Definitions and clinical guidance on the enteral dependence component of the avoidant/restrictive food intake disorder diagnostic criteria in children

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ABSTRACT

The aim of the current paper is to offer definitive guidance on weaning children who are reliant on nasogastric/gastrostomy feeding tubes. To date, no internationally recognised definitions or principles for interventions exist and clinics have been reliant on creating their own unique intervention criteria. To achieve the aim, two goals are set out within the current paper. The first goal was to definitively define the process of tube weaning. In order to achieve this, both tube dependency and oral eating also required definitions. It is necessary for these two additional definitions to fully understand the process of tube weaning and the transition that the child is making within these clinical interventions. The second goal of this paper was to propose a set of minimum measurement criteria within a tube weaning protocol so that different clinical practices and perspectives may be measured accurately. This would then allow outcomes from different clinical services to be compared for efficacy. The culmination of this paper is a set of five core principles that should govern clinics that adhere to the auspices of evidence-based practice. These principles, if adopted, will provide the basis of a set of internationally recognised criteria within this field of paediatric gastroenterology.

INTRODUCTION

The placement of a nasogastric/gastrostomy tube is necessary to prolong a patients' life [1]. In addition, it has been shown that placing a nasogastric/gastrostomy tube has positive quality of life benefits and decreases stress around mealtimes for the family of children who have them fitted [2]. Despite the perceived clinical necessity to place nasogastric/gastrostomy tubes, gastroenterological and paediatric surgical staff should consider that a prolonged period of nasogastric/gastrostomy tube feeding is associated with higher mortality rates in some groups of children [3, 4] and has several associated serious short- [5] and long-term complications [6-9]. Both the positive and negative outcomes of using feeding tubes have been systematically reviewed [e.g. 10].

Several negative effects have been reported following the placement of nasogastric/gastrostomy tubes. These include: elevated parental stress [11, 12], emotional and economic costs [13], and adverse effects on maternal identity [14]. Furthermore, the act of placing the tube removes the child's endogenous motivational factors to consume food [15], is not as effective at eliminating appetite regulation cues compared to oral eating [16] and instantly ascribes them with a diagnosable psychological disorder under the Diagnostic and Statistical Manual V (DSM-V) [17-19].

The complications and increased mortality rate in children with nasogastric/gastrostomy tubes has not resulted in lower usage. Indeed, the rates of placing these tubes have increased from inception [20] to negligible amounts in 1990

to nearly two hundred a year a decade later in just one French hospital [21]. Although it could be argued that this is due to success in neonatal care [22], the predominant reason for placing a nasogastric/gastrostomy tube appears to be gastro-oesophageal disease, neuromuscular conditions and failure-to-thrive [23] and specifically to maintain a child's growth trajectory despite these medical ailments [10]. There are many preliminary medical guidelines/considerations for inserting feeding tubes; with most relating to the insertion, care and medical management [e.g. 24, 25]. Additional clinical guidance concerning successful intervention to remove nasogastric/gastrostomy tube has recently been requested [25], yet this cannot be achieved until consensus concerning what constitutes a successful wean has been published [26]. Despite the lack of guidance, several successful treatment strategies have allowed children to transition from their nasogastric/gastrostomy tube to full oral eating. These include simple hunger provocation (i.e., to gradually decrease the amount that is fed through the nasogastric/gastrostomy until the child is compelled to eat orally; e.g. [15]), hunger provocation combined with psychotherapeutic techniques through play therapy (e.g. [27]), and behavioural therapy (e.g. [28-31]).

Recent collation of the literature for the use of feeding tubes in children with neurological impairments concluded that there is large heterogeneity in both definition and outcomes [10]. The heterogeneity likely stems from the variety of conditions that may result in the placement of a feeding tube. With a variety of conditions requiring feeding tubes, this inevitably leads to a variety of different management strategies and treatment regimens depending on the needs of the individual child. For example, some children with cardiovascular or respiratory ailments may require the feeding tubes to top up their calorie intake. In contrast,

children with gastrointestinal or neurological conditions may be completely reliant on their feeding tubes for all their nutritional needs. Despite the heterogeneity in the need to place and the management strategies of feeding tubes, consistency within the decision-making process can be reached when the feeding tube is no longer required. Instead of focusing on the reason for placing the tube to provide definitions, less heterogeneous definitions can be provided based on the decision to remove the feeding tube. The advent and acceptance of such definitions allow professionals to create and uphold standards of treatment. Therefore, to achieve internationally accepted minimum standards for nasogastric/gastrostomy tube weaning, it is important that the use of specific terms are unambiguous. The aims of the current paper are to (a) deconstruct the differential use of the terms ‘tube dependency’ and ‘tube weaning’ that are currently defined within the literature related to the transition from tube feeding to oral eating. Oral eating will also be defined to allow a full interpretation of the tube weaning process and propose a suitable intervention target. (b) An evaluation of what would constitute best evidence based practice within the field of nasogastric/gastrostomy tube weaning to aid children to transition to oral eating will be proposed. The goal is to offer a list of measurable outcomes that should be used to assess any tube weaning programme. (c) And finally to propose a list of criteria that would aid clinicians in structuring their interventions to ensure the best possible outcome is achieved that is measureable and comparable. Through these aims, the goal of the current paper is to clarify clinical decision-making criteria on tube weaning, defining what could be considered an effective intervention based on a set of standard measures and harmonising the disparate approaches that currently exist within the literature based on evidence-based principles.

Tube dependency

Two overarching and competing definitions exist within the literature on gastrostomy tube feeding that explicitly refers to the term *tube dependency*. The objective of the current subsection is to provide an operational definition of the term *tube dependency*. Potential repercussions of accepting one or other of the definitions will be critiqued, as well as their ontological roots discussed.

The term *tube dependency* has two competing definitions. The first definition relates to patients' inability to swallow [32]. The most common application of the term *tube dependency* relates to need as a synonym for survival. This definition is attributed to fields outside of gastroenterology, primarily oncology (e.g., [33, 34]). Interestingly, continual presence of the tube for long-term management of the ailment in fields outside of gastroenterology was attributed to the failure of a surgical or chemotherapeutic intervention [35, 36]. Although predominantly found in the surgical and oncology literature, the term *tube dependency* has been used in the context of being essential for maintaining the patient's life in the gastroenterological literature too (e.g. [37]). The overarching outcome of the first definition of *tube dependency* follows the literal definition for the term 'dependent'. Within this definition, the patient is dependent upon the tube to aid delivery of nutrition.

The second definition of the term *tube dependency* derives from the psychological construct of dependency – the individual's overreliance or perceived need of the tube to function adequately (e.g. [27]). This secondary definition offers two additional criteria to the term *tube dependency*. The first addition conflicts with the previous

medical definition of ‘need’. This component suggests that the tube was not needed; rather there is a perceived need. The patient, family or professional team believes there is a need for the tube to remain in place. The continued use of the tube alleviates the anxieties of getting the child to eat or removes prolonged periods of conflict during mealtimes. The second caveat added to the definition of *tube dependency* is that the gastrostomy tube is unnecessary and that the child can transition to oral feeding if provided with the correct motivation and taught the skills to eat orally [38].

The term *tube dependency* may undermine the long-term prognosis of a patient. A professional's perception that the patient was dependent on their tube or has a tube dependency may affect clinical decision-making to transition to oral eating [6, 39]. If the perception is that the child will have a *tube dependency* then there will be little reason to assess if the child has improved or enquire if the child has spontaneously started to eat. For roughly half of all children fitted with a gastrostomy tube, this intervention will be part of a long-term management strategy [9], it is important that it is not assumed to be necessary.

The decision to insert a gastrostomy tube has been defined by Sullivan [37]. Readers interested in decisions to place feeding tubes are referred to this source. Within Sullivan's paper, guidance on the factors that should be considered at the point of placement include: If a nasogastric tube has been in situ for longer than six weeks; If the duration to feed the individual profoundly impacts other aspects of their development (usually defined as mealtimes that take many hours to complete); low weight to height ratios; and dysphagia (inability to perform a functional swallow).

None of the reasons offered by Sullivan [37] suggests long-term *tube dependency.* Each factor offered by Sullivan [37] should be considered transient or triaged against the child's social development and/or medical requirements at that moment in time. The assumption that the tube is placed with a transient need will incorporate the potentially conflicting definitions found within the current literature. Once the child recovers from their medical ailments then they have effectively become the problem of a psychological/allied health professional specialist [40], as the continued use of the tube as a treatment would be considered unnecessary or overly intrusive.

In sum the most appropriate definition of tube dependency would be:

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.

Tube weaning

There is a notable absence of definitions of *tube weaning* within the literature. The only definition of tube weaning explicitly offered is that by Trabi and co-authors [41]. Their definition is simply the cessation of tube feeds or removal of the tube itself. This definition does not consider if the child has successfully transitioned to oral eating or how much of their child's nutrition is met post tube weaning. Within the tube weaning literature, the inclusion criteria, which is the best possible indicator for defining the reason for tube weaning a particular child is heterogeneous. Some

authors have indicated a reason for their programme or tube weaning intervention. These reasons typically include terms such as pathological food refusal [15] or feeding disorders [26]. Without defining the term *tube weaning*, within the context of transitioning to oral eating it is not possible to assess what was a successful tube weaning outcome. It is proposed that children may be discharged without adequate oral nutrition alongside the removal of the nasogastric/gastrostomy tube. This might increase a potential for the child to relapse to a situation where by they are not consuming sufficient nutrition and without the ability to replace nutrition through the gastrostomy tube. Therefore, the clinical risk resulting from ambiguous definition is high. Within this sub-section, the term *tube weