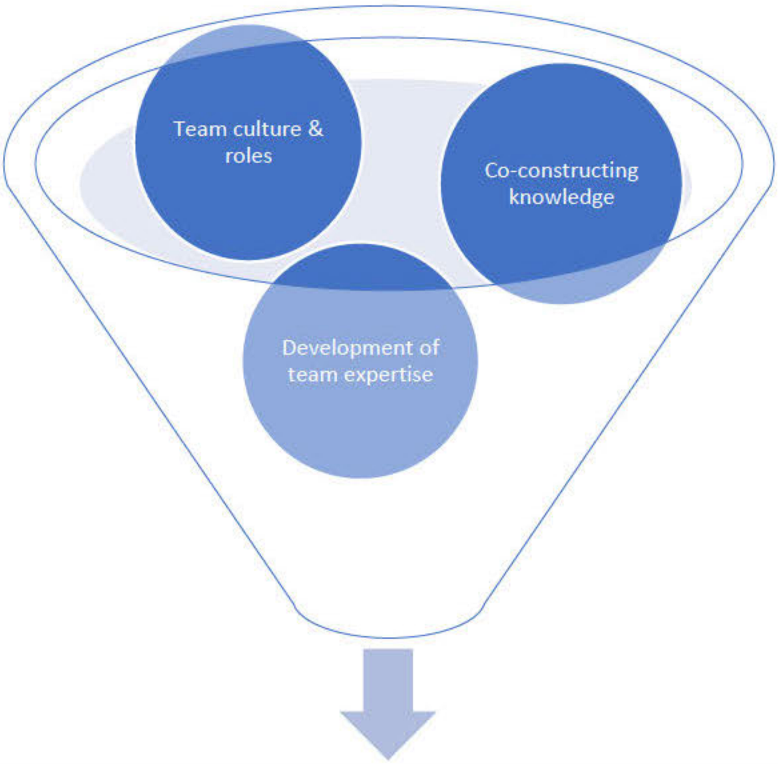
Clinicians are becoming more aware that while direct 'telling' (as per traditional teaching methods) may be easier and faster for the health professional in the short term, it results in reduced efficacy over time for the client because they are not the driver of change (McNeil, Addicks & Randall, 2017). An alternative to traditional teaching is client-centred health behaviour change. Incorporating the principles of client-centred change would promote a deeper understanding of each family unit's experiences, challenges, and strengths. This could be undertaken using motivational interviewing, which facilitates parents as healthcare partners and helps focus on partnership, acceptance, compassion, and evocation (Miller & Rollnick, 2013). It uses a strengths-based mindset and collaborative approach to lasting behaviour change (McNeil et al., 2017). In the case of weaning a child, 'the client' in the first instance encompasses the parents responsible for implementing change within the home environment for the child to then adapt and learn from. Teaching a child to eat and teaching an adult to facilitate this skill within the child requires behaviour change within both participants of the dyad. Change within only one party may not be sustained if it is not supported by the appropriate change in the other party, hence the importance of understanding and using the best change agents available for each family unit. Working collaboratively with each team member and bringing an open, inquisitive, and malleable mindset for every new family dynamic embraces the principles of constructivism learning.

Constructivism Learning Theory

Constructivism was introduced in Chapter 10 (p. 199) as an alternative to traditional teaching methods. As explored throughout this research, learning can take place in many forms, from the explicit (e.g., direct teaching) to the implicit (e.g., adaptation of the environment), and from the extrinsic (e.g., behavioural) to the intrinsic (e.g., self-determination). Constructivism learning sits on the plane of implicit and intrinsic learning. It is grounded in the philosophy that knowledge is a human construction and people of all ages are active learners (e.g., intrinsic self-motivation) of dynamic and ever-changing knowledge and therefore require a learning environment (e.g., implicit) that provides the opportunity for 'hands-on' involvement and interaction (Bada, 2015; Tam, 2000; Thomas, Menon, Boruff, Rodriguez & Ahmed, 2014). Within the constructivism model, traditional teaching, via a more experienced person imparting knowledge to others to be rote learnt, is replaced by the learner actively seeking the next piece of information. In this way, the learner gains a deeper understanding—through their inquisitiveness, experimentation, and construction of meaning—of what the information means and how they can use it (Bada, 2015). Therefore, within constructivism, the teacher's role becomes that of a coach, facilitator, and provider of feedback on an equal footing rather than one of authority and directive as per traditional teaching methods (Bada, 2015).

Working collaboratively in the context of tube weaning, parents and therapists become co-constructors of knowledge regarding an individual child's responses and reactions to changes within the mealtime and tube-feeding environment. Not only does this speak to the autonomy component of SDT (as described in Chapter 2, p.97), but it also supports all team members' feelings of relatedness by being a supported and integral part of the chosen therapy. Allowing team members, including parents, to experiment and provide feedback will enable them to build knowledge and experience the resulting outcomes firsthand. With repeat opportunities, parents can learn to build trust, safety, and understanding of how to best support their child in learning to eat, thus validating their competence as effective and capable parents (D'Arrigo et al., 2020). This invaluable information forms part of the family's expertise and may best be facilitated through teams promoting a strengths-based/growth mindset approach, as discussed further in Principle 2. Figure 31 highlights the components that contribute to parents as key team members.

Parents are key members of the therapy team



CLINICAL RECOMMENDATIONS

- Parents join the team at the same time the rest of the team is selected.
- Develop flexibility within team members' roles and responsibilities to allow for times when a team member may be absent.
- Allow team members to co-construct intervention plans in an interdisciplinary manner.

FUTURE RESEARCH RECOMMENDATIONS

- Design a framework for developing team culture including morale, mutual trust, and shared team understanding of jointly agreed upon goals.
- Explore strategies to develop health professionals listening, reflecting, and negotiating skills when working with the families of tube-fed children.

Figure 31: Key considerations and clinical and research recommendations from Principle 1

PRINCIPLE 2: Parents require equal support and therapy as children throughout the tube-feeding and tube-weaning process

A typical therapy approach when working with children experiencing developmental delay across one or more areas of learning is for therapists to provide direct teaching and learning opportunities for the child (Law, Garrett & Nye, 2003). In this way, therapy often focuses on a child's *physical* skill development, which, during feeding therapy, may include bringing food to their mouth themselves, closing their lips around a straw or spoon, or learning to move food from side to side in the mouth. For a child to learn these new skills, they must be able to self-regulate within the mealtime environment—for example, they must be able to adapt to change, self-calm, and maintain socially tolerable reactions and engagement (Cole, Michel & Teti, 1994). To achieve this, an infant might use a range of intrinsic strategies to manage distress, such as rhythmical sucking, gaze redirection, and repositioning their body. When these self-soothing strategies are unsuccessful, a caregiver's sensitive and reliable extrinsic assistance often remains the most effective way to calm and re-engage them (Cole et al., 1994). As discussed in Chapter 1 (p. 33), this is referred to as co-regulation and describes how emotional stability (regulation) can be achieved for both partners through the influence of one person's emotional state on another person (Sroufe, 1997).

In time, and with practice and experience, children use strategies they learn through co-regulation to maintain an emotionally stable response to a situation, referred to as self-regulation. The ability of a child to self-regulate develops from infancy through the caregiver's attempts to comfort a distressed infant at a level appropriate for the level of distress (Sroufe, 1997). The theoretical basis of self-regulation correlates strongly with Bowlby's Attachment Theory (see Chapter 2), whereby children who receive consistent emotional support from their caregiver are likely to develop a secure attachment, which promotes self-regulation (Bowlby, 1969). Conversely, if an infant is unable to self-calm and their distress is not consistently or sensitively responded to by others, they are more likely to learn that emotions cannot be managed by themselves or others; therefore, they may develop insecure attachments with their caregiver/s (Holmes, 2014).

Understanding self- and co-regulation plays a fundamental role in a tube-dependent child learning to eat and drink. At the same time, developing this understanding is not a physical skill that a therapist can train a parent to implement, like they may facilitate messy food play or drinking skills.

Parents may require coaching and external support to reflect on and interpret their child's often subtle cues and communication and how best to respond to these. A child's emotional skills must also develop for mealtimes to succeed. Coaching alone may not be enough if the parent cannot maintain their emotional homeostasis in the context of their child's distress. An experienced health professional who understands infant and child communication and who has the skills to support parents in recognising and responding to their emotional state and their child's cues is best placed to provide this support. Well-functioning teams support self- and co-regulation for each other; however, the circumstances of the parents on the team mean that they face challenges as discussed in Chapters 8 and 9, which place them at a greater risk of dysregulation. Tension may be felt by health professionals as they strive to maintain equality between all members of the team, while at times providing therapeutic support to the parent team members.

Sequentially, therapy would first support parents' self-regulation, then facilitate parents to co-regulate their child, and then allow the child to self-regulate. When a child can manage being upset without the support of an adult, such as a sensory defensive child coping with messy food on their hands or managing a taste of unfamiliar food, they can remain open to new experiences and increase their learning. In contrast, a child who is unable to self-regulate in an unfamiliar environment may require external regulation (co-regulation) to return to a calm and attentive state without further escalation of emotion. To illustrate, this may be a child who depends on the calming sucking provided by a dummy. Their ability to remain calm and relaxed at mealtimes is likely affected when the dummy is removed, yet they cannot learn to eat and drink while the dummy remains in their mouth. Another example is the child who cannot sit at the table in their chair for longer than a few minutes before wanting to get down and communicating this via crying and distress. If co-regulation is not provided, a child may resort to maladaptive behaviours such as head banging, self-harm, or intensifying their behaviour to elicit a response from a parent (Hong & Park, 2012). The success of re-engaging a child in the original task of sitting at the table depends on the parent's skill to interpret and respond to these cues—a skill for which parents often require explicit teaching and coaching.

By participating in therapy sessions, parents are exposed to and taught strategies they can practice at home. The ability of family members to understand and implement strategies is central to the wellbeing and development of the child (Raising Children Network, 2021). While all team members play the pivotal role of being a change agent, parents must be emotionally and physically able to undertake agreed team decisions (of which they are equal members) regarding therapy strategies. A high level of personal emotional self-regulation is required in the examples given above for parents to successfully support their child to re-engage in the mealtime experience. Maintaining parental self-regulation is often affected by the multiple medical and therapeutic demands placed upon them, as well as the trauma responses triggered when hearing their child crying. Some parents of children with undiagnosed genetic conditions have reported that '*not coping is not an option*' (Aldiss et al., 2021, p. 592); however, with the mindset that '*I can do everything*' (Aldiss et al., 2021, p. 591), parental capacity is at risk of emotional instability and physical exhaustion, depression, anxiety, and stress (Pederson et al., 2004). This was also mentioned by the parents interviewed in the study reported in Chapter 9. They commented on the full-time role of managing medical and therapeutic responsibilities and the emotional and physical exhaustion this resulted in (Lively et al., 2022).

Some of the daily challenges reported by parents (of PEG-fed children) relate to everyday practicalities such as disturbed sleep, trouble feeding in public, and lack of respite. Others relate to deeper psychosocial conundrums such as division within the family, managing the attitudes of others, and reduced opportunities to bond with their baby (Brotherton et al., 2007; Lively et al., 2022). A consideration for health professionals is increasing their awareness of their vital role in facilitating parents' ability to cope with their child's medical needs. This can be achieved by promoting parents' understanding of their role in their child's care and ensuring that they feel their contribution is manageable and has meaning (Aarthun et al., 2019). As such, when inviting or expecting parents to be critical implementers of feeding (or any) therapy, therapists must be cognisant of how the requests they are making of parents align and interact with the other daily demands.

Daily tasks such as home duties (e.g., washing, shopping, bill paying), caring for other children, and paid employment responsibilities may be non-negotiable for some parents. Awareness of non-negotiable parental responsibilities and their functional capacity may best be addressed by using a family-centred approach encompassing the family's goals, expectations, daily life, and family values (Raising Children Network, 2021). Within the team structure, parents can be supported with the strategies that are most functional and achievable for their family rather than working through the therapy goals as determined by the therapist. In practice, support may need to be provided through a network of health professionals, social care, and support groups. It may highlight to health professionals the need to provide assistance and information across a broader scope than only their clinical expertise (Brotherton et al., 2007). Further research may focus on best practices for health professionals to upskill and provide guidance to parents across areas outside of their specialty.

Within the approaches to tube weaning identified in Chapter 4, parents play differing roles in therapy implementation as described in Chapter 4 and Principle 3 below. Individual parents have differing capacities to interpret and implement feeding therapy advice, and each member of the family unit has a unique capability. Parents' ability to incorporate changes to feeding schedules and routines may be reduced when their responsibilities of maintaining daily essential medical interventions are considered. In addition, health professionals on the therapy team must consider the emotional impact (trauma) that parents experience in response to unexpected events such as a pre-term, traumatic or unexpected birth, or a resultant diagnosis of ongoing disability (Evans & Coccoma, 2014).

Trauma, as it may relate to tube-fed children and their parents, was discussed in Chapter 8. The effects of past trauma on parenting capacity as a result of witnessing medical interventions are well documented and include stress, depression, distorted parent–child relationships, impaired social and relational functioning, reduced parenting satisfaction, heightened reactivity, and anxiety (Christie et al., 2019; Shonkoff & Phillips, 2000). Some parents of children with complex medical needs witness single or multiple resuscitation events of their child. While most families recover from a traumatic medical illness or injury (which may last a finite time), 30% experience ongoing post-traumatic stress symptoms (PTSS) (Price, Kassam-Adams, Alderfer, Christofferson & Kazak, 2015). Findings from research exploring the effect of family members witnessing a loved one's emergency resuscitation highlighted the increased risk of them experiencing PTSS one-month post-event (Erogul et al., 2020). Parents' memories of traumatic experiences may be brought to the forefront and reinforced daily in what may feel like an infinite manner each time they provide a tube feed. The effects of depression, anxiety, and stress may interfere with the parent's ability to regulate their own and their child's emotional state, incorporate the child within family mealtimes, and respond to their child's feeding cues (Hong & Park, 2012).

Parents were clear in the study presented in Chapter 9 that the key to providing helpful support to them as team members lies in being the right type at the right time (Lively et al., 2022). This aligns with comments made by parents of children with special healthcare needs who reported that they required interventions specific to certain issues and at different timepoints over the lifespan of their child's disease (Bradshaw et al., 2019).

How, then, do health professionals provide support to parents when tension may exist between the health professional supporting the parents therapeutically while also respecting them as equal team members, and what type of support is required? This question may be considered through the lens of the increasingly prevalent trauma-informed practice strength-based framework. This framework respects diversity and places value on the relationship between professional and patient through promoting safety, trustworthiness, choice, collaboration, and empowerment (Leitch, 2017; Mental Health Australia, 2014). This aligns further with Principle 1 to maintain equality between professionals and parents. It can also be used to support parents in implementing functional and relevant therapeutic change within their home environment. The next section will explore one learning framework that therapy teams may consider as a way of providing therapy to parents so that they may, in turn, implement these strategies within the home environment.

Strength-Based/Growth Mindset Learning Framework

Weaning is not a one-size-fits-all approach. Given the variability between family units, the unique relationships between children and their primary carers, and the individual experiences each family unit has faced, it is impossible to prescribe one method of weaning that will work for every family. Strength-based learning principles could be used with families to capitalise on a growth mindset. This approach is likely to promote and develop skills that the child and their parents can require, expand on, and implement.

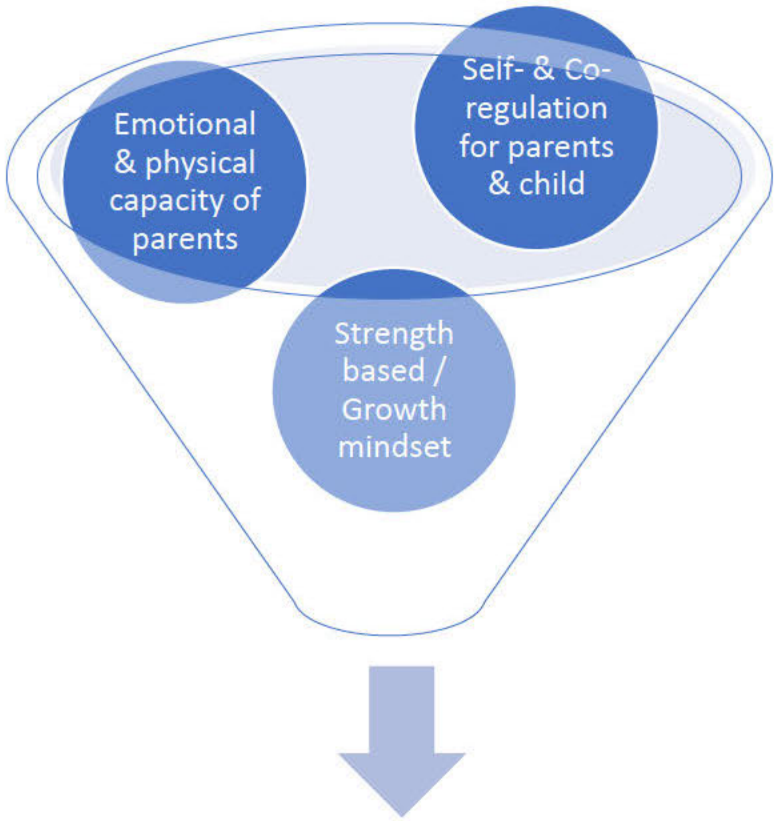
Strength-based learning considers a person's skills and respects their ability to grow and change by using those skills to enable development. The strengths perspective values an individual's ability, competency, goals, and beliefs. It uses opportunities and resources within the individual, family, and community to support change (Saleebey, 1996). A systematic review undertaken to explore parents' learning needs in the context of having a child with a chronic condition highlighted the role of health professionals in this regard (Nightingale et al., 2015). Of specific interest was the ability of the professional to form relationships with parents, their ability to tailor their teaching to everyone at a level appropriate for them (i.e., not too much or too little information), and the professionals' awareness of the parents' goals and needs (Nightingale et al., 2015). The sentiment expressed by Nightingale and colleagues implies the professionals are 'teachers' who impart information to the parents. This does not align with the philosophy of parents as equal team members (as per Principle 1); however, it draws upon the tension created when parents are potentially unaware of their goals and needs and rely on health professionals to provide this information.

