Variables impacting the time taken to wean children from enteral tube feeding to oral intake

Emily J **Lively** (BSLP)[1,2], Sue **McAllister** (PhD)[3], Sebastian H **Doeltgen** (PhD, MSLT)[1,2]

[1] Speech Pathology, College of Nursing and Health Sciences, Flinders University

[2]Swallowing Neurorehabilitation Research Laboratory, Centre for Neuroscience, Flinders University

[3] Faculty of Health Sciences, The University of Sydney

Address correspondence to:

Emily Lively, Speech Pathologist and PhD candidate

College of Nursing and Health Sciences, Flinders University

GPO Box 2100, Adelaide, South Australia 5001

Ph: +61 (0)8 7221 8817

Fax: +61 (0)8 8204 5935

Email: will0472@flinders.edu.au

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Abstract

Objectives: This study investigated biological factors which may influence the time taken for children to wean from enteral to oral intake.

Methods: Retrospective case-note audit of 62 tube fed children (nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG)) aged 6 months to 8 years, participating in an intensive tube weaning program. Program design included family focused mealtimes, child autonomy and appetite stimulation. A regression model was developed which shows the combination of variables with the most predictive power for time taken to wean.

Results: Data from 62 children who were highly dependent (minimum 93% of calories provided enterally) on tube feeding for an extended period of time (mean = 2.1 years) were analysed. Children's mean BMI z-score at time of weaning was -0.47 (SD 1.03) (mean weight = 10.54kg) and 54 (87%) presented with a range of medical conditions. Forty-four children (71%) remained completely tube free at 3 months post intervention and an additional 5 children (10%) were fully tube weaned within 10 months of program commencement. Type of feeding tube, medical complexity, age and length of time tube fed all significantly correlated with time taken to wean. Logistic regression modelling indicated that the type of feeding tube in combination with the degree of medical complexity and time tube fed were the strongest predictors of time taken to wean.

Conclusion: Biological factors usually considered to impact on successful weaning from tube feeding (volume of oral intake, oral skill or mealtime behaviours) were not relevant, however the type of feeding tube in combination with the degree of medical complexity and time tube fed were the strongest predictors. The impact of psychosocial factors should be investigated to identify if these mitigated the effects of the biological variables.

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Key Words:

Tube weaning; paediatric; clinical indicators; inpatient; oral intake

What is known?:

- Enteral tube weaning can be a complex and emotional process
- Medical, psychological, emotional, oral motor, oral sensory, nutritional and care giver capacity all impact on a child’s ability to learn to eat orally
- Varying approaches are used to teach tube fed children to eat
- Inter-disciplinary intensive tube-weaning programs are successful in tube weaning

What is new?:

- Prior oral experiences, mealtime behaviours and amount consumed orally prior to weaning do not impact the time taken to wean.
- Combination of type of tube, length of time tube fed prior to weaning and complexity of medical conditions provide the strongest predictors of time taken to wean. Less medically complex children fed by nasogastric tubes wean more quickly.
- BMI z-scores do not predict the length of time to transition to oral feeding.

Introduction

Infants born with chronic medical conditions are surviving in greater numbers due to improved medical treatment and technology (1). 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 (2, 3, 4). Tube feeding frequently persists beyond medical stability due to behavioural and stress responses (5, 6, 7). Internationally, approximately 4/100,000 children require enteral tube feeding (8) which is costly, impacts social, psychological, medical and general development and causes high levels of parental emotional and psychological stress (9, 10).

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 (11, 12), multidisciplinary child initiated (8, 13, 14, 15, 16) or netcoaching approaches (17). 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 (12, 15,17, 18, 19).

Variables that influence weaning include the child's medical complexity, type of tube used for feeding and age (20, 21). 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 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 Phase 1 and 2 of the intensive tube weaning program within the audit time frame. Demographics of the children included are presented in Table 1 below.

Description of intervention program

The intensive intervention program was conducted in close collaboration with the families. It was supported by an inter-disciplinary 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 weaning, comprehensive assessment undertaken by a SLP, Dietitian and OT explored medical and developmental background, historical and current tube feeding practices, current feeding regime, 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 (eg. Winnie Dunn Sensory Profile(22)), observation, questionnaire (23) 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 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/surgery and health had remained stable over at least the last 2-3 months; no diagnosed dysphagia; weight maintenance; plateau of mealtime skill through outpatient treatment; and parental capacity/readiness and overall family context to support transfer of skills to 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 whilst reducing overall calories (see Table, Supplemental Digital Content 1, 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 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/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, matched 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 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/drink behaviours, specific food suggestions, enteral 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 appropriate local human research ethics committee. 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 impact on weaning outcomes (19, 24) 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 grouping of children into descriptive categories for analysis. The rating charts for oral skills and mealtime/food interaction were developed by two Speech Pathologists with a minimum 10 years 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 10 years paediatric feeding experience. The majority consensus for the medical classification was accepted.

Oral skills were classified into 10 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 and/or combinations of these (Table 2).

Mealtime feeding/food interaction behaviour variables were classed into 5 categories (Table 2) which clinically represented different stages of food interaction commonly observed in the children seen in this program.

The type of medical condition(s) are 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 2). 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, Supplemental Digital Content, 2 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 (25). 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 in order to decide which variables to include in subsequent logistic regression analysis. Variables that had a significant impact on the time taken to wean were: type of feeding tube; medical complexity; age; and length of time tube-fed (all $p<0.05$; Table 3 & Table SDC 3). In order to avoid effects of multi-collinearity, non-parametric analyses of the relationships between age and duration of tube feeding was then undertaken which showed a high correlation between these variables (Spearman's $r=0.89$, $p<0.001$). Therefore, only 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 time taken to wean in the preliminary Cox regressions were excluded from further analyses (summarised in Table, SDC 3).

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, prematurity level was not considered in subsequent analyses.

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

Finally, a three step logistic regression model was developed that incorporated the variables of time tube-fed prior to wean, 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 time taken to wean (Table 3).

<u>Results</u>

Data from 62 children were available (mean age 2.4 year, 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 time of weaning was 10.54kg (SD 2.98) and 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 completion of the 7 day intensive period 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 time taken to wean. However, adding type of tube to the regression created the strongest predictive model of time taken to wean (Table 3).

Finally, survival analyses comparing 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 1). However, medical complexity did not differ between children who were fed via an NG or a PEG tube ($X^2=1.60$, $p = 0.207$).

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 time taken to wean

We explored several biological factors generally assumed to be correlated with time taken to wean. For example, a child's age and time tube fed prior to the weaning period positively correlated with 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 time taken to wean as it was anticipated that a more medically fragile child may be more difficult to wean because life-saving 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 NG tube provided greater motivation to transition faster to oral intake, although this was not formally evaluated in this study. Of note, children with a NG tube were not significantly less likely to have a medical complexity rating of “moderate-severe”.

Factors not correlating with time taken to wean

In preliminary analyses, we explored several variables usually assumed to potentially influence 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 by some teams based on the parameter of not yet eating/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 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. We note, however, our sample size compares well with international tube weaning literature where participant numbers vary from single case studies (26), to 10 (27) and 221 participants (15). In these studies children were medically healthy (ie. 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 ratings scales is 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 suggests that, of the variables presumed to impact on time to weaning, time tube-fed and type of feeding tube combined with 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, 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 which involves mutual trust and respect of 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.

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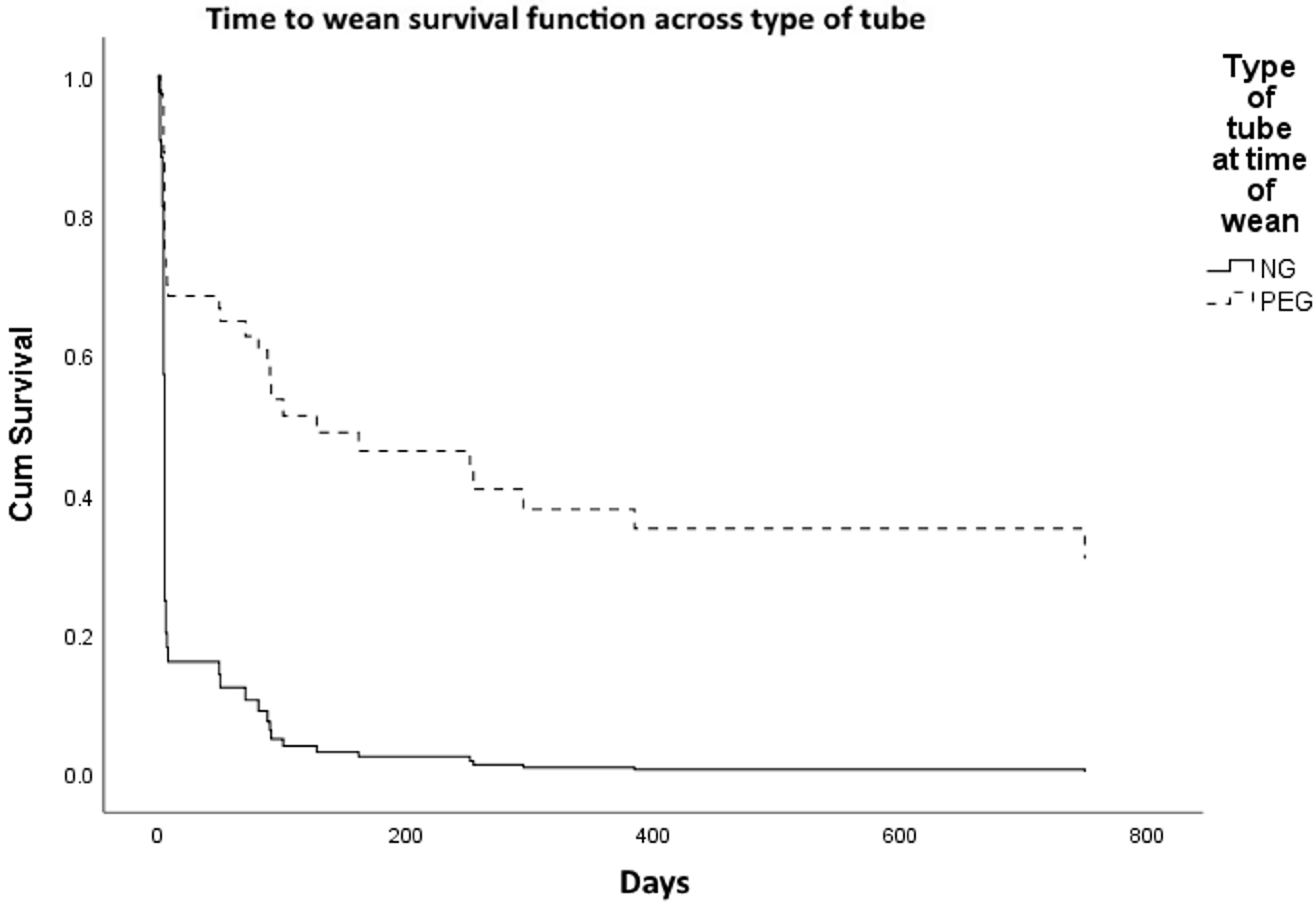
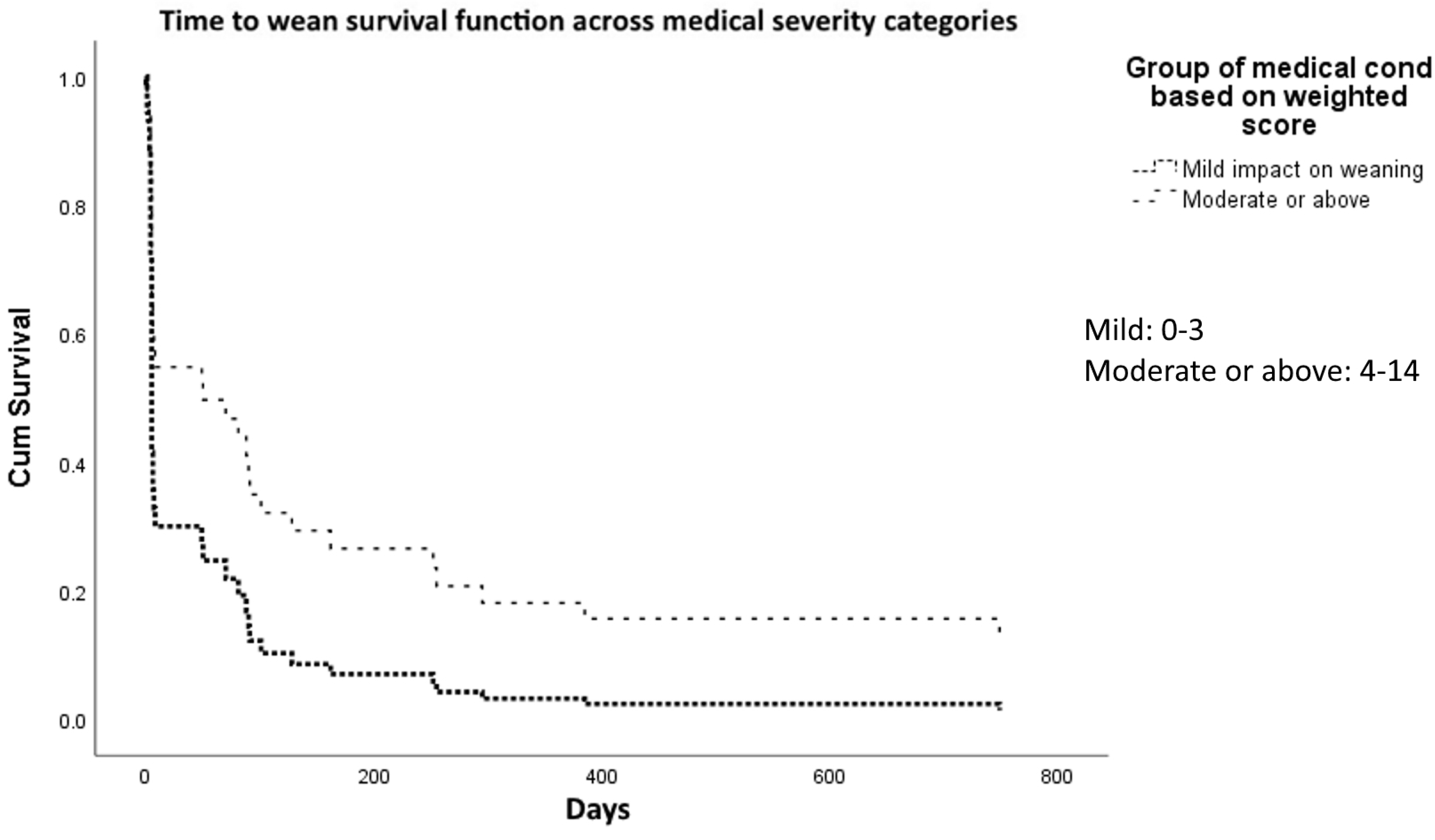
Supplemental Digital Content (SDC) Legend:

Table, SDC 1 - *Outline of clinical hunger provocation, intensive therapy and follow-up program*

Appendix, SDC 2 - *Development of Classification System for Medical complexity relating to tube-weaning.*

Table, SDC 3 – *Variables not included in the regression model*


Time to wean survival function across type of tube
Type of tube at time of wean
NG
PEG
Cum Survival
1.0
0.8
0.6
0.4
0.2
0.0
0
200
400
600
800
Days


Time to wean survival function across medical severity categories
Group of medical cond based on weighted score
Mild impact on weaning
Moderate or above
Mild: 0-3
Moderate or above: 4-14
Cum Survival
1.0
0.8
0.6
0.4
0.2
0.0
0
200
400
600
800
Days

Participant Characteristics	
Gender	28 female, 34 male
Age at commencement of pre-wean (years)	Mean 2.4 (SD 1.71) Range 0;6 to 7;7
Level of Prematurity (WHO preterm birth categories)	Group 1, Extremely Preterm (< 28 weeks): n = 13 (21%) Group 2, Very Preterm (28-32 weeks): n = 5 (8%) Group 3, Moderate to Late Preterm (32-37 weeks): 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 prior to weaning (years)	Mean 2.1 (SD 1.75) Range 0.21 – 7.5
BMI z-score at pre-wean	Mean -0.47 (SD 1.03)
Weight (kg) at pre-wean	Mean 10.45 (SD 2.98)
% of required calories provided via tube feeding at pre wean	93% (SD 21.12)
Co-existing medical factors	54 children (87%) had co-existing 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%)

Table 1: Overview of the participant characteristics

Oral skills	**Rated 1 to 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 to 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 (i.e. predicted easiest to wean) 2. moderate impact on weaning 3. severe impact on weaning (predicted hardest to wean).

Table 2: Rating system used to categorise variables into oral experiences; mealtime feeding/ food interaction behaviours and medical complexity.

	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				
Variable	**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**				

Table 3: Multiple regression model of variables identified in preliminary analyses to have a significant impact on time taken to wean

X^2=Chi square value; B = Beta value; SE = Standard error for Beta; P = Value of probability; Exp(B) = Odds ratio; CI = Confidence interval

Supplemental Digital Content File

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	Skype 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) Skype 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	Skype or Clinic review with Speech Pathologist (as per above)
6 weeks post discharge	Skype or Clinic review with Dietitian (as per above)
8 weeks post discharge	Skype or Clinic review with Speech Pathologist (as per above)
12 weeks post discharge	Skype or Clinic review with Dietitian (as per above). Subsequent review sessions arranged with Dietitian or Speech Pathologist as clinically indicated.

Table 1: Outline of clinical hunger provocation, intensive therapy and follow-up program

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.

Supplemental Digital Content

Appendix 1: Development of Classification System for Medical complexity relating to tube-weaning.

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 – 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.

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

Table, Supplementary Digital Content 3: Variables which were not included in the regression model

X^2= Chi square value; B = Beta value; SE = Standard Error for Beta;

P = Value of probability; Exp (B) = Odds ratio; CI = Confidence Interval