Strength-based learning and behaviour change come from the 'bottom up', with gradual acquisition and explicit teaching of the next skill level based on the individuals' current functioning and implicit knowledge (Sun, 2012). This is in comparison to working from a deficit-based model, in which skills the person does not possess are highlighted as 'atypical' or 'disordered', or the focus is on repairing situations that have contributed to a person's functioning at any given time (e.g., trauma or environment) from the 'top down'. In this model, the knowledge that is lacking is explicitly taught and then assimilated by the individual into a meaningful form (Sun, 2012). Top–down teaching may not commence where the learner is at, and it relies on the learner being able to link any subtle but important steps they may require to master the skill being taught.

Augmenting and building upon someone's strengths can be facilitated by a health professional or community member supporting the person to become empowered, resilient, and part of a larger community group, which are the core values of a strength-based perspective (Saleebey, 1996). These values can be used by external influencers (e.g., therapists) to mould the environment around which a child or parent exists, for them to seek to intrinsically improve their abilities, problem-solve challenges to progress, and amalgamate with like-minded people around them. In promoting the development of these values, the child's and parents' self-determination (as outlined in Chapter 2) is supported, thereby contributing to the maintenance of behaviour change over time (Ryan et al., 2008).

Behaviour change over time is an essential concept for tube weaning because acquiring a new developmental skill sits on a continuum rather than being a standalone, finite process. The parents interviewed in Research Project 3 (see Chapter 9) remain fragile, doubting, sceptical, and easily triggered by previous medical and developmental setbacks following the acute weaning phase (Lively et al., 2022). Just as a child requires multiple opportunities to practice, master, and then remain confident with the many new skills relating to eating and drinking orally, so do parents. Specifically, parents require repeat positive exposure and experiences to cement their confidence in facilitating their child's autonomy within family mealtimes and reading and responding to their mealtime cues. As such, a critical role of the weaning team should encompass the provision of ongoing relevant, timely, and strengths-based support to parents beyond the timeframe of any intensive weaning therapy program. Additional clinical and research considerations for supporting parents are illustrated in Figure 32.

Parents require equal support and therapy as children throughout the tube feeding and tube weaning process.



CLINICAL RECOMMENDATIONS

- Health professionals to consider that tube weaning needs to support both the child's and parent's physical and emotional capacity.
- Health professionals co-construct functional strategies with parents for them to implement and maintain their child's oral eating recognising the family's circumstances and strengths.

FUTURE RESEARCH RECOMMENDATIONS

- Develop an evidence-based resource to increase health professionals' awareness of the type and level of support parents require.
- Determine best practices for providing the support identified in the previous recommendation and upskilling health professionals' in being able to provide this.

Figure 32: Key considerations and clinical and research recommendations from Principle 2

PRINCIPLE 3: Intervention teams should provide clear and realistic expectations and information to parents from the commencement of tube feeding

Many of the parents interviewed for the parent study presented in Chapter 9 first experienced tube feeding when their child was born prematurely or required medical intervention resulting in hospitalisation. Even with a prior indication of a level of postnatal challenges, parents could not prepare themselves mentally, physically, or emotionally for the reality of a premature or unwell baby. The uncertainty of their baby's condition caused significant distress, and the unfamiliarity of an intensive care environment and parents' reliance on the healthcare team left them feeling helpless (Thiele et al., 2016).

Tube feeding is sometimes the least of parents' worries given the medical, emotional, physical, psychological, and logistical challenges that often come with having a baby in intensive care (Lively et al., 2022; Serlachius et al., 2018). At the time, parents may not be able to comprehend the often longer-term nature of tube feeding, and this may be further limited by their feelings of guilt, grief, anger, anxiety, and trauma at having a baby who requires additional medical intervention (Thiele et al., 2016). For this, parents may also feel obliged to consent to the medical treatment advised by their healthcare team (Dadich et al., 2021). For example, the environment at the time of the tube placement was reported by parents as one of confusion (through lack of information), hopelessness, and despair at coming to terms with their child's health challenges (Dadich et al., 2021). Providing information to parents in an easily accessible and readily understandable format on the role of tube feeding at different timepoints in their child's treatment may help dissipate some of the uncertainty that parents reported in our research study. This includes pre-empting and supporting the intense emotions that are often triggered, such as the implications of disability/anomaly and the isolation often brought about by tube feeding (Åvitsland et al., 2013; Dadich et al., 2021; Lively et al., 2022).

Based on the outcomes of the evaluation of parent experiences outlined in Chapter 9, the following pieces of information will likely be helpful for parents to receive at the beginning of their and their child's tube feeding and weaning journey, rather than learning this information through trial and error.

Likelihood of Discharge from Hospital with a Tube

Parents are unlikely to have previously encountered the intensive care experience and are therefore unaware that their child may be discharged home, requiring all or some tube feeds. Although many children are discharged home from NICU on full oral feeds, some require home enteral feeding. For example, 16% of premature infants admitted to a Wisconsin intensive care unit required mixed oral and tube feedings, and 8% were fully tube-fed at discharge (Jadcherla et al., 2010).

Sharing with parents the likelihood of their child being discharged with a feeding tube is important because ongoing tube feeding is a contributor to parental stress. The stress levels of mothers in a Japanese and New Zealand NICU were found to increase the longer their babies remained tube fed and for those that relied solely on tube feeding (Ichijima, Kirk & Hornblow, 2011). The thought of their child going home with a feeding tube may result in some parents placing more pressure on the feeding experience to encourage their child's oral intake. This could include frequent or more forceful food or fluid offerings despite clear cues from the child that they are disinterested (Adams et al., 2020). To counteract this potential pressure, early feeding training and information are important because parents may feel that, to avoid going home with a feeding tube, it may be better to 'push' their child while in hospital in order to 'fix' the feeding challenges.

Enacting and practicing strategies such as responsive tube feeding in the NICU before discharge can facilitate confidence and problem-solving skills for parents while still in a supportive environment (Toivonen et al., 2020). To help mitigate some of their concerns, parents could benefit from knowing realistic expectations for a successful transition to and maintenance of oral feeding (Lively et al., 2022). Additionally, developing a plan for tube removal (when appropriate) by proactively supporting parents whose child remains partially or fully tube-fed can be facilitated by providing evidence-based information relevant to their family situation.

The intention of this principle highlights that parents require forewarning that their child may need enteral nutrition in the home environment. However, being armed with information before discharge from the hospital setting reassures parents that there is a plan to move towards oral feeding.

Normalising Mealtimes for Tube-Fed Children within the Home Environment

Tube feeding in some acute settings is often still enacted as a 'medical procedure' with specific processes and steps to ensure medical sterility, predetermined volumes of fluid given at specific times, and with clear documentation (Ludwig & Waitzman, 2007). Parents have spoken of the alienation they experienced—not only from their babies but also from the greater community—at being unable to nourish their babies as other parents would (Lively et al., 2022; Serlachius et al., 2018).

Tube feeding can be provided in ways that are more typical of oral feeding, and there are advantages to the child and family in considering these aspects when tube feeding at home and in the hospital. For example, health professionals can support parents by rephrasing and thus restructuring parental mental representations from '*my baby is tube fed*' to '*my baby has oral experiences with supplementary tube feeds*'. In this way, parents are coached to first and foremost approach feeding as they would for an orally fed child, even if the child is unsafe for oral feeding. In doing so, they attempt to reduce the impact of tube feeding stimuli (e.g., parents holding a syringe or no oral stimulation during a feed) being introduced during the sensitive period of feeding development (Skuse, 1993), as described in Chapter 1. Strategies to mirror an oral feed in a young child include holding the baby close to their body, sharing the feeding experience through facial expressions and communication, and providing a level of oral stimulation/massage/touch that may or may not include food and fluids (depending on the child's swallow safety). Older children could be seated at the table during family meals and provide opportunities for autonomous food exploration as would be available for an orally fed child learning to eat. Promoting tube feeding methods that do not require an adult to hold the syringe directly above the child will also assist. This position will allow an adult to engage in everyday mealtime actions, such as using two hands for cutlery and sitting without holding a syringe in the air and normalising the visual input that tube-fed children observe and imitate at mealtimes.

Family mealtime experiences are essential for developing mealtime skills, as described in Chapter 1. Often, only one parent is trained in tube feeding, which typically places the responsibility of other siblings and mealtimes on the other parent (if present) (Dadich et al., 2021). How a child tolerates each tube feed is specific to that child and may vary daily, making it challenging to predict how tube feed experiences unfold daily (Dadich et al., 2021). Unpredictability of feed times and tolerance can be disruptive to the goal of shared family mealtimes; therefore, guiding families on how to amalgamate tube feeds and family mealtimes is crucial. Future research may focus on team members and parents working together to trial and evaluate effective strategies for the translation of research evidence regarding the feeding and mealtime development of tube-fed children, into practice.

Another obvious difference between tube feeding and typical oral feeding is the often-prescribed schedule of feeds to ensure sufficient calories are provided. This may be necessary to recover from surgical interventions or 'catch-up' growth from prematurity (Dovey et al., 2018). However, it frequently results in babies being fed, whether awake or asleep, hungry, or satiated, rather than being fed depending on the infants' hunger cues (Dovey et al., 2018). Being fed on a schedule means the baby rarely has the opportunity to express its hunger, and many parents report that they are unaware of or misinterpret their baby's hunger cues. Parents often require individualised training to interpret these cues (El Aziz & Abd El Aziz, 2017); however, working with parents to co-construct knowledge regarding their child's cues may provide intrinsic learning opportunities for parents (i.e., parents are not reliant on health professionals to interpret and inform them of their child's cues). Intrinsic parent learning will, in turn, support the longer-term interpretation of and response to their child's mealtime cues. All team members have skills and information to learn from each other and help each other to learn so they can provide better support to the child learning to eat. Health professionals may empower parents to transition from a prescribed feeding regimen to one that allows the baby to express their needs and to recognise their cues. This facilitates responsive feeding for the parents by allowing them to read, interpret, and meet their baby's needs. In turn, it can provide parents with satisfaction with and gratitude for their fundamental role of parenting—being able to provide for their baby. The acute medical and outpatient feeding teams can monitor growth and health, with volume adjustments and strategies implemented to fill shortfalls while respecting responsive feeding principles (Samane et al., 2022).

Normalising the way that tube feeding is implemented will instil the same feeding and mealtime learning experiences in a tube-fed baby that are typical for an oral baby. In doing so, these experiences are brought to the forefront rather than the more foreign and alienating tube-feeding experiences.

Common Side Effects of Tube Feeding

The side effects of tube feeding have been well documented, but parents are often unaware of them (Krom et al., 2019). Parents have reported feeling uncertain about tube feeding and medical information relating to their child (Hopwood et al., 2020; Serlachius et al., 2018). Anticipatory counselling regarding the frequent side effects of tube feeding—some of which are discussed below—could further reduce uncertainty and worry.

Frequent Vomiting

For tube-fed children, the effects of prematurity on the gastrointestinal system, neurological impairment, and a somewhat rigid tube-feeding schedule can result in frequent vomiting, gagging, nausea, and coughing (Krom et al., 2019; Pahsini et al., 2016). Vomiting affects nutritional intake and medication administration. Parents can be plagued over whether to re-feed their child to facilitate weight gain or accept that their baby has lost calories or crucial medication through vomiting (Brotherton et al., 2007). Feeding times are extended, with additional cleaning time required, and some parents fear feeding in public (Brotherton et al., 2007).

Vomiting contributes to adverse feeding experiences for the child, with frequent feelings of acid reflux and burning sensations (Zangen et al., 2003) and, in many circumstances, slow growth (Wilken, Bartmann, Dovey & Bagci, 2018). These feelings of discomfort are often unanticipated by parents (Brotherton et al., 2007; Hopwood et al., 2020). By working with parents to identify specific signals, clinicians can empower parents to provide nourishment by respecting a baby's satiation cues rather than via a prescribed regimen. Parents generally feel comfortable stopping an oral feed if their baby vomits. However, under the traditional model of tube feeding, parents are often encouraged to feed until a prescribed amount is given (Ludwig & Waitzman, 2007). Tube feeding can be normalised by proactively building parents' trust in providing nutrition in line with their child's cues to reduce or stop vomiting and facilitate improved growth and enjoyable feeding experiences. Building parents' confidence to trust in their child's interoception (i.e., the feeling of having had 'enough') while still within a supported and medically monitored environment can support these skills for their transition home (Toivonen et al., 2020).

Tube Reinsertion

As previously discussed, NGT/OGT reinsertion may cause discomfort or trauma for children (p. 66); however, they require changing every 6–8 weeks for infection control (Best, 2019) or if they are dislodged through general activity or accident. NGTs are usually re-sited by trained nurses or doctors, which involves a visit to the emergency department or by a HEN support team.

The process of re-siting an NGT involves the removal of the old tube as well as the adhesive from the child's cheek. Younger children are often wrapped in a blanket to restrict arm movement. Older children are asked to sit still or may need to be restrained by an adult while the tube is inserted into their nostril and pushed down their oesophagus to their stomach. If any resistance is felt or gagging or vomiting occurs during siting of the tube, the tube must be retracted and tube placement attempted again (Women's and Children's Health Network, 2021). To check for the correct tube placement in the stomach and not into the lungs, stomach contents are aspirated and pH levels are checked (Best, 2019). Once the correct tube placement is confirmed, the tube is again secured to the cheek using adhesive (Women's and Children's Health Network, 2021).

In time, some parents choose to learn how to re-site the tube. This may save trips to the ED and, in some cases, may be vital for families living regionally or rurally with reduced access to medical support. While the benefits of reducing time spent in the ED and limiting the number of medical exposures are appealing, parents must be made aware of the possible downsides of re-siting their child's tube themselves. For example, the physical act of restraining their child and the emotional guilt and trauma some feel about inflicting pain can potentially compromise the parent–child relationship (Dadich et al., 2021; Ferguson & Campbell, 2007). This is particularly important, because a trusting and stable parent–child relationship is critical for successful feeding and mealtime experiences (Dunn Klein, 2019). In the interviews presented in Chapter 9, some parents reported that they wished they had not learned to re-site the tube, with resurfacing feelings of guilt and regret. Some parents vividly recalled the haunting images of having to physically restrain their child while aiming for correct tube placement, at times requiring multiple attempts [P10, P12]. These feelings resonated with parents in Krom et al.'s (2019) study, with 57% of parents describing tube re-siting as traumatic and 31% stating that it is unpleasant. Ongoing refusal of oral stimulation by their child following attempts at tube reinsertion can leave a parent feeling more helpless and possibly rejected by their child (Adams et al., 2020).

Oral Aversion/Food Aversion

In addition to affecting parents, the invasive nature of frequent NGT placement can lead to oral aversion. As outlined in more detail in Chapter 1, oral aversion refers to the '*reluctance or refusal of a child to be breastfed or eat, manifested as gagging, vomiting, turning head away from food, or avoidance of sensation in or around the mouth (e.g., toothbrushing or face-washing)*' (National Library of Medicine, 2022). Parents and clinicians may be unaware that aversive feeding responses can lead to ongoing stress, which negatively affects growth (Wilken & Bartmann, 2014). Just over half (51%) of medical and allied health staff working at Queensland Children's Hospital (Australia) who participated in a survey on tube feeding and weaning awareness indicated oral aversion as a frequent complication of tube feeding (Syrmis et al., 2020). Oral aversion is not often included in tube feeding information provided to parents, and it is not clearly communicated to professionals as a potential side effect of tube feeding (Syrmis et al., 2019). Therefore, it is essential to increase all team members' understanding of the aetiology and psychosocial and environmental factors that may contribute to oral or feeding aversion (Edwards, Davis et al., 2015). Bringing awareness to the strategies to avoid or mitigate this barrier can progress a child's oral intake.

An honest discussion between the acute team and parents early in the tube-feeding process regarding possible complications such as frequent vomiting, tube reinsertion, and oral aversion will allow parents to be more prepared and understand their options before these possible events occur.

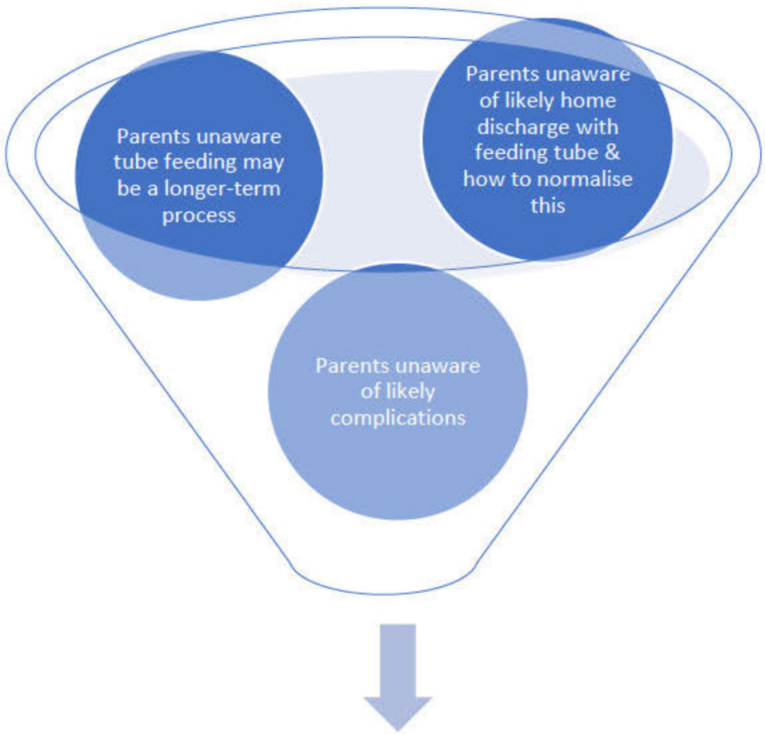
Tube Weaning is a Longer-Term Process

As described in Chapter 1, learning to eat is a skill that, in the typically developing baby, takes 6–12 months to develop, with further mastery up until 2–3 years of age (Morris & Klein, 2000). Weaning a typically developing baby to solids is a gradual developmental process and is not expected to occur within a designated timeframe (Medical Dictionary for the Health Professions and Nursing, 2022). Tube weaning could be approached in the same manner. When feeding teams frame weaning as a continuum of feeding therapy instead of a 'one-off' intervention, realistic expectations can be developed together. Parents and health professionals often emphasise tube weaning if it is clinically appropriate for the reasons identified in Chapter 1 ('Effects of Enteral Tube Dependency, p. 64-70). Parents must understand that, irrespective of the length of time of any given program, joining the team to implement a weaning program does not guarantee that their child will be tube free and consuming a wide variety of textured foods and fluids upon completion. Instead, intensive weaning programs should be framed as a springboard to the next phase of mealtime skill development, with ongoing improvements occurring following the program. By setting realistic expectations that weaning programs are not a 'one-stop shop', parents may be set up to celebrate the gains they and their child makes.

Some children, such as those with developing oral interest, intake, and skill, are able to be slowly weaned from tube feeding through outpatient services and have not required more intensive tube-weaning therapy. The three research projects presented in this thesis have focused on children for whom outpatient therapy has not resulted in a change in oral intake. For them, their parents and the healthcare team have deemed participation in a weaning program as the next phase of therapy. A recent survey of professionals working with tube-fed children in an Australian hospital highlighted that 46% of respondents (150 in total) were unaware of when to start planning for a tube wean (Syrmis et al., 2020). The uncertainty from health professionals about the appropriate time to consider weaning can add to parental anxiety and stress about how and when their child's tube dependency will abate. Before discharge, acute medical teams, together with parents, could consider developing a plan for who would manage the subsequent phases of therapy, how the phases would be managed, and what they might involve. An example given by one parent made it clear that '*you don't send a child home from hospital with a broken leg without a plan to get the cast off and get them walking again*' (Lively et al., 2022, p. 6). The same should hold true for children discharged with a tube. Jointly developing an informed plan based on agreed short- and longer-term goals helps provide direction for families. Written information to augment this plan may include options for accessing therapy, the key team or contact person, frequency of review/therapy, members of the outpatient feeding team, and what to expect in follow-up appointments.

Figure 33 summarises the key information that should be provided to parents from the onset of tube feeding to support their understanding of realistic tube-feeding expectations. Suggestions for future research are also proposed.

Intervention teams should provide clear and realistic expectations and information to parents from the commencement of tube feeding.



CLINICAL RECOMMENDATIONS

- Discuss with parents the advantages and disadvantages of tube feeding prior to them providing informed consent for feeding tube placement.
- Address any knowledge gaps that health professionals on the team may have to develop and improve team cohesion.
- Parents to be supported by health professionals on the team to master feeding and mealtime skills for home transfer while still in the supported hospital environment.
- Health professionals to provide parents with information regarding common complications of tube feeding, strategies to minimise these, and options for feeding therapy. This information should be provided across different learning platforms such as written, auditory, and visual to support different learning styles.
- An individualised co-constructed therapy plan should be developed by the team that includes goals, agreed therapy frequency, and therapists involved.

FUTURE RESEARCH RECOMMENDATIONS

- Determine best practice feeding and mealtime development for children requiring feeding tubes to develop an evidence-based information package for parents.

Figure 33: Key considerations and clinical and research recommendations from Principle 3

PRINCIPLE 4: The decision to wean is multi-factorial

Many considerations must be acknowledged when determining whether it is appropriate to transition a child from tube dependency. It is essential to consider the child's biological and skill-based parameters in the context of the broader environment around the child. Whose responsibility and role is it to initiate and commence weaning? The French working group that presented a position paper on tube weaning suggests criteria for beginning weaning, but not who is responsible for determining whether those criteria are met (Clouzeau et al., 2021). The answer likely varies depending on individual programs and which of the three approaches to weaning and related theories has determined the program design. A Canadian intensive weaning program uses the psychologists' assessment of the caregiver and child's readiness for oral feeding to determine the commencement of weaning (Cipolla et al., 2022), which may inadvertently exclude feedback or concerns from other team members regarding weaning suitability. The program discussed in Chapters 7 and 9 highlights that parents may drive the need to research weaning options, but the decision to wean is a cumulation of information from medical, speech pathology, mental health, occupational therapy, and dietetic disciplines in conjunction with the parents (Lively et al., 2022). This is similar to the weaning initiation described by Hopwood et al. (2022), whereby the parents' agency to drive change for their tube-fed child dictated the process until the whole team was onboard. It may take one team member to initiate the discussion regarding weaning readiness—whether that be the parents or a health professional—and who this is must be clear from the outset. If it is to be the parents, careful consideration is required for parents to be supported to make an informed decision about commencing weaning. Without someone to start these discussions, some children may remain tube-fed longer than required (Dunitz-Scheer & Scheer, 2022).

Although I have described weaning on a continuum from tube feeding to oral eating (see Chapter 10, p. 200), the point of moving from tube maintenance to tube weaning (see Figure 29) is discussed in the context of the following 8 potential eligibility criteria that were reported in a comparison questionnaire encompassing 12 international weaning programs (Gardiner et al., 2014). The order in which they are presented does not represent the weighting of each one in determining tube-weaning readiness. Instead, the interplay of the factors that are relevant to each child and family is more likely to indicate whether a child and the parents are in a position to commence tube weaning.

1. Medical Stability

Given the often-complex reasons a child may initially require tube feeding, it is not uncommon that repeat surgical and medical interventions are necessary (Ferguson & Campbell, 2007). Surgical intervention requires pre-surgical fasting and post-surgery recovery. The inability to offer food and fluids during these times may exacerbate parental and health professionals' concerns regarding the health and growth of the child. Because medical stability is a prerequisite for many tube-weaning programs, weaning could be considered once all short- to medium-term planned surgeries are completed (Gardiner et al., 2014).

2. Safe Swallow

As outlined in Chapter 1 (p. 11), the ability to swallow safely relies on a complex and precisely orchestrated sequence of neural messages and muscular contractions. The consequences of an unsafe swallow could be aspiration and respiratory compromise. For these reasons, all published tube-weaning programs explored throughout this research require a child to swallow safely before commencing weaning, with assessment and treatment undertaken as per the information presented in Chapter 1.

A clinical discrepancy remains around using VFSS studies as a diagnostic requirement for swallowing safety and effectiveness. These assessments provide a snapshot image of a child's swallowing in that specific medical environment (radiology department of a hospital); however, that environment may be unfamiliar and distressing for a child. A child who is crying and upset may not adhere to requests to swallow, or their crying may affect their swallow. In addition, many tube-fed children are orally defensive and do not allow food or drink into their mouths. Subjecting them to an imaging procedure that requires them to ingest food and fluid is unlikely to yield productive results and should be considered with caution (ASHA, n.d.-c). An indication of safe swallow capacity could be drawn from a child's ability to manage their saliva or multiple refluxes or vomits without recurrent aspiration (Dunitz-Scheer & Scheer, 2022).

In addition to the safety of the swallow, another consideration is strength, speed, and coordination. As with other motor patterns, practicing the sequence will strengthen neural and motor pathways and improve this movement (Robbins & Klee, 1987). Children who have not been allowed to practice swallowing (i.e., those who are ‘nil by mouth’) may not have a coordinated swallow for food or fluids. Children require the physical practice of swallowing to build coordination of saliva and food and fluid management. It remains a clinical dilemma that instrumental swallow assessments may identify aspiration, which is not evident in observational or day-to-day swallow assessments in typical eating environments. Therefore, introducing oral intake to facilitate a child’s practice of swallowing forms part of a risk assessment completed in collaboration with parents and monitored closely by a trained health professional (Radford et al., 2020).

Safe or coordinated swallowing is likely affected by the presence of an NGT as discussed in Chapter 1. The length of time considered appropriate for an NGT to remain in place varies between weaning centres. Some argue that those requiring longer-term tube feeding should transition to GT feeding as soon as possible to reduce oral aversion and allow the child to develop their physiological swallow pattern because the presence of an NGT has been shown to alter the physiology of swallowing in adults (Suiter, 2014). Other professionals who manage tube feeding in the United States and Canada indicated that transitioning from an NGT to a GT was perceived as a barrier to improving oral eating (Abdelhadi et al., 2021). As reported previously, in the United States, it is often common practice—and for some weaning centres it is a requirement—to transition from an NGT to a GT if tube feeding is to last longer than six weeks (Gardiner et al., 2014). Dunitz-Scheer and Scheer (2022) suggested that if tube feeding is to last longer than 2–3 months, an NGT should be replaced with a GT. In Australia, anecdotally, it is less commonplace to undergo surgical GT placement following 6–12 weeks of NGT feeding. Many children remain with an NGT for months and years for reasons raised in Chapter 1, Part 2 (p. 52). This is known to affect their oral sensory processing and their feeding development (Dodrill et al., 2004), but it should not preclude them from the option of tube weaning (Lively et al., 2019). Although a child may not swallow substantial amounts before weaning, the increased motivation to practice swallowing food or fluids during the weaning process can facilitate volume consumed and precision (Lively et al., 2019).

3. Understanding a Child's Growth Pattern

Biologically, some babies may remain small but track consistently on their own percentile on growth charts (University of Rochester Medical Center, n.d.). This includes healthy babies as well as premature babies, babies with inter-uterine growth retardation, genetic predisposition, metabolic or neurological compromise, or specific syndromes (e.g., Down syndrome). Otherwise, medically healthy babies' growth may always sit at the lower end of the percentile growth curve, even if they have not faced other challenges. Equally, medically compromised children may never achieve 'catch-up growth' despite the best efforts of all involved to support this via tube feeding (Di Maria et al., 2013). For this discussion, growth refers to a child's weight and height as it changes to reach maturity (Becker et al., 2015). These measurements are tracked via percentiles and plotted on a growth curve over time (see Figure 34). They are gender and condition-specific, reflecting the known impact of some conditions on growth. According to the Centers for Disease Control and Prevention (CDC), growth charts should never be used in isolation for diagnostic purposes but should augment other clinical information about an individual child (CDC, n.d.).

Children who have typically struggled to gain weight despite the best efforts of fortifying oral and enteral feeds may be referred to as having faltering growth. Faltering growth, previously known as 'failure to thrive', is defined as '*a slower rate of weight gain in childhood than expected for age and sex*' (National Institute for Health and Care Excellence, 2017, p. 20). Given the often endless worry and concern by themselves or health teams regarding their child's growth, many parents fear reducing their child's enteral caloric input for the therapeutic gain of oral skills (Lively et al., 2022; Wright et al., 2011), particularly in the instance of faltering growth.

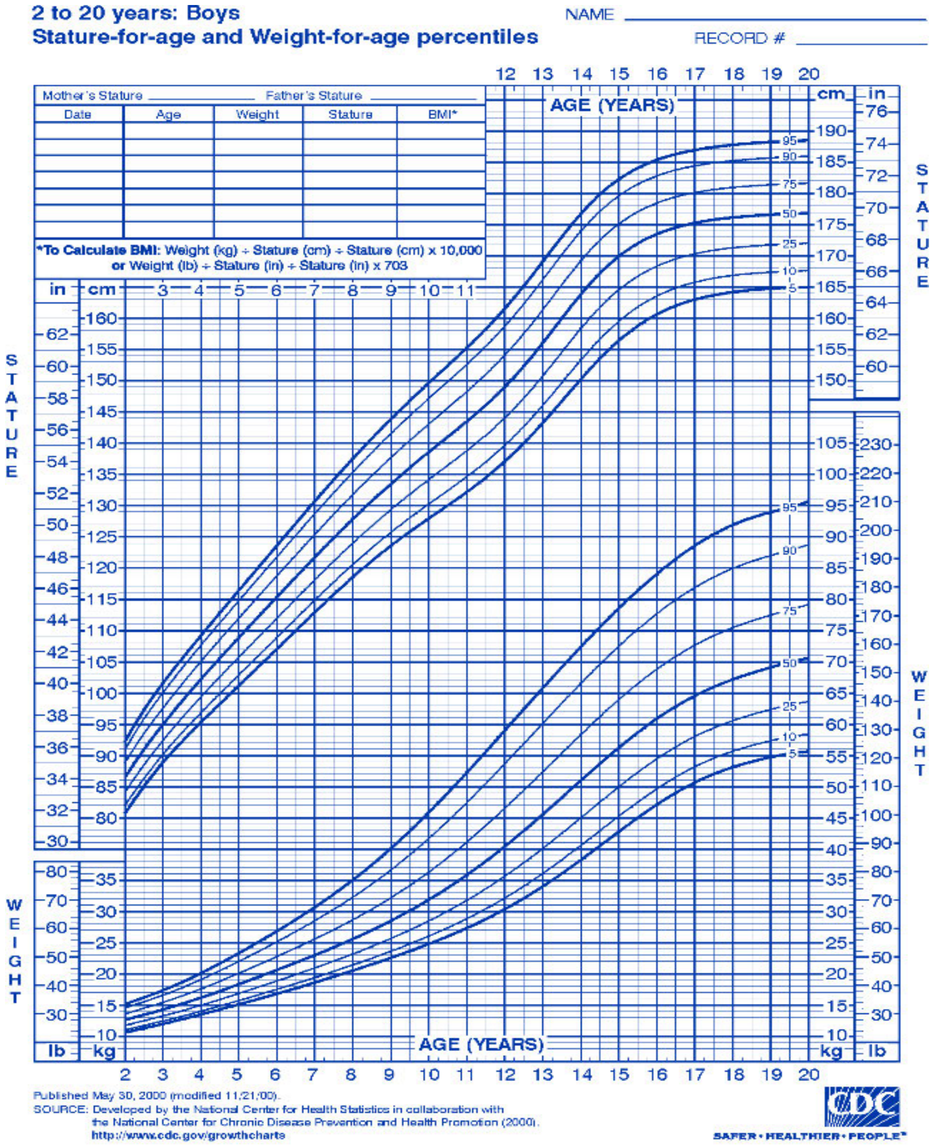


Figure 34: Example of CDC growth chart length and weight (boys)
(CDC, n.d.-a)

BMI is another indicator used by some weaning teams to reflect a child's growth. It is also used as an inclusion criterion for weaning by some teams (e.g., Wilken et al., 2015). BMI indicates excess weight, which may comprise muscle mass, fat, and bone density. BMI charts are not widely available for children under 2 years; therefore, growth charts for children under two years, as per Figure 34, are used to plot weight and height for age and sex (WHO, n.d.-a). BMI may be used in children over two years of age and reported as z-scores (standard deviations from the mean) or percentiles (indication of growth relating to other children of the same age and sex) (CDC, n.d.-b) (see Figure 35). Children are considered malnourished (undernourished) when illness causes poor absorption of nutrients or food, or when growth and development are impeded by the lack of energy and protein in their diet (Becker et al., 2015). A child may fall within a 'healthy' weight category but still be undernourished, which is why tracking growth over time is important (Satter, 1990).

Percentile	**z-score**	**Weight classification** **Nutrition status**
Less than 5th percentile	< −2 SD	Underweight Faltering growth Moderate undernutrition
5th percentile to less than 85th percentile	−1.9 to −1.0 −2 to 1 SD	Mild undernutrition Healthy weight
85th percentile to less than 95th percentile	>1 to 2 SD	Overweight
Equal to or greater than the 95th percentile	>2 to 3 SD	Obese

Figure 35: Interpretation of BMI in children over two years of age
(Anderson et al., 2017; Becker et al., 2015; CDC, n.d.-b)

Reviewer feedback from Research Project 2 in Chapter 5 (Lively et al., 2019) stated that tube weaning should not be recommended in children with faltering growth and a BMI of <−1.0 or 90% of ideal body weight (~15th percentile). They asserted that this would place these children on the continuum of being malnourished (undernourished) (Becker et al., 2015). This contrasts with guidelines produced by the CDC that classify children over the age of 2 years as being underweight if they are in less than the 5th percentile (height for weight ratio/BMI) (CDC, n.d.-b).

Despite this clear clinical recommendation from the reviewer, few published programs report this as an inclusion criterion for weaning. Only one paper was found with a clear guideline requiring BMI to be above the tenth percentile (Wilken et al., 2015). This was reported to be based on 'national standards'; however, no further reference was provided. In a survey of international weaning programs, only two out of the eight program respondents had a weight requirement for acceptance to wean (Gardiner, Vuillermin & Fuller, 2017). For one Australian behavioural approach, this parameter required the child to be within two standard deviations of the mean for weight. For the other—a United States program that focused on oral encouragement—the 'absence of malnutrition' clinically reflecting the child's BMI (as determined by their dietitian) was a pre-requisite. A position paper released by a working group of French medical and allied health professionals in 2021 suggested that weaning should not be undertaken in children with a weight-for-height BMI z-score of −2 or less (Clouzeau et al., 2021), which is in contrast to Wilken et al. (2015) (<−1.0) and the reviewer of our previous paper (<−1.0).

Placing a strict weight or BMI measure as an inclusion criterion will remove the opportunity for slighter children to learn to eat. Of note, 30–45% of tube-dependent children have been reported to be malnourished (Dunitz-Scheer & Scheer, 2022; Ishizaki et al., 2013; Pearce & Duncan, 2002). This suggests that even though these children are tube-dependent, the tube is not meeting their nutritional or growth needs, so weaning is not increasing their risk of malnourishment and may mitigate against the malnourishment. Giving malnourished, tube-dependent children the opportunity to learn to eat and drink orally was supported by Lively et al. (2019). In her program, the mean BMI of participants was −0.47 (SD 1.03), placing some of them in the 'mild undernutrition' range (Becker et al., 2015). However, the participants' BMI z-scores did not predict the time taken to wean. Wright et al. (2011) additionally showed that tube-fed children with 'exceptionally low' BMIs might be explained by a low lean mass (rather than low-fat mass) as a result of physical disability rather than reducing the calories provided via tube feeding.

For parents to realistically consider the effect of weaning on their child's growth (weight, height, and head circumference), they require an accurate interpretation of their child's growth pattern *over time* instead of a once-off reported weight figure, percentile, or BMI score (Clouzeau et al., 2021).

4. Cognition

Although learning to eat is a developmental skill and nutrition is known to play an important role in brain development (Cusick & Georgieff, 2016), little information is reported by tube-weaning programs on the developmental or cognitive ability of the cohort being weaned, and cognitive assessment is rarely undertaken as a pre-requisite to tube weaning. Of eight programs reviewed by Gardiner et al. (2017), only one (Kluge Children's Rehabilitation Centre) used cognition as a determining factor for reducing tube-feed volumes. While Showa University Hospital (Japan) routinely collected data on cognitive capacity, it was not used as a decision-making factor as to whether to wean or not. In their study, 69% of participants had 'mild mental retardation' (classified as an IQ in the range of 50–85), and 11% had moderate mental retardation

(IQ less than 50). One-quarter of the children (25%, n=7) who were not weaned in this study had either mild or moderate mental retardation (Ishizaki et al., 2013). Wilken and Jotzo (2008) found that a child's developmental capacity did not influence weaning outcomes. Similarly, an outpatient tube-weaning program supporting five children with developmental delay showed optomistic results, including transfer to and maintenance of oral intake within the home environment (de Moor et al., 2007).

It is important to consider the potential advantages for the child's cognitive and general development following tube weaning, because research has highlighted that tube feeding is correlated with developmental delay (Beckenbach, 2011). Parents have reported noticeable improvements in their child's speech, language, social, gross, and fine motor skills almost immediately once they have learnt to eat and drink (P1, P3, P7, P8). These parent reports are also supported by other research findings that have shown statistically significant improvements in children's self-help, social skills, motor skills, and communication both during and following tube weaning (Beckenbach, 2011).

This emerging research, coupled with clinical observations and parent reports, highlights the need for further measurement of developmental outcomes post-weaning. Since 2011, no studies have compared pre- and post-weaning changes in cognitive and general development. It may be challenging to tease apart the direct relationship between weaning and improvements in development given the individual influences of a child's environment. Whether 'catch-up' development occurs once the known critical periods for developing speech, language, and gross and fine motor skills have passed is not yet empirically known (Nickerson, 2021). However, as improvements in other areas of development continue to be reported by families, it is a valid area requiring further detailed research. This information may help inform parental decisions regarding the timing of weaning, as the positive effects on development and cognition may outweigh concerns and trepidation regarding their child's ability to wean (Lively et al., 2022).

5. Age

Research outcomes have shown that the longer a child is tube-fed, the longer the weaning process may take, regardless of chronological age (Lively et al., 2019; Trabi et al., 2010). As an example, a 4-year-old child with a feeding tube placed at two years of age (and who therefore has prior oral experience) may wean in a shorter time than a 4-year-old who has been tube-fed since birth and is likely to have less mealtime experience and more oral aversion. This is likely associated with the deeper consolidation of the psychological association the child makes between tube feeding and satiation (Clouzeau et al., 2021). However, young children may be compromised if weaning commences when they are not medically stable or will require surgery in the short to medium term (Clouzeau et al., 2021). Health professionals may therefore assume responsibility early in the cycle of tube feeding to commence discussions regarding timing and options for weaning to optimise developmental outcomes.

6. Oral Sensitivity

Oral sensitivity relates to how someone reacts to sensory information from food, fluid, and non-edible items within the mouth, and these reactions may be hyper-reactive, hypo-reactive, or defensive (Bean, 2013). As described in Chapter 2 (p. 58), tube-fed children often present with oral aversion or oral protection, yet many children labelled with oral aversion will spontaneously mouth toys and non-edible items (Dodrill et al., 2004). They are acutely aware of what is 'safe' for them (something that does not appear like food or fluids) and can tolerate these oral sensory experiences. Other children remain orally averse to all experiences—food and non-food-related (Edwards, Davis et al., 2015). As discussed in Chapter 1, oral sensitivity or aversion could be considered a high-level safety mechanism for these children. Memories of previous undesirable experiences may contribute to conditioned avoidance of food and facial stimulation (Dodrill et al., 2004). With time, exposure, and autonomy, orally defensive children can build trust in bringing foods and fluids to their mouth (Edwards, Davis et al., 2015). Children with oral sensitivity learn that nothing untoward will happen if they put something edible in their mouth, and they are able to overcome their fear when given an intrinsic reason to do so, such as hunger. With each self-initiated oral experience, they gradually desensitise themselves, and even children with severe oral aversion can successfully learn to eat and drink (Edwards, Davis et al., 2015).

One may suggest that oral sensitivity should not be used as a marker for unsuitability for weaning, but rather as an indicator that the child requires an opportunity for autonomy and non-pressured oral exploration multiple times a day. Per Bandura's SCT (1977), children learn from their environment through modelling, opportunity, and autonomy, thereby facilitating intentional reactions and responses. Incorporating oral exposure and opportunities through the child's environment can be achieved in multiple ways—for example, as part of a targeted therapy activity or on incidental occasions as part of a family's daily activities. It can be the health professional's role to collaboratively identify and problem-solve these opportunities with parents.

7. Prior Interest/Eating Experience

Professionals may consider that a tube-fed child cannot be weaned if they cannot demonstrate a variety of required skills, such as biting, chewing, swallowing, sitting at a table, and cutlery use. For example, in a survey of tube-weaning practices, three programs stipulated mealtime interest and prior eating experience as part of their eligibility criteria (Gardiner et al., 2014). Other tube-weaning programs stipulate that children require 'highly competent oral motor skills' before they are accepted into the program (Harding et al., 2010). These specific eligibility criteria may be in place because of the available team resources (e.g., funding, staffing) and the expertise of the treating team rather than these being relevant pre-requisite skills. It is important to consider that these skills can be adversely affected by tube feeding, and therefore are likely not well developed (Arvedson & Brodsky, 2002; Morris & Klein, 2000; Wolf & Glass, 1992).

Although it has been shown that it is easier for tube-fed children with previous oral experience to restart oral intake (Senez et al., 1996), the research presented in Chapter 7, in conjunction with previous research, has shown that children do not require any pre-requisite oral skills (other than a safe swallow) or mealtime behaviours to commence weaning (Gardiner et al., 2017; Lively et al., 2019). For example, prior oral experience (e.g., mouthing or swallowing food or fluid) and mealtime behaviours (e.g., sitting at the table or engaging with food) did not influence the time it took children to wean from tube feeding (Lively et al., 2019); therefore, children with no prior oral intake are still able to learn how to eat and drink successfully.

Another essential consideration in the decision to wean is whether NGT placement is the cause of poor oral skills or whether tube feeding masks underlying dysphagia or feeding difficulties (Dodrill et al., 2004). Underlying dysphagia may only be uncovered once the child shows a level of oral interest and intake and can then be therapeutically managed by the team as clinically indicated. In relation to this principle, a lack of or poor oral skills alone must be considered in the context of how much opportunity a child has had to develop them.

Opportunity for oral intake and oral refusal may be perpetuated for some children by all of their required calories being provided via tube feeding or by constant feelings of nausea or reflux as a result of overfeeding (Byars et al., 2003; Mason, Harris & Blissett, 2005). Clouzeau et al. (2021) suggested that tube-feed volumes be adjusted promptly to alleviate vomiting and promote satiety and spontaneous oral exploration. Children should be allowed the experience of feeling hunger and subsequently develop eating skills as a result (Hartdorff et al., 2015) because 'f*eeling hunger is a precondition for learning to eat! … we can confidently say that without hunger, nothing will work*' (Dunitz-Scheer & Scheer, 2022, p. 155).

If children need to reach a predetermined level of oral skill and mealtime experience before weaning can commence, they may be waiting beyond necessity, perpetuating oral aversion, and missing vital developmental windows of opportunity (Dunitz-Scheer & Scheer, 2022).

8. Understanding the Emotional and Physical Capacity of Parents

Many parents come to depend on their child's feeding tube because it ensures the provision of specific nutrition and medication (Cipolla et al., 2022). Tube-weaning teams must be mindful of the reliance that some parents place on having the feeding tube in place. When discussing tube weaning, *all* team members, including the parents as key team members, must consider their emotional and physical suitability. This includes supporting parents to acknowledge and address any possible doubt, insecurity, or psychological dependency they may have regarding the tube or tube weaning (Dunitz-Scheer & Scheer, 2022).

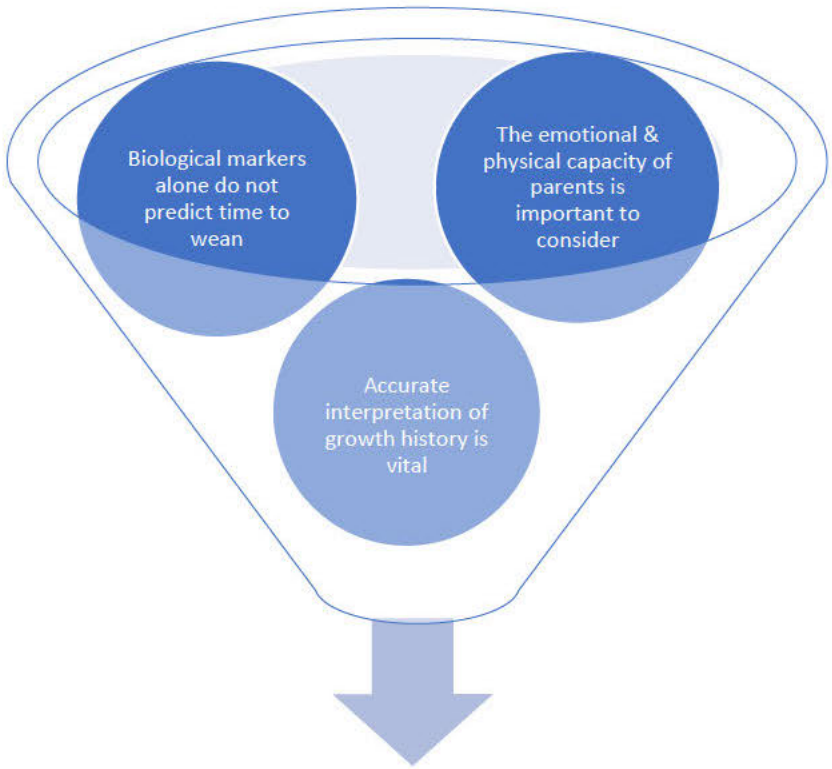
Chapter 9 provided research data from parents who had reached a point of seeking an alternative to tube feeding and were motivated to find an option for their child to learn to eat and drink, despite being unaware of what this would involve psychologically for them (Lively et al., 2022). The self-initiation of weaning and determination expressed by these parents may not reflect all parents with a tube-fed child. Some may be awaiting approval or recommendation from health professionals that (i) weaning their child is appropriate and (ii) they can provide a pathway for such therapy. These recommendations depend on the feeding team's experience, expertise, and confidence (Syrmis et al., 2020). If these options are available, some parents may feel obliged to follow medical advice and undertake tube weaning as the next prescribed process (Dadich et al., 2021). They may need to be made aware of or prepared for the changes to their day-to-day life, as well as the personal mental strain that tube-weaning may provoke. Even motivated parents do not fully comprehend the physical and emotional challenges that tube weaning can bring (Lively et al., 2022). Physically, during weaning and beyond, parents are required to prepare multiple meals a day for their child (perhaps of differing textures to their family meal), which may be more time-consuming than using preprepared commercial formulas. Parents are required to eat with their child and family five or six times a day, which may add additional physical demands on them to be present and engaging when perhaps they may have used their mealtimes as an escape or break from their child. Parents' physical resilience may be tested as children transition to oral intake if their child's behaviour, sleep, and bowels are impacted due to changes in their previously established feeding routines, their body adapting to fewer calories during the transition, and adapting to digesting different foods and fluids. Parental readiness therefore becomes an essential component of tube-weaning planning and is now reflected, but not well defined, in clinical practice recommendations for tube weaning (Clouzeau et al., 2021). A lack of definition of 'parental readiness' makes it difficult to determine if a parent is ready to undertake the challenges of tube weaning and may become an unnecessary or unfair barrier.

In addition to considering the emotional and physical capacity of parents, Shalem et al. (2016) highlighted the importance of assessing the parent–child interaction. They propose that this should form a considerable component of treating tube-fed children, as discussed in Chapter 8. While parents are part of the team, they sometimes require support themselves to engage in a meaningful way with their child to support their development (discussed further in Principle 5). This support may be provided by other members of the team who have experience in parent–child relational and emotional development.

Summary

Weaning readiness requires consideration of both the child's and parents' capacity to attempt and maintain new tube and oral mealtime routines. Commencing tube-weaning in the absence of careful consideration of at least the above indicators may result in reinstating or maintenance of tube feeding. Each family likely presents with differing combinations of variables for the weaning team to reflect on and discuss together to co-construct future oral eating and drinking goals for the child. Figure 36 illustrates the multiple components and clinical and future research directions to consider in the context of tube-weaning decision-making.

The decision to wean is multifactorial



CLINICAL RECOMMENDATIONS:

- Provide parents with clear and accurate interpretations of their child's growth history over time and the contribution that tube feeding has added to their growth. This will aid parents' decision-making.
- Health professionals should undertake a holistic assessment of *all* of the components that contribute to successful eating rather than focusing on a specific skill deficit. This includes parent and child factors.

FUTURE RESEARCH RECOMMENDATIONS:

- Design and implement a research project to measure the developmental outcomes post-weaning across areas such as speech and language, gross and fine motor skills, social and cognition.

Figure 36: Key considerations and clinical and research recommendations from Principle 4

PRINCIPLE 5: Weaning programs should be thoughtfully designed with their theoretical underpinnings clearly communicated

Weaning is complicated and, because of the complex and unique interactions between each child, their parents, and the other team members, no two weans are ever the same. As presented throughout this research, when teaching a child to eat and drink, there is much at stake physically and psychologically for both the child and the parent. Weaning is not something you 'just try and see how you go'; rather, it is a process that commences when all team members agree that it is the next clinically indicated pathway and that the pathway chosen is one that resonates with the family. Principle 5 was derived from the review of weaning program philosophies (see Chapter 4) that highlighted key differences in how weaning may occur. For parents to be clear on the expectations of them and their child when accepting a place on a weaning program, health professionals themselves must be clear in the approach they take, as well as the implications of this approach based on the evidence and theories that support it.

Parents who were interviewed as part of Research Project 3 (see Chapter 9) described the emphasis they placed on their child being able to wean successfully (Lively et al., 2022). Parents described their thoughts relating to tube weaning—for example, '*they would be able to put on more weight if they could eat*' [P9], '*it (tube weaning) was always something that was on our radar. It was always something that we were thinking about*' [P6], and 'a*s much as we knew it [tube feeding] was doing her good, it also inhibited her life*' [P7]. Weaning teams should remain cognisant of their responsibility to provide clear information and explanations to parents about the program they offer or are recommending given the level of resolution hoped for by parents.

Chapter 4 describes the literature review undertaken as part of this research series to classify and synthesise the many published international weaning programs (Lively et al., 2020). This review has contributed clear information regarding the underlying philosophies incorporated by each program. There are fundamental differences between the programs relating to the learning principles they employ, how they view the 'problem' of tube feeding, and appropriate interventions to solve the problem. To illustrate, a family may favour a *behavioural* approach to weaning because they consider their child's acceptance (or non-acceptance) of food or fluids as learned responses. Therefore, the parents may believe that these responses need to be modified using psychological strategies. Other families may emphasise the *medical* aspect of eating; therefore, using medications to stimulate appetite or interest in eating may be their preferred option. In contrast, a family may acknowledge that their child has limited acceptance of (or refuses) oral food and fluids because it has never been 'the norm' for them. Using a *child- and family-centred* framework, contextual changes such as adjustments within the environment, the family, and the parent–child relationship may feel more comfortable for those families. Two principle differences concerning behavioural, biomedical, and child- and family-centred approaches have been extracted from synthesising the literature analysed in the scoping review (see Chapter 4). These differences lie in (i) the timing of enteral feed reduction and (ii) the involvement of parents (Lively et al., 2021).

In the following paragraphs, the theoretical underpinnings regarding enteral feed reduction and parental involvement in weaning will be presented for each of the three approaches identified in the scoping research study (Lively et al., 2021; see Chapter 4). In addition, the potential benefits and disadvantages of each approach will be discussed. This is important because health professionals must clearly understand the choice of the therapeutic approach they are providing or recommending and how it is delivered. In addition to maintaining relevant and current knowledge of programs and outcomes, health professionals must be able to communicate this information to parents successfully. Parents are then better able to make an informed decision about tube weaning and participate as equal partners in the weaning team.

Theoretical Underpinning 1: Enteral Feed Calorie Reduction to Promote Hunger

International consensus indicates that during tube weaning, weight loss of up to 15% of the child's starting weight is accepted (Hartdorff et al., 2015), but more typically, a guide of up to 10% weight loss is used and recommended (Clouzeau et al., 2021; Dunitz-Scheer et al., 2009; Lively et al., 2019; Wilken et al., 2013). Weight loss while weaning should be considered in the context of the child's developing oral interest, mealtime behaviours and oral safety and motor skills. A review of the therapeutic process is required if, over the course of weaning, a child continues to lose weight without an improvement in their interest in engaging with food or their swallowing function.

The reduction of tube calories will be explored below in relation to *when* the calories may be reduced and the *amount* and *pace* at which they are decreased in the broad context of the three approaches to weaning.

Timing of Feed Reduction

As described in the research documented in Chapter 4, the role of hunger provocation varies between approaches. This is related to fundamental disparity about whether to a) teach a child the acceptance of and skills for eating and drinking first and then (once swallowing food/fluids) reduce their tube-feed volume; b) manipulate appetite through the use of medications or sensory stimulations; or c) reduce their tube-feed volume to facilitate intrinsic motivation to eat and drink, which is thought to reinforce the child's desire to perform this behaviour and subsequently improve their acceptance of and skills for oral eating and drinking (Gardiner et al., 2017). The timing for tube-feed reduction may influence a parent's decision regarding which approach resonates best for them and their child.

a) Behavioural Approaches to Tube Weaning

The theoretical principle underlying behavioural approaches refers to a child learning the oral and sensory skills for eating and swallowing before reducing caloric intake via the feeding tube. Two published behavioural tube-weaning programs manipulated tube volumes before commencing the program (Byars et al., 2003; Silverman et al., 2013); however, in general, tube volumes are only manipulated commensurate with the volume of oral intake once mealtime skills and ingestion of food or fluid occurs (Lively et al., 2019).

Teaching children the required motor skills to bite, chew, and swallow is considered the primary goal by those using a behavioural approach to tube weaning. These skills are fundamental for increasing the volume of food consumed orally and can be challenging to teach to a child who has yet to acquire them developmentally. Tangible rewards are usually offered in therapy activities to promote children's participation; for example, after chewing and swallowing five bites of a new food, a highly preferred toy may be given for 1 minute; however, the child may only undertake the request (e.g., take five bites or accept the spoon in their mouth) to receive the external reward. Non-behaviouralists would view this as rewarding external motivations rather than developing a child's internal motivation to eat (Trabi et al., 2010). In the context of a behavioural approach to weaning, these rewards are required to reinforce the desired behaviour and engage a child in a task they may not be personally motivated to engage in. This is important because it has been suggested that tube-dependent children may lack the personal motivation to consume foods and fluids orally because they do not feel hunger (Dunitz-Scheer & Scheer, 2022). In clinical practice, I have frequently likened this to *'being made to eat a roast dinner after finishing Christmas lunch and pudding*'. Therefore, for families undertaking behavioural feeding therapy, parents must be mindful that their child may feel full or even feel overfull, yet still be asked to bring food to their mouth and swallow it. This may reinforce for children that eating provides little personal enjoyment and may bring about an even more uncomfortable state.

For parents, behavioural approaches may reduce their anxiety regarding potential weight loss and their child's nutrition. Tube volumes are only reduced if the same number of calories has been consumed orally; therefore, a child's calorie and nutritional intake are minimally affected. This may relieve stress for the parents; however, it may place additional pressure on the child or create new avoidance strategies for an activity they may not be motivated to partake in or enjoy.

b) Biomedical Approaches to Tube Weaning

Specific medications have been trialled as the principal weaning strategy to stimulate appetite, with the outcome being that a hungry child will reach for food (Davis et al., 2016). In addition, weaning programs have utilised olfactory and oropharyngeal stimulation via a variety of sensations (touch, temperature, smell) to encourage oral interest (Munakata et al., 2008; Senez et al., 1996). Parents should be informed about how the medication is expected to affect appetite, the average length of treatment, indicators that the treatment is effective and side effects other than those on appetite. As with any medication, each person reacts differently, and the effects may be dose-dependent, requiring trial-and-error administration. With many unknown outcomes of this approach to weaning, it may be difficult for teams to provide parents with information on a clear therapeutic pathway.

Minimising weight loss during weaning is a priority for many parents (Cipolla et al., 2022; Lively et al., 2022). Therefore, understanding whether or how tube-feed volumes are reduced and within what expected timeframe is valuable for parental decision-making. A child's usual tube-feed volumes were maintained within biomedical approaches except for the olfactory program described by Munakata et al. (2008). In this program, if oral intake exceeded 100 g, the subsequent feed volume was adjusted by the amount consumed. No other decreases to tube-feeding volumes were reported by biomedical approaches, meaning that weight loss was likely to be minimised.

Limited to no evidence was found in any of the biomedical studies for their methods of eliminating tube dependency (Davis et al., 2016; Munakata et al., 2008; Senez et al., 1996); therefore, this approach may have limited scope of use for successful tube weaning.

Both behavioural and biomedical weaning approaches are designed such that 'something' or 'someone' 'does something' to the child with a subsequent response. These two approaches assume that learning to eat occurs because of an external influence—an adult encouraging oral intake by offering a favoured outcome (e.g., a toy to play with) or the interaction of a medication on a child's physiology. Therefore, oral eating and drinking are assumed to be out of the child's internal control. This is in stark contrast to the child- and family-centred approaches to tube weaning that will now be discussed.

c) Child- and Family-Centred Approaches to Tube Weaning

Child- and family-centred approaches are based on the premise that for a child to learn to eat, they must have internal motivation to do so. Children are supported to discover the value of oral food and fluids at their own pace by promoting their intrinsic drive (via tube-feed reduction) to bring food or fluids to their mouth. In doing so and reaping the *internal* rewards (e.g., feeling less hungry or thirsty, enjoying the taste), the child is more likely to repeat the behaviour and increase their oral intake. This follows the theoretical principle of operant conditioning in that rewarding a behaviour is more likely to increase that behaviour to be displayed again (Skinner, 1938). However, unlike traditional behaviour therapy, there is no external reward for a child choosing to eat. The reward remains intrinsic to the child and relates to their self-determined feelings of satiety, self-confidence, inclusion, and achievement (Deci & Ryan, 1985).

Internal motivation to eat is affected if the tube feeding volume is maintained at the usual amount. Health professionals calculate this amount to ensure optimal hydration and nutrition. However, a theoretical underpinning of child- and family-centred approaches is that calorie reduction is a critical process required at various stages before and during weaning to induce hunger (Lively et al., 2019). This can be daunting for many parents who may have spent months, or sometimes years, focusing on and helping their child to grow and gain weight (Cipolla et al., 2022; Lively et al., 2022). Parents may be emotionally challenged when knowingly providing fewer calories via the tube, yet not observing their child eating at least the same number of calories (Cipolla et al., 2022; Lively et al., 2022). For some, watching the scales decrease each day or seeing their child lethargic or emotional may add further stress and pressure to the mealtime environment (Lively et al., 2022).

Observing and reflecting on the child's behaviours and responses to tube-feed volume reduction provides an indication to the team regarding the suitability of the pace of tube-feed reduction. This information can be obtained by monitoring the child's energy levels, lethargy, self-engagement at meals, and urine and bowel output (Pollow et al., 2018). During weaning, these clinical and behavioural indicators may differ from the child's typical presentation, so parents may need additional support from the team through this phase to contextualise these observations. Reinforcing the underlying philosophy of inducing hunger may refocus them on the overarching goal of facilitating their child's trust and engagement with food to increase their oral intake. As the parents reported in Cipolla et al.'s (2022) study, supporting them in managing their worries and anxiety allowed them to continue with the weaning program. Similarly, the parents interviewed as part of Research Project 3 (see Chapter 9) indicated that the guidance they received from therapists during weaning to facilitate an emotionally supportive mealtime allowed their children to experience self-initiated and enjoyable food interactions and increased oral intake (Lively et al., 2022).

The benefits of reducing tube-feed volumes have been well documented and, in conjunction with psychological and sensorimotor intervention, now form a recommendation as best practice for tube-weaning *some* children. Further research is required to understand 'which' children this relates to (Clouzeau et al., 2021). However, the clinical recommendation guideline does not indicate the *optimal* time when tube-feed volumes should be reduced. The fundamentally different theoretical foundations of weaning approaches influence the timing of when tube-feed volumes are reduced. This information can be communicated and discussed with parents in conjunction with understanding how quickly and how much tube-feed volume will be reduced as part of their informed decision-making.

Pace and Volume of Tube-Feed Reduction

A position paper on best practices for weaning published in 2021 indicated that during day-to-day meals, providing excessive calories via tube feeding should be avoided to encourage spontaneous oral intake (Clouzeau et al., 2021). In addition to when tube-feed volumes are reduced, programs vary regarding the volume and pace (i.e., rapid or slow) at which feed is reduced. Rapid tube-feed reduction refers to reducing tube volumes by ≥ 40% of the child's initial nutritional volume within three days (Dunitz-Scheer et al., 2011). The effect on weight must be considered when assessing the amount and rate at which feed is decreased. The pace and volume of tube-feed reduction is discussed below in reference to the three identified weaning approaches.

a) Behavioural Approaches to Tube Weaning

In general, behavioural approaches to learning to eat reduce the feed volume at a pace and volume determined by the number of calories consumed orally by the child. Food and fluid volume is weighed pre- and post-meal, and the number of calories consumed is calculated. This number of calories is deducted from the next scheduled tube feed (see Chapter 2 and summary in Lively et al., 2021). In this way, the child leads the pace and volume of feed reduction. This can prove successful if the child swallows food and fluids, but it may appear counterproductive if the child has limited or no oral intake.

However, two published behavioural programs reduced tube-feed volume before admission. In one of these programs, a 50% feed volume reduction occurred prior to admission, with subsequent reductions during the program (5–16 days, average 11.4 days) commensurate with oral intake (Byars et al., 2003). An approach by Silverman et al.'s (2013) team ceased tube feeding at admission and subsequently introduced fluid or formula supplementation if medical parameters indicated it was required.

Notwithstanding these two examples, behavioural approaches generally afford limited fluctuations in weight because any volume reduced from tube feeding is matched by previous oral consumption. As discussed with the timing of tube-feed reduction, the pace and volume at which tube feeds are reduced during behavioural approaches may reduce parental concern and anxiety regarding weight loss and energy levels.

b) Biomedical Approaches to Tube Weaning

Biomedical approaches mostly maintain the enteral feed volume, as indicated in the timing of enteral feed reduction; therefore, the pace at which tube amounts are reduced is negligible. In the only biomedical study that reduced feed volumes, the pace and volume were determined by the quantity consumed orally by the child (Shine et al., 2018). Therefore, as per behavioural approaches, the amount and speed at which tube volumes may be reduced are reliant on the child ingesting food or fluids. In turn, variability in weight remains limited. In contrast, this may not be the case with child- and family-centred approaches, which actively reduce tube-feed volumes to promote oral interest and ingestion.

c) Child- and Family-Centred Approaches to Tube Weaning

Self-determination is one of the theories underpinning child- and family-centred approaches. As discussed in Chapter 2, SDT states that internal motivation drives changes in behaviour. Therefore, it is central to child- and family-centred weaning programs that hunger—one of the pertinent internal motivators to eat—is facilitated to drive changes in eating and drinking behaviours.

Gardiner et al. (2017) compared the pace at which hunger induction occurred across eight international tube-weaning teams. Using the above definition of rapid tube-feed reduction, 50% of the teams interviewed aligned with rapidly reducing enteral calories to promote eating. For example, the three-week inpatient weaning program described by Brown et al. (2014) commenced, on average, with a 73% reduction in typical tube-feed volumes on Day 1 and subsequent reductions over the remaining three weeks of therapy. Those participating in the weaning program audited in Chapter 7 underwent a gradual reduction to 40% of their typical daily calories three days before admission. Again, the continued reduction of calories proceeded in line with medical indicators (weight loss, blood glucose levels, hydration, and constipation) and mealtime skill acquisition (Lively et al., 2019).

In contrast to Silverman's behavioural approach described above, child- and family-centred approaches do not entirely cease tube input until the child demonstrates adequate oral skill and intake to maintain their growth without further weight loss. This supports the child's energy and concentration requirements when learning a new skill and reduces large fluctuations in medical parameters such as blood glucose levels and hydration (Kindermann et al., 2008; Lively et al., 2019; Pollow et al., 2018).

It is important to remain cognisant that children commencing weaning with a higher BMI are more likely to take longer to wean; therefore, they may require a more significant drop in enteral volumes before oral intake improves (Trabi et al., 2010). This is likely due to two reasons. First, overfeeding via a tube may occur because the child cannot respond and regulate their appetite; instead, they are fed a set number of calories per day. These children need to burn more body energy stores before they feel hungry. Second, in this specific study, children with a higher BMI relied on enteral feeding for a more extended period; therefore, they may be considered to have a greater level of tube dependency than younger children (Trabi et al., 2010).

One aspect of the weaning program design that parents often require explicit information about is how the number of calories provided by tube feeding is adjusted. This incorporates knowledge transfer from therapists regarding the timing, pace, and volume of tube-feed reduction. In addition, known risks and benefits of weight loss that may occur in conjunction with feed reduction should be presented. Clearly communicated pathways for tube-feed calorie reduction will allow families to make an informed decision that aligns with their values, comfort levels, and suitability for their child and family.

Theoretical Underpinning 2: Involvement of Parents/Carers in Tube Weaning

As mentioned above, the second distinct difference between weaning program philosophies is the role of the parent throughout therapy. Many lifesaving interventions are recommended and provided by medical teams. However, as reflected by some parents who participated in the child- and family-centred tube-weaning program presented in Chapter 9, '*tube weaning is the first thing I had to undertake myself*' (Lively et al., 2022). Therefore, prior to commencing any program, parents must understand their role and the expectations placed upon them by different weaning approaches while respecting their role as key team members who may also require therapeutic support. This is another example of the tension that may be experienced between team members, as discussed in Principle 2.

The theories underlying a child's learning, the engagement of parents, and the benefits and drawbacks of the parent role are discussed in the next section for the three approaches to weaning identified in Chapter 4.

(a) Behavioural Approaches to Tube Weaning

Behavioural models of tube weaning incorporate the principles of child learning described in Chapter 2 (p. 81). Behavioural models assume that the child acquires new skills through manipulation of the environment surrounding them to elicit a desired response. In the context of learning to eat and drink, the child's natural responses are shaped and altered to the desired response through adult feedback and reaction. The child learns to respond expectedly (e.g., accept the spoon into their mouth or not spit out the food) because of the consequence that will result if they respond alternatively (e.g., the adult will look away from them for a set amount of time or remove a favourite toy). As per this example, a family who views their child's food refusal as 'behavioural' may feel more comfortable with an external therapist teaching their child new behaviours at mealtimes. This may reflect that their attempts are not making lasting changes to their child's food or fluid acceptance. These parents may have low confidence, energy, or threshold for managing their child's behaviour. They may feel an 'expert' is better able to teach their child, or they may hold concerns about setting boundaries and providing undesirable consequences for fear of upsetting a potentially delicate parent–child relationship.

Behavioural-based tube-weaning programs initially remove the parents from the learning environment to teach the child adaptive food interaction behaviours (Blackman & Nelson, 1985). This may be counterproductive for children with a secure or insecure ambivalent attachment (as described in Chapter 2, p. 91) because they find separation from their trusted caregiver distressing (Bowlby, 1978; Main & Western, 1982). In a state of distress, these children are less likely to acquire new mealtime skills (Hong & Park, 2012).

Consideration should also be given to children who display an insecure avoidant or disorganised attachment with their primary caregivers. This cohort may show little awareness when separated from their carer and may place their energy into what is occurring within their environment (i.e., an attentive therapist) as a strategy to suppress their feelings of rejection by their less-responsive parents (Bosmans et al., 2020). As such, they may flourish in the company and teaching of another person who fills the emotional void left by their parent and whom they come to trust; however, this has implications for the sustainability of new mealtime skills when their parents are reintroduced to the environment.

In addition to *who* is providing the teaching, the question of *where* the teaching is provided is of relevance to behavioural therapy programs. New eating skills and behaviours may only remain evident within the conditioning environment they are reinforced in, because behavioural theory teaches learned responses to set situations rather than adaptive thinking and responses (Levine & Munsch, 2014). This includes the transferability of these skills, dependent on the adults in the learning environment and the conditioned prompts or circumstances required to elicit the expected response. Low birth-weight infants (i.e., due to prematurity) frequently require enteral tube feeding, and studies have shown that 50–70% of low birth-weight infants experience, among other complications, learning difficulties and behaviour challenges (Aylward, 2003). Children with learning difficulties often require consistency and precision to complete activities. Minor alterations to the feeding cues they have been taught (e.g., a different person, use of intonation, or substituting words) may lead to them misunderstanding the expectation and not being successful at eating independently (Adams et al., 2020). Some examples in the context of a tube-fed child learning to eat include a child who is hungry but has learned that an adult must place a spoon in their mouth rather than self-initiating picking up the food and feeding themselves, or a child who feels satiated but has been taught to '*have five more bites*'; therefore, their natural hunger cues and appetite are overruled. Each time appetite sensory cues are overridden (i.e., interoception as discussed in Chapter 2), the child's experience that '*it doesn't matter how you feel, keep eating*' is reinforced (Schmitt & Schoen, 2022).

When considering interventions for undesired or maladaptive mealtime behaviours, it is essential to acknowledge the foundation of these responses. For example, a child who is unable to tolerate the sensation of wet, sticky textures on their hands is unlikely to want to use their fingers to self-feed repeatedly. Reactions to messy hands may result in a 'fight-or-flight' response, fearing the danger of this sensation, and becoming upset and emotionally dysregulated, with subsequent avoidance. In turn, the parent may become hypervigilant about cleaning up spills, feeding their child with a spoon, or removing the texture from the child's vicinity to avoid repeated distress. What commenced as a physiological response to sensory input subsequently resulted in environmental and situational adaptations from the child and the parent to prevent this perceived negative experience from being repeated. This avoidant behaviour is not reflective of a child being naughty; rather, in line with behavioural learning theory, it is the child's survival strategy when placed in this situation. In this instance, removing a child from their parent and placing them with an unfamiliar adult in a feeding therapy situation that likely involves touching and interacting with food may exacerbate their inhibitive response behaviours.

(b) Biomedical Approaches to Tube Weaning

Biomedical approaches refer to a child receiving a specific treatment in a prescribed manner, such as the administration of appetite-stimulating medication, sensory stimulation, or a direct reduction in tube-feed volumes with no additional behavioural or psychosocial influences (Lively et al., 2020). Biomedical approaches often require the parent to act as a medication or feed volume administration facilitator. Tube weaning may appear as another medical intervention to implement, and one into which they have limited control or input for parents who manage and administer their child's daily medical care. This approach does not view the environment surrounding the child (e.g., significant adults, social observations, teachers) as necessary for the acquisition of developmental skills (e.g., eating and drinking) and therefore does not align with any theories of child development, attachment, or learning.

Many tube-fed children experience complex gastrointestinal difficulties such as necrotising enterocolitis, food intolerances or allergies, gastrointestinal reflux, constipation, or nutrient malabsorption (Patel, 2016). Some parents may align with a medical intervention to teach their child to eat as a continuum of the pharmaceutical intervention they provide their child, and as an attempt to afford their child a seemingly optimal physiological opportunity.

(c) Child- and Family-Centred Approaches to Tube Weaning

Child- and family-centred approaches to tube-weaning align closely with many theories of child development, including Bandura's (1977) SCT, Bronfenbrenner's (1977) Ecological System Theory, Bowlby's (1978) Attachment Theory, SDT (Deci & Ryan, 1985), and aspects of Ayres' (1964) Sensory Integration Theory. These theories recognise the influence of the broader environment that encompasses a child and affects their learning. Parents are an integral part of weaning programs that use a family-based approach. As described in Chapters 4 and 7, therapists work with parents to co-construct knowledge about how to facilitate mealtime skill development within their child. During weaning, this may prove challenging for those with an insecure avoidant, ambivalent, or disorganised attachment with their child. Children who experience these relationships may present as distant, rejecting, and hypervigilant. This may become problematic for a child and their parents when participating in a structured weaning program because they encounter sensory-stimulating mealtimes that include sights, odours, and sounds of food and people conversing. The child is likely hungry and frustrated because they have not yet determined that eating or drinking will assist them. They may lack energy as a result of reduced calorie intake, making it more difficult to persist. The parents may be physically exhausted and emotionally fragile. When their child rejects their attempts to help and support, they may feel equally dejected and dissociate from the learning goals and strategies.

Unlike Bowlby's work on attachment as described in Chapter 2, which focused solely on the mother's attachment to their baby, the parent reflection research presented in Chapter 9 considers the relationships a child has with both parents, because each may play an important and specific role in their upbringing. As evidenced by the research presented in Chapter 9, mothers and fathers participated in the audited tube-weaning program, bringing their coping strategies, concerns, interpretation of past experiences, strengths, and optimism. In fact, some parents reported that it was the support of their partner that gave them the strength to continue with the weaning program; however, Bowlby's (1978) original Attachment Theory focused solely on the mother and her responsibility for forming attachments. It may be more helpful to consider a learning theory of attachment whereby behaviours are considered in the context of the effect of neurobiological and endocrinological processes on children's experiences of responsive care (Bosmans, Bakermans-Kranenburg, Vervliet, Verhees & van Ijzendoorn, 2020). Rather than focusing on maternal responses to their child as the only pathway for emotional and behaviour development, the learning theory of attachment considers the child's learned reactions to positive and negative reinforcement by any of their caregivers in situations of distress (Bosmans et al., 2020). In this way, particularly regarding learning to eat, a health professional can coach a parent (mother or father) on how to consistently respond to their child crying, throwing food, or wanting to leave the table. Each parent may have different comfort levels with boundary setting and behavioural management, which can be confusing for a child faced with a challenging situation (i.e., a hungry tube-fed child learning to eat and drink). With consistent guidance by parents to support their child to regulate in this challenging environment, the child's behaviour will be gradually shaped to a more functional response that, in time, will become the child's usual behaviour.

Summary of Theoretical Underpinnings 1 & 2

During program development, critical thinking and an understanding of the differences in theories of development and learning (for both children and adults) are required. In addition, the team's stance on hunger provocation and parents' understanding of their child's growth and contribution to potential weight loss can play a crucial role in the outcome for some children. Health professionals working with families must understand these principles to explain the program's rationale clearly and confidently to parents. Using the evidence-based practice (EBP) framework provided by Dollaghan (2007), parents can be supported to make informed decisions through (i) health professionals disseminating the best external research and the best practice evidence, (ii) understanding the clinical experience offered by the health professional, and (iii) reflecting on their own preferences and beliefs (Dollaghan, 2007). Dollaghan's EBP framework requires health professionals to remain updated with current research data and be able to (i) interpret this knowledge for other team members and families within their clinical expertise and boundaries, and (ii) transfer this knowledge in a meaningful way to team members and parents. The next section further explores how the interpretation and transfer of knowledge from health professionals to parents best occurs to augment parents' understanding of how the design of weaning programs may affect weaning outcomes.

Using an Evidence-Based Practice Framework for Information Sharing Between Health Professionals and Parents

For health professionals to provide accurate and current knowledge to parents, they must be able to interpret and incorporate published research outcomes with their clinical experience and translate this meaningfully into clinical practice (Dollaghan, 2007). This requires an understanding of the interplay between the clinical research outcomes and the financial and organisational contexts of each workplace (Ward, Smith, Foy, House & Hamer, 2010). The ability to translate EBP requires each professional to interpret and implement research based on their prior experience and knowledge and their belief in their own skill set and proficiency. This can only be enacted within the constraints and capacity of their workplace (Wilkinson, Hough & Hinchliffe, 2016).

Using the framework of Social Constructivism (discussed in Principle 1) and EBP principles, professionals interpret new information and knowledge in the context of their existing clinical knowledge and build upon this in a manner that is meaningful to them (Bada, 2015; Dollaghan, 2007). As a result, they become a dynamic constructor of their knowledge rather than rote learners and implementors of research outcomes (Hutchinson & Huberman, 1994). Health professionals can determine best practice in engaging a child and family in tube-weaning by integrating evidence with knowledge developed through clinical practice. Parents are equal team members with prior knowledge and experience of their child to contribute. Both parents and health professionals can communicate their knowledge and information to co-construct personal knowledge with each individual family. The third principle of EBP relates to respecting the family's preferences and values. Providing clear information regarding the theoretical reasoning for the approach that a weaning team takes will allow families to construct their knowledge regarding tube weaning. Following this, the health professionals and parents may co-construct a weaning program tailored to the individual needs of the child and family.

Although health professionals remain the primary source of information to parents (NHS Quality Improvement Scotland, 2007), many health professionals are not familiar with the timing, process, or expected outcomes of tube weaning (Syrmis et al., 2020). Health professionals must be able to integrate the most up-to-date external and internal research findings with their clinical expertise and the setting within which the therapy will take place (Dollaghan, 2007; Mayer, 2010), in addition to relying on the intuition and learnings of more experienced colleagues (Turner, 2014). These details are then incorporated with information from clinical interactions with the child and family and discussions regarding their preferences for the team to remain informed of realistic therapeutic pathways (Dollaghan, 2007). It could be considered unethical for health professionals to act in a patient's best interests if the patient is unaware of what their best interests are (Kaldjian, Weir & Duffy, 2005), and this does not facilitate an inclusive team approach. However, it remains impossible to provide evidence from research for the infinite clinical and client presentations of any unique family unit. Therefore, research outcomes must be interpreted and integrated into clinical practice with a degree of justifiable extrapolation (Walker & Bukhari, 2018).

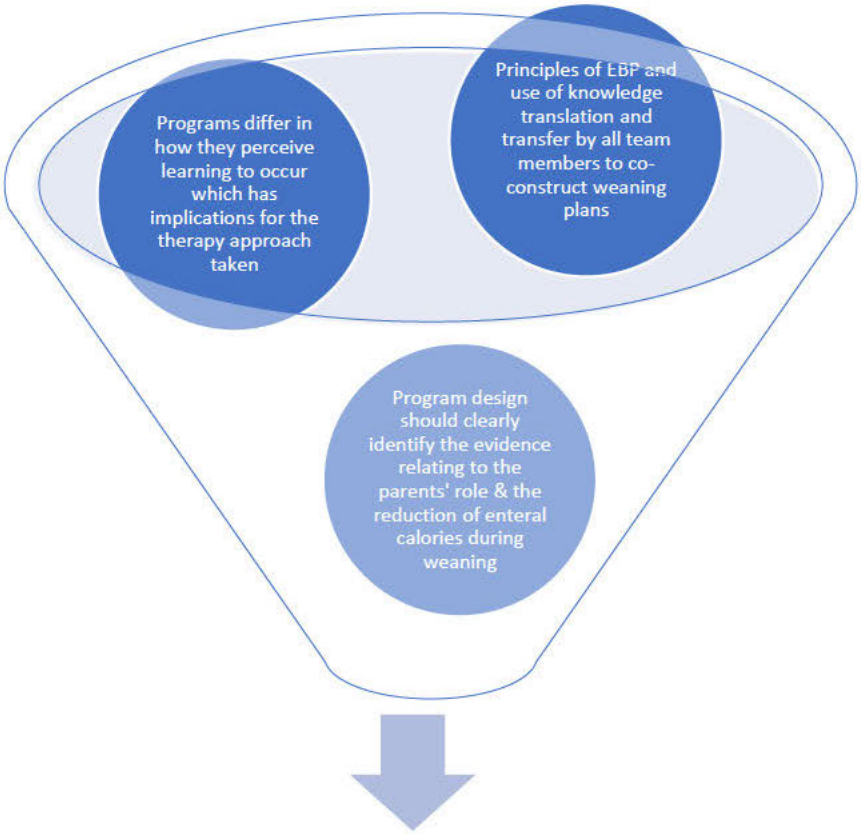
Knowledge transfer to facilitate informed decision-making may be supported by communication aids in various forms to augment verbal information. This can include podcasts, booklets, handouts, short videos, and illustrative graphics (Dollaghan, 2007). Providing material in various formats and languages can support parents' understanding and interpretation when acute stress, anxiety, exhaustion, and possible depression may impede their ability to reason about goal-directed rather than habit-based decisions (Porcelli & Delgado, 2017).

For tube weaning to noticeably improve a child's oral eating and drinking ability, the team must consider the research available on best practices for tube weaning, their clinical knowledge, competence, and confidence. In addition, consideration must be given to practical ways of incorporating this information into a therapy program based on the health professionals' workplace's financial, organisational, and practical constraints. Future research may focus on exploring the weaning outcomes of implementing one set of recommended best practice guidelines that are based on literature reviews and expert consensus (Clouzeau et al., 2021). If compared with previously documented weaning outcomes, new data from future research may contribute to a set of research-based best practice guidelines for tube weaning.

Furthermore, health professionals must consider the family's ability to take the information disseminated by the team and use this evidence within the constraints of their home life. Each family member brings their circumstances and knowledge to the child's therapy program and acts as an extension of the evidence-based knowledge imparted by the health professionals. Variability exists from one child and family to the next depending on how each family member interprets the information and their capacity to implement the suggested or agreed strategies. This highlights the importance of working to a person's strengths and increasing their confidence and capacity at their level. This may be achieved by using the ideologies of strength-based learning (bottom–up approach) (described in Principle 2) rather than instructing from the 'top–down' and expecting parents to understand and undertake tasks outside their skill set.

Figure 37 illustrates the key considerations for a weaning program design, which may influence a parent's decision-making. Clinical and future research directions are also suggested.

Weaning programs should be thoughtfully designed with their theoretical underpinnings clearly communicated



CLINICAL RECOMMENDATIONS

- A variety of printed, visual, and auditory resources should be used to present information regarding the many stages of tube feeding and tube weaning to parents.
- Therapists should maintain current knowledge of the philosophies and research underlying therapy approaches both within their service delivery and external weaning options.
- Therapists should remain cognisant of clinical experience within their team, organisational constraints, and integrating this with parents' preferences and requirements.

FUTURE RESEARCH RECOMMENDATIONS

- Future studies may explore how tube-weaning programs incorporate recently published clinical tube-weaning guidelines and recommendations into their practice. This will allow identification of the effects of these guidelines on children's and parents' experiences and weaning success.
- A pilot program incorporating the tube-feeding and weaning principles as proposed by Clouzeau et al. (2021) could be developed. Program design should incorporate the recommended guidelines, including the principles outlined in this thesis, and should involve a scaffolded evaluation framework of the implementation process as well as weaning outcomes.

Figure 37: Key considerations and clinical and research recommendations from Principle 5

Integrating the Theoretical Foundations of the Proposed Principles with How a Tube-Fed Child Learns to Eat

This section explores how strategies for health behaviour change, coupled with the principles of constructivist theory, EBP, and a strength-based growth mindset approach, can form a proposed model of care for tube weaning.

Tube weaning involves multiple layers of all team members iteratively co-constructing learning, which may occur between any combination of health professional and health professional; health professional and child; health professional and parent; parent and parent; or parent and child. At any given time, this learning occurs at a pace and extent that each participant is comfortable with.

In feeding therapy and teaching a tube-fed child to eat, the 'client' becomes the child who may be learning to eat *and* the parents who support that child's learning. As discussed in Principles 1 and 2 (p. 204-213), the shifting dynamic between the parents at times being the client, while also being active team members, highlights the tension that may result as this balance is negotiated. This thesis has described different methods by which learning to eat may occur, incorporating the child on their own (behavioural approaches), external interventions such as medications (biomedical approaches), or both the child and their family (child- and family-centred approaches). To explain the rationales behind these different methods, the ideas presented in this thesis have drawn upon many theories of learning and development. In bringing together these theories, I propose that the behaviour change required to teach tube-fed children to eat may best be undertaken by incorporating the philosophies of constructivism, self-determination, ecological systems and EBP. These philosophies each give leverage to the participation and abilities of the child, the parent, and the health professional in a multidirectional manner, as depicted in Figure 38. The circular representation depicts the fluid interplay between theories of learning that complement and complete each other while focusing on the person they relate to (i.e., the child).

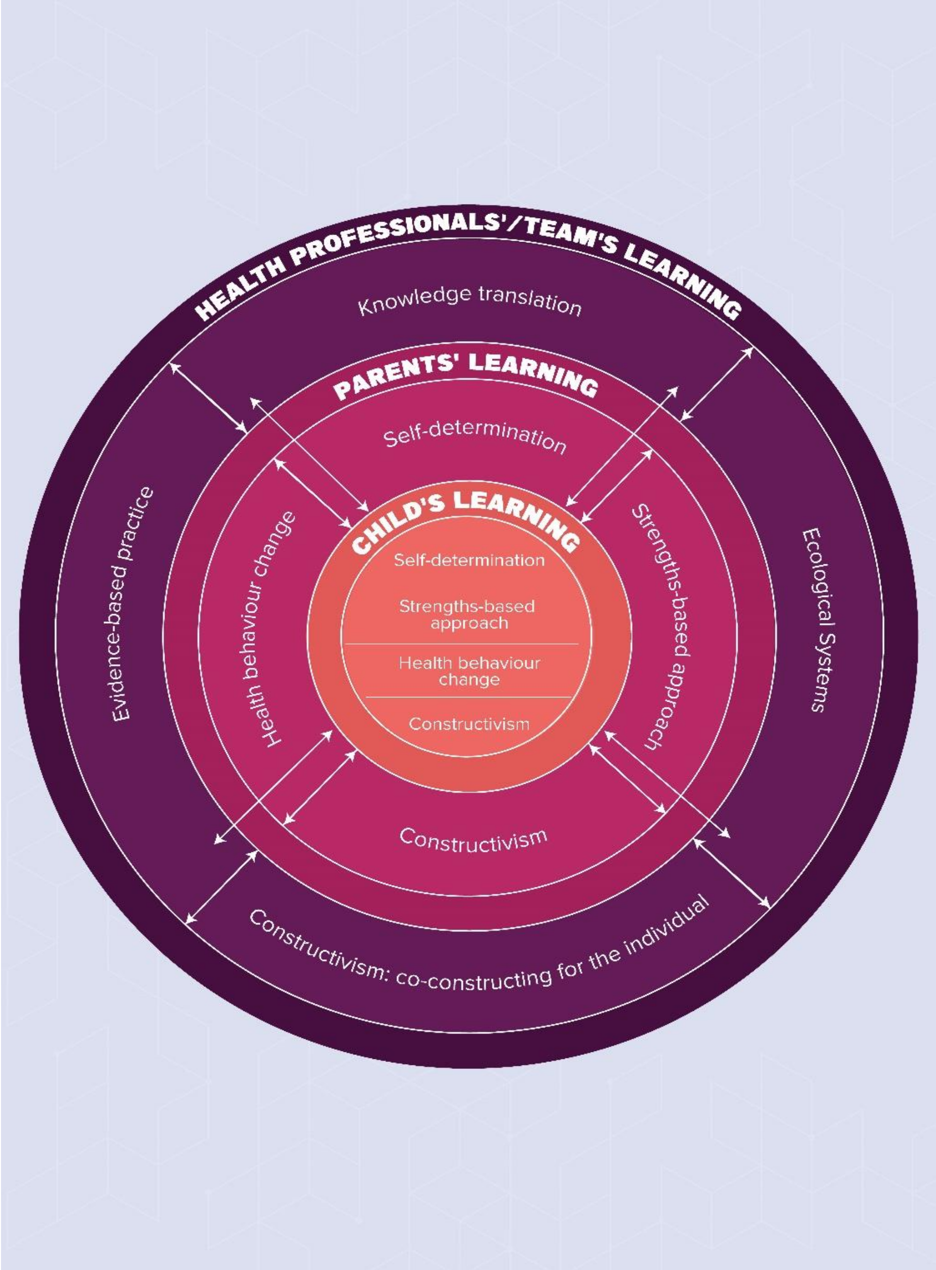


Figure 38: Interactions between the multiple theories influencing the participants of tube weaning

In this way, the curiosity and self-directed exploration of the child and the parent involved in mealtimes become the drivers of the learning for that dyad or family. The goal of seeking an oral alternative to tube feeding places families who seek tube-weaning options into a cohort of self-initiating and self-determined people who are keen for behaviour change and maintenance of this change. Using the previously described child- and family-based weaning models, the child and the parents are direct participants in mealtimes and therefore immersed in the 'hands-on' environment promoted by the strategies derived from applying the principles of Constructivism Theory. The health professional's role is to facilitate the environment to allow learning to occur rather than taking a 'therapist' role (i.e., one of a traditional teacher). In addition, the health professional provides feedback to both the child and the parent, specifically to promote ongoing change and experimentation. For example, at the end of a meal, the therapist may offer to a child, '*your tummy says, "thank you for filling me with food, now I have energy"'* or '*your lips were very dry, and then you had a drink and made them wet again—you fixed them all by yourself*'. This verbal feedback offers specific, targeted information about the cause and effect of their new eating behaviours and creates desirableassociations for the child rather than a generic phrase of '*good eating*'. It offers the child the opportunity to process this information, take meaning from it themselves, and then apply this knowledge in a subsequent setting. Upon self-initiated application of this feedback, the child's self-determination to strive for competence and autonomy places them in the position to internalise and integrate their new learning into future situations (Ryan et al., 2008).

Likewise, engaging parents in a reciprocal feedback conversation regarding their interactions at mealtimes can promote collaborative identification of what is and is not working, and problem-solve strategies to address the ongoing challenges. Using reciprocal feedback opportunities makes it clear to parents that they can be equal team members, and concurrently these same feedback interactions should be facilitated between all team members. To illustrate how this may be implemented during tube weaning, I will use the example of a parent who frequently asks their child, '*would you like some peas?*' during dinner. Using traditional teaching methods, the therapist may interject with '*don't ask your child if they would like peas*', to which it is hoped the parent will stop this behaviour. A constructivist would allow the moment to pass and, at the end of the meal, ask the parents to reflect on '*what happens each time you ask your child if they would like some peas to eat*'. The parent may reply '*they say "no"*', to which the therapist has facilitated the parent realising that asking a question relating to trying the food is likely to result in a clear '*no*' response from their child. Using EBP principles, the health professional may facilitate parents identifying that their pattern of repeatedly asking their child to do something they dislike or find difficult is likely to result in automatic refusal. Instead, team members could collaboratively problem-solve alternative ways to manage the situation with the knowledge that children are more likely to strive for autonomy by exploring and attempting an opportunity themselves when indirect modelling, rather than direct pressure, is given (Deci & Ryan, 1985). In the example above, placing peas on everyone's plate with a nonchalant '*peas for mum,* *peas for dad, some for Jonny and some for you*' gives the child the opportunity for autonomy and self-learning based on their observing of the modelling occurring around them (e.g., everyone else eating their peas). Parents can observe firsthand the response of their child and further consolidate their learnings on ways to facilitate mealtime success when provided with opportunities at subsequent mealtimes to incorporate this feedback and share their learnings as a team member to facilitate collaborative goal setting and strategising.

In addition to change within the child and their parents, meaningful learning co-occurs among the other team members. If all team members contribute their values, capacity, past experiences, and prior knowledge, relevant and achievable therapy goals can be co-constructed.

However, these goals and associated strategies may need further interpretation and adaptation based on the child's and parents' capacity to implement them. The health professionals, in part, can be flexible and creative around their knowledge and the family's capacity, keeping the end goal in sight to further promote and facilitate opportunities and development for the parents and child.

The reflective exercise presented at the start of Chapter 1 described how a child's internal conflict and dialogue may play out when deciding whether it is worth the effort to '*take a bite*' or continue with the trusted and familiar tube feed. Taking a bite involves so much more than appears on the surface. This chapter has presented clinical and research considerations to support the physiological, psychological, and psychosocial aspects for the child and the parents of '*taking a bite*'. The team's influence on being part of the next step of oral intake has been highlighted and, per the parents' feedback in Chapter 9, contributes significantly to success.

CHAPTER 12: CONCLUSIONS

The underlying questions that motivated this research were '*How are different teams weaning children?*', '*Can clinical indicators be used to predict weaning outcomes?*' and '*How can we better support parents through the tube feeding and weaning experience?*' Three research studies were developed to address these questions, encompassing a scoping review of the current literature (see Chapter 4), a quantitative retrospective case note audit (see Chapter 7), and a qualitative-designed parent interview (see Chapter 9).

The cumulative outcomes of this research reinforce that weaning is not a linear process whereby cessation of tube feeding results in successful eating and drinking. The synthesis of the findings presented in this thesis contributes to providing parents with an understanding of the basis upon which tube-weaning programs may be designed. With increased access to tube feeding and weaning information via the internet and social media support groups, parents are more empowered to ask questions and understand the best approach for their child and family. The chapters presented in this thesis offer clarity for parents on the difference between weaning approaches and the factors that may influence weaning success and therefore contribute to their decision-making.

Health professionals and healthcare teams may use these research findings to reflect on their knowledge and understanding of the theoretical basis of the therapy they provide. Clinical practice may be improved by teams integrating current research regarding learning theory, models of weaning, and knowledge of the contributors to feeding tube dependency. In addition, developing health professionals' clinical and theoretical knowledge of tube weaning can, in turn, support clearer information and knowledge transfer to better inform parents. Effective integration of parents as equal team members and attention to team functioning that enhances practice will also contribute to the weaning experience.

This thesis contributes to parents' and professionals' understanding of the physiological factors that can contribute to weaning outcomes. With this knowledge, parents and professionals can be better equipped in the decision-making process by giving children the opportunity to learn to eat and drink. Historically, empirical data (e.g., BMI) have been used as an indicator for attempting weaning, inhibiting some children's opportunity to wean. Parents have reported that medical teams are reluctant to suggest weaning because of factors such as their child's inability to eat or drink '*enough*' or they do not yet weigh '*enough*'. Greater awareness among families and healthcare teams regarding the relative effect of these variables on a child's capacity to learn to eat and drink may enable more children to access weaning programs. This may be possible once information regarding influencing variables and some of the principles developed in this research program have been incorporated into clinical practice and evaluated.

The synthesis of this research culminated in developing five proposed principles by which healthcare teams can improve the tube-feeding and tube-weaning experience for the child and their family. These principles were generated from data gathered through interviews with parents about their firsthand tube-feeding and weaning experiences. The aim of exploring and analysing their lived experience and feedback was to contribute thoughtful, practical, and relevant recommendations to all those involved in enteral tube feeding and weaning.

Tube feeding is lifesaving. Although parents may experience '*secondary*' tube dependence, many parents come to '*hate*' the tube that saved their child's life because of the unforeseen challenges they subsequently endure. The journey from tube to oral eating can be slow, and many detours may be needed along the way as a result of medical, developmental, and emotional barriers from the child and the parents. As this research has demonstrated, the knowledge, experience, and compassion of health professionals on the team also influence weaning outcomes. '*Taking a bite*' is much more complex than first thought. While placing and removing a feeding tube is a medical procedure, the step in the middle—learning to eat—is not. Multiple factors may influence a child's ability to move from tube to oral feeding, and some of these were explored throughout the three research projects presented in this thesis. Factors include the approach to tube weaning, innate biological and physiological components, and the capacity of parents to fulfil their role during weaning. These considerations have been amalgamated into a proposed model of care for health professionals working with tube feeding and weaning. The model of care includes strategies derived from the principles developed from the objective and qualitative research findings, and they draw upon many theories and EBP.

The extent to which children and families can manage the transition from tube to oral eating and drinking safely and physically differs from child to child and from family to family. The weaning journey varies substantially between children depending on the weaning program undertaken, the experience of the health professionals involved, the child's biological makeup, and the parents' capacity. This research has contributed five fundamental clinical tube-weaning principles that encompass considerations from the above-identified points of variability to allow all families to be supported in developing functional and enjoyable mealtimes, no matter what their journey has been.

EPILOGUE

In 2015, I initiated a personal clinical improvement project with the Flinders University Department of Speech Pathology to audit and present my clinical tube weaning work. This stemmed from a desire to critically appraise and improve my clinical practice and provide parents and health professionals with objective research-based information and options regarding tube weaning. The need for robust research data for Australian weaning programs is lacking but is important given families have access to weaning options world-wide.

Eight years and 90,000 words later, I have delved deep into the literature, theories and practices of international tube weaning and presented these to national and international audiences. At the commencement of the project, I was unaware of each family's breadth of experiences with their healthcare teams and how this shaped their hopes, beliefs, and desires for their child's future achievements.

The personal impact of completing this study is reflected in my day-to-day interactions with families and the dissemination of research information to the clinical team I have the pleasure of working with. My colleagues have valued regular updates on current evidence-based research related to their clinical area of enteral feeding or weaning. This has enabled them (and me) to develop and enhance the clinical recommendations we make to the clients in our practice.

I now use the research outcomes more readily as an educative tool with external professionals who may have concerns or differing views on and experience with weaning. This brings confidence and a solid EBP framework to our therapeutic practice. Anecdotally, families have reported increased confidence in having research data available when considering therapy options. Their decisions are further supported by a clearer understanding of therapy goals and the process for achieving them.

I am proud to have contributed a new set of research-based clinical practice recommendations which reflect the challenges of learning to eat and drink from the tube-fed child and parents' perspective, to support best practice tube weaning.

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APPENDICES

Appendix 1:

SEARCH ENGINE/DATABASE	List of Search Terms Used
Medline	1. enteral nutrition/ or Intubation, Gastrointestinal/ or gastrostomy/ or jejunostomy/; 2. (feeding tube* or enteral feeding or enteral nutrition).tw; 3. (gastrostomy or nasoenteral or gastrointestinal intubation or gavage or jejunostomy or nasogastric).tw.; 4. 1 or 2 or 3 5. infant, newborn/ or child/ or infant/; 6. (baby or babies or child* or p?ediatric* or infant* or newborn* or preschool* or toddler*).tw.; 7. 5 or 6 8. (wean* or discontin* or cessation or ceas*).tw. 9. 4 and 7 and 8
CINHAL	S1 (MH "Enteral Nutrition") OR (MH "Feeding Tubes") S2 (MH "Intubation, Gastrointestinal") S3 (MH "Gastrostomy") OR (MH "Gastrostomy Tubes") OR (MH "Gastrojejunostomy Tubes") S4 gastrostomy OR nasoenteral OR jejunostomy OR nasogastric S5 "feeding tube" OR "enteral feeding" OR "tube weaning" OR "enteral nutrition" S1 OR S2 OR S3 OR S4 OR S5 S7 (MH "infant, newborn") OR (MH "infant") OR (MH "child") S8 baby or babies or child* or p#ediatric* or infant* or newborn* S9 S7 OR S8 S10 wean* or discontin* or cessation S11 S6 AND S9 AND S10
Scopus	("feeding tube*" OR "enteral feeding" OR "enteral nutrition" OR "gastrostomy OR nasoenteral OR "gastrointestinal intubation" OR gavage OR jejunostomy OR nasogastric) AND (baby OR babies OR child* OR p?ediatric* OR infant* OR newborn* OR preschool* OR toddler* OR neonat*)
Web of Science	("feeding tube*" OR "enteral feeding" OR "enteral nutrition" OR gastrostomy OR nasoenteral OR "gastrointestinal intubation" OR gavage OR jejunostomy OR nasogastric) AND (baby OR babies OR child* OR p?ediatric* OR infant* OR newborn* OR preschool* OR toddler* OR neonat*) AND (wean* or discontin* or ceas* or cessation)
Google Advanced Search	Paediatric OR pediatric OR tube weaning OR feeding tube OR tube weaning program OR weaning

Appendix 1: Key words used to search databases for articles and reviews in English (Chapter 4 p. 113)

Appendix 2:

Article Details	Title
	Included/Excluded
	Year Published
	Country
Description of Research	Study Design
	Therapy approach/Philosophy
	Goals of research
	Reference to carer
	Type of statistical analysis used
	Pros of their program as reported by the authors
Characteristics of Participants	Number of participants
	Age
	Type of tube
	Gender
	Medical/Developmental diagnoses; reason for tube feeding
	% calories initially via tube
	Duration of tube feeding prior to weaning
Description of Treatment	Length of program
	Location of program
	Composition of therapy team
	Criteria for weaning readiness
	Pre weaning assessment process
	Program format
	Outcome measures reported
	% change in weight pre/post program
	Outcomes/Results

Appendix 2: Data charting form used to extract information from published tube weaning programs (Chapter 4 p 115)

Appendix 3:

Day	INTERVENTION
Pre-admission (Days 1–3)	Pre-wean plan completed by family in home environment Gradual reduction of calories via tube to 40% of initial volumes Fluid and electrolyte levels balanced via tube during this period using electrolyte solution Families continue with oral offerings and mealtimes as per initial evaluation goals and recommendations
Admit Day 1 (Monday)	Commencement of intensive program in hospital Families and therapists involved in all meals and 1 snack (1 snack family do on their own) Therapists providing routine development, parent coaching and management of behaviours (child, parent or sibling) during the meal and post-meal feedback/goal setting Tube used to give 40% of usual calories at breakfast time then not used throughout day (unless clinically indicated via hypoglycaemia) Goals for each meal depended purely on the capacity and progress of the individual child and their family unit and included state regulation at the table, self-initiation of food/drink interaction behaviours, parental/sibling interactions at mealtimes, child autonomy Additional top up tube feeds given at night once child asleep at an amount and rate calculated as suitable for hydration, to manage extensive weight loss and maintain blood glucose levels based on oral intake that day.
Day 2 (Tuesday)	Families and therapists involved in all meals and 1 snack as per day 1 Additional top up tube feeds given at night or during day sleep if/as required—amount determined by Paediatrician and Dietitian
Day 3 (Wednesday)	Therapists involved in 3/5 meals Additional top up tube feeds given at night or during day sleep if/as required—amount determined by Paediatrician and Dietitian. Amount actively reduced each night until no longer required If child is deemed hydrated and fasting blood glucose levels WNL, nasogastric tube will be removed post breakfast. Increasing venues for meals
Day 4 (Thursday)	Therapists involved in 2–3/5 meals
Day 5 (Friday)	Therapists involved in 2/5 meals with evening meal in social setting
Day 6 (Saturday)	Therapist involved in breakfast meal, with family managing the day by themselves
Day 7 (Sunday)	Discharge home with final Paediatrician and Speech Pathologist review
1 week post-discharge	Telehealth or Clinic review (pending proximity of the family home to the clinic) with Speech Pathologist. This included a shared mealtime with behaviour/sensory/oral motor observations, problem-solving challenges of the first week at home, urine and stool output, height, weight, food diary, enteral feed volumes (these details were provided to Dietitian for further input if required). Recommendations regarding foods, texture, oral strategy, mealtime management were given as required and liaison with Dietitian pending weight, hydration and oral intake.
2 weeks post-discharge	Paediatrician review (with child's usual Paediatrician or General Practitioner) Telehealth or Clinic review with Dietitian. This involved shared mealtime and observations, height, weight, hydration (urine and stool report), 3 day food diary completed by parents, enteral 'top up' volumes, preferred foods/textures. Liaison with Speech Pathologist post review if required for strategies regarding food/texture/mealtime behaviour/fluid tolerance.

	Infant Mental Health support to parents as required and negotiated on an individual basis
4 weeks post-discharge	Telehealth or Clinic review with Speech Pathologist (as per above)
6 weeks post-discharge	Telehealth or Clinic review with Dietitian (as per above)
8 weeks post-discharge	Telehealth or Clinic review with Speech Pathologist (as per above)
12 weeks post-discharge	Telehealthor Clinic review with Dietitian (as per above). Subsequent review sessions arranged with Dietitian or Speech Pathologist as clinically indicated.

Note: 'Therapists' are either a Speech Pathologist, Occupational Therapist, Dietitian or Infant Mental Health specialist all trained and experienced in tube weaning, mealtime management and feeding disorders.

Appendix 3: Outline of clinical hunger provocation, intensive therapy and follow-up program (Chapter 7 p. 152)

Appendix 4:

Principles of Intervention	Parents and siblings included Autonomy and self-initiation Nonchalance Emotional regulation
Therapy setting	Family mealtimes seated at the table
Frequency of food offerings	5-6 meals and snacks a day 2-3 hours between meals and snacks
Length of food offerings	Meals – up to 30 minutes Snack 15-20 minutes
Foods offered	Family meal options served via family-style serving at the table No specific number of foods offered
Textures offered	Variety of textures pending the child's oral ability, currently accepted foods. Textured selected as ''natural' components of the family meal where possible (e.g., rather than a bowl of puree meat and vegetables for the tube fed child there may be natural yoghurt, smashed avocado, bean paste if the meal is nachos/tacos as options as part of the greater family meal)
Generalisability	Meals occur in a range of social settings throughout the program (e.g., hospital, café, restaurant, playground) Seating positions around the table vary to encourage variability within mealtimes and adult support Gradual fading of therapists' attendance from Day 3 to promote parental practice and self-reflection

Appendix 4: Summary of Lively Eaters intensive therapy program intervention strategies (Chapter 6, p. 145)

Appendix 5:

Southern Adelaide Clinical Human Research Ethics Committee

Government of South Australia
Southern Adelaide Health Service

Ethics application approval

28 May 2015

Dear [redacted]

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." No hard copy correspondence will be issued.

Application Numbers: 238.15

Title: Retrospective case note audit of children who have accessed a multi-disciplinary intensive enteral tube weaning program (Lively Eaters) from November 2010 - April 2015

Chief investigator: [redacted]

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. The approval extends to the following documents/changes:

- SAC HREC Clinical Audit Application form dated 28 March 2015
- Audit Spreadsheet dated 22 May 2015

Approval Period: 28 May 2015 to 28 May 2016

Please read the terms and conditions of ethical approval below, as researchers have a significant responsibility to comply with reporting requirements and the other stated conditions.

For example, the implications of not providing annual reports and requesting an extension for research prior to approval expiring could lead to the suspension of the research, and has further serious consequences.

Please retain a copy of this approval for your records.

Flinders Medical Centre

The Flats G5 – Rooms 3 and 4

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TERMS AND CONDITIONS OF ETHICAL APPROVAL
Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions.

As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below.

Researchers have a significant responsibility to comply with the *National Statement 5.5.* in providing the SAC HREC with the required information and reporting as detailed below:

1. **It is the policy of the SAC HREC not to provide signed hardcopy or signed electronic approval letters**, as our office is moving to electronic documentation. The SAC HREC office provides an unsigned electronic PDF version of the study approval letter to the Chief Investigator/Study Manager via email. These email approvals are generated via the email address research.ethics@health.sa.gov.au which can be linked back to the SAC HREC.
2. **If University personnel are involved in this project**, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. **Compliance** with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To **immediately report to SAC HREC** anything that may change the ethical or scientific integrity of the project.
5. **Report Significant Adverse events (SAE's)** as per SAE requirements available at our website.
6. **Submit an annual report on each anniversary of the date of final approval** and in the correct template from the SAC HREC website.
7. **Confidentiality** of research participants MUST be maintained at all times.
8. A copy of the **signed consent form** must be given to the participant unless the project is an audit.
9. Any **reports or publications derived from the research** should be submitted to the Committee at the completion of the project.
10. All requests for **access to medical records** at any SALHN site must be accompanied by this approval email.
11. To **regularly review the SAC HREC website** and comply with all submission requirements, as they change from time to time.
12. The researchers agree to use **electronic format** for all correspondence with this department.

Kind Regards

[redacted] SAC HREC

Appendix 5: Ethics approval for Research Project 2 (pg 154)

Appendix 6

The impact of co-existing medical conditions proved challenging to categorise as the sum of individual medical conditions does not necessarily equate to a 'larger problem' and equally, one medical condition may have a more significant impact on feeding ability and behaviours than another. In order to be able to quantify in some way the perceived complexity of a child's medical condition with regard to how it would influence the child's ability to wean from their feeding tube, three clinicians who were independent from the project, experienced in tube weaning (at least 10 years feeding experience each) and from a variety of allied health disciplines (Speech Pathology, Dietetics and Infant Mental Health) participated as independent raters.

Each rater was given a list of medical conditions that the children included in this study presented with, as identified from their medical records. Each rater then independently gave a rating of 1–3 points to each medical condition, based on how, in their clinical experience, each condition would impact on the tube weaning process. Majority consensus was used to resolve any discrepancies in scores between raters.

PERCEIVED IMPACT OF MEDICAL CONDITIONS ON WEANING OUTCOMES

Rating Scale:

1. least impact on weaning (ie. easiest to wean)
2. moderate impact on weaning
3. severe impact on weaning (hardest to wean)

	Mild (1)	**Moderate (2)**	**Severe (3)**	**Consensus**
Chromosomal disorder	**√ √**	**√**		**1**
Congenital heart disease	**√**	**√ √**		**2**
Respiratory complications		**√ √ √**		**2**
Malformation/disease of GI tract			**√ √ √**	**3**
Food allergies	**√**	**√ √**		**2**
Neurological disorder		**√ √**	**√**	**2**
Oncology	**√ √**	**√**		**1**
Congenital metabolic conditions		**√ √**	**√**	**2**

These scores where then assigned to each child, based on their cluster of medical conditions. For example if Child A had a chromosomal disorder (score 1) + malformation/disease of GI tract (score 3) + respiratory complications (score 2) + food allergies (score 2) they would be assigned a score of 8 (see table below for all combinations based on this data set). Children with no remaining organic reason for tube feeding, but still fed via a tube, were assigned a 0 rating for the purpose of this rating scale.

Combinations of Medical Conditions Children Presented with Note—some children had the same cluster of conditions and therefore 62 cases are not presented.	**Weighted Score**
Chromosomal disorder + congenital heart disease + respiratory complications	5 (1+2+2)
Medically healthy/no significant medical history	0
Chromosomal disorder +malformation/disease of GI tract +respiratory complications + food allergies	8 (1+3+2+2)
Chromosomal disorder + congenital heart disease + food allergies	5 (1+2+2)
Neurological disorder	2
Chromosomal disorder + food allergies	3 (1+2)
Oncology	1
Respiratory complications	2
Neurological disorder + chromosomal disorder +malformation/disease of GI tract + congenital heart disease +respiratory complications + food allergies	12 (2+1+3+2+2+2)
Congenital heart condition + respiratory complications	4 (2+2)
Congenital heart condition + respiratory complications + chromosomal disorder	5 (2+2+1)
Congenital heart condition + respiratory complications + malformation/disease of GI tract	7 (2+2+3)
Congenital heart disease	2
Chromosomal disorder + malformation/disease of GI tract + Congenital heart condition + respiratory complications	8 (1+3+2+2)
Chromosomal disorder + respiratory complications	3 (1+2)
Chromosomal disorder + congenital heart disease	3 (1+2)
Chromosomal disorder + congenital metabolic conditions + congenital heart disease	5 (1+2+2)
Chromosomal disorder	1
Neurological disorder + congenital heart disease	4 (2+2)
Chromosomal disorder + Congenital heart condition + respiratory complications	5 (1+2+2)
malformation/disease of GI tract	3
Chromosomal disorder + malformation/disease of GI tract + congenital heart disease	6 (1+3+2)
Neurological condition + chromosomal disorder + respiratory complications	5 (2+1+2)
Neurological disorder + chromosomal disorder + malformation/disease of GI tract + congenital heart disease	8 (2+1+3+2)
malformation/disease of GI tract + congenital heart disease	5 (3+2)
chromosomal disorder + malformation/disease of GI tract + congenital heart disease + respiratory complications	8 (1+3+2+2)
Neurological disorder + chromosomal disorder + respiratory complications	5 (2+1+2)
Neurological disorder + chromosomal disorder + food allergies	5 (2+1+2)
Malformation/disease of GI tract + congenital heart condition + food allergies	7 (3+2+2)
Neurological disorder + respiratory complications	4 (2+2)
chromosomal disorder + congenital metabolic conditions + congenital heart disease	5 (1+2+2)
chromosomal disorder + congenital heart disease + food allergies	5 (1+2+2)
chromosomal disorder+ malformation/disease of GI tract	4 (1+3)
chromosomal disorder + congenital heart disease + respiratory complications	5 (1+2+2)
malformation/disease of GI tract + congenital heart disease + respiratory complications	7 (3+2+2)
Congenital metabolic conditions	2
Chromosomal disorder + malformation/disease of GI tract + respiratory complications	6 (1+3+2)

Final weighted scores ranged from 0 to 12. In an attempt to dichotomise the perceived medical complexity levels due to small numbers in each of the weighted score categories and due to the exploratory nature of this analysis, we grouped all children assigned complexity scores of 0, 1, 2 and 3 (n= 32) into a 'mild impact on weaning' group and all children assigned complexity scores 4 and above (n=30) into a 'moderate to severe impact on weaning' group. This was undertaken in an attempt to capture the complexity of the influence of medical conditions in a regression model that is acknowledged to be limited by a small participant sample.

During statistical analysis these groups were then collapsed into two final categories 'easy' and 'hard' to wean, as per the regression analysis.

Appendix 6: Development of Classification System for Medical complexity relating to tube-weaning (Chapter 7 p. 155)

Appendix 7

VARIABLE	Chi-square	B	SE	P	Exp (B)	95% CI for Exp (B) Lower/Upper
Age	X^2 = 16.3	−0.04	0.01	0.001	0.96	0.94/0.99
Duration of tube feeding prior to weaning	X^2 = 15.03	−0.04	0.01	<0.001	0.96	0.94/0.98
Gender	X^2 = 0.36	0.17	0.29	0.551	1.19	0.68/2.08
Weight-for-length at admission	X^2 = 0.03	0.02	0.12	0.862	1.02	0.81/1.29
BMI z-score at admission	X^2 =0.002	0.01	0.11	0.965	1.01	0.81/1.24
Pre-wean oral experiences	X^2 = 14.88			0.381		
Pre-wean oral experiences (1)		9.83	87.60	0.911	18673.81	0.00/<0.00001
Pre-wean oral experiences (2)		11.13	87.60	0.899	68268.36	0.00/<0.00001
Pre-wean oral experiences (3)		11.04	87.59	0.900	62159.66	0.00/<0.00001
Pre-wean oral experiences (4)		11.56	87.60	0.895	104676.1	0.00/<0.00001
Pre-wean oral experiences (5)		10.47	87.59	0.905	35155.70	0.00/<0.00001
Pre-wean oral experiences (6)		10.38	87.59	0.906	32056.01	0.00/<0.00001
Pre-wean oral experiences (7)		9.50	87.60	0.914	13382.85	0.00/<0.00001
Pre-wean oral experiences (8)		10.06	87.60	0.909	23173.63	0.00/<0.00001
Pre-wean Mealtime behaviours	X^2 = 7.58			0.147		
Pre-wean Mealtime behaviours (1)		1.24	0.52	0.018	3.46	1.24/9.64
Pre-wean Mealtime behaviours (2)		0.71	0.47	0.130	2.03	0.81/5.05
Pre-wean Mealtime behaviours (3)		0.85	0.43	0.049	2.34	1.00/5.44
Pre-wean Mealtime behaviours (4)		1.08	0.55	0.049	2.95	1.01/8.66
Level of Prematurity	X^2 = 0.17	-.013	0.32	0.681	0.88	0.47/1.63

Appendix 7: Variables which were not included in the regression model (Chapter 7 p. 156)

X^2= Chi square value; B = Beta value; SE = Standard Error for Beta;

P = Value of probability; Exp (B) = Odds ratio; CI = Confidence Interval

Appendix 8

[redacted]

From:	Human Research Ethics
Sent:	Monday, 15 July 2019 8:44 AM
To:	[redacted]
Subject:	8355 ETHICS approval notice (15 July 2019)
Importance:	High

Dear Emily,

Your conditional approval response for project 8355 was reviewed by the interim Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.:	**8355**
Project Title:	Parents' reflections on their experience of their child's transition from tube to oral feeding during an intensive intervention program
Principal Researcher:	Mrs Emily Lively
Email:	[redacted]
Approval Date:	15 July 2019
Ethics Approval Expiry Date:	**31 December 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments.

Additional comments:

Once available, please provide the name and contact details for the research assistant, and confirmation they have no conflict of interest.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:
   - all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

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- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the **15 July** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval web page.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the modification request form).

First Report due date:	**15 July 2020**
Final Report due date:	**31 December 2022**

Student Projects
For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details If the contact details of researchers, listed in the approved application, change please notify the Committee so that the details can be updated in our system. A modification request is not required to change your contact details; but would be if a new researcher needs to be added on to the research / supervisory team.

4. **Adverse Events and/or Complaints**
   Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

[redacted]

[redacted]

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

Proactively supporting our Research

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Appendix 8: Ethics approval for Research Project 3 (Chapter 9 p. 178)

Appendix 9

Speech Pathology

Swallowing Neurorehabilitation Research Lab

College of Nursing & Health Sciences

GPO Box 2100
Adelaide SA 5001

Flinders University Social and Behavioural Research Ethics Committee

Parents' reflections on their experience of their child's transition from tube to oral feeding during an intensive intervention program

Semi structured Interview Script and Exploratory Questions

Interviewer:
My name is XXXXXX and I am a member of the research team who are exploring your personal experiences/emotions/fears as you taught your child to eat and drink orally.

Thank you for making yourself available to discuss your experiences. I would like to reassure you I do not know any of your child's or family history and have not seen any of your confidential medical or health records.

You would have received the information sheet which explained that this interview will be audio recorded for later analysis. I would like to remind you that your information will be treated confidentially throughout the entire analysis process and will be transcribed and de-identified by a professional transcription company. Do you have any questions before we begin?

Question 1:

Could you start by telling me about you and your child's journey and experience with tube feeding (as observed by you)?

Prompt – Thanks for this background information….how did *you* actually feel throughout this journey.

- Thanks for sharing about your child's journey – where is your child at you at now with the tube, are you still using the tube at any times?

Question 2:

Was the idea of tube weaning ever discussed with you or was it something that over time you realised you would need to facilitate/explore/push for?

Question 3:

When you progressed towards starting the tube weaning process what were your expectations/concerns/worries/main hopes?

Question 4:

Can you tell us about your child's growth history (before weaning) and how this impacted on whether you wanted to engage with the tube weaning process or not?

Interviewer – Remembering that the program occurred first in the hospital with the intensive phase and then your transfer home and maintenance and development of skill at home. Can we explore your experience with the weaning process when you were in hospital for the intensive phase

Question 5:
Thinking about the intensive, hospital phase:

Could you see changes in your child's eating/drinking skills? If you could what did you notice that gave you confidence that your child's eating/drinking skills were developing during the tube weaning process?

If not – can you explain how your expectations were not aligned with what you were seeing?

Follow up: How did you define success? (Interviewer – only use these words/terms if parents are unable to provide a response…….eg. calories, volume of food, quality of mealtimes, self-initiation, nutrition, balanced diet).

Interviewer: Now thinking about the transfer from the supported hospital environment back to your home for the first 4-6 weeks at home……

Question 6:

What were your thoughts/feelings/experience in moving from the supported intensive environment back into your home environment? Where there particular challenges?

Any additional support you would have wanted at the time?

Question 7: Looking back, what were some strategies or supports or resources you found helpful?

Follow up: Can you elaborate how or why they were helpful?

: Were there any resources/advice you wish you had during your child's weaning journey that you didn't have at that time?

Question 8: What strategies or supports or resources were <u>not</u> helpful?

Follow up: Can you elaborate how or why they were <u>not</u> helpful?

Question 9:

At what point did you really believe that your child was doing this and was an oral eater and drinking?

Interviewer: The next few questions relate to the whole journey, not just upon returning home.

Question 10:

What were some of the 'high moments' you recall?

Follow up: What emotions characterised these "high moments"?

When your child was eating/drinking well, how did that impact you/your family/the next mealtime (probe this further)

How did you deal with these "high moments"?

Question 11:

What were some of the 'low points' you recall?

Follow up: What emotions characterised these "low points"?

When your child wasn't eating /drinking well, how did that impact you/your family/the next mealtime? (Probe this further)

How did you deal with these "low points"?

Question 12: Looking back at the weaning process, in your opinion, did your parenting styles (for each parent) influence your child's weaning process?

Follow up: If so, how?

Question 13: If you were to go through the process again with your child, what would you do differently?
Follow up: What do you wish you knew before you began last time?

Appendix 9: Interview guide used for Research Project 3 (Chapter 9 p.181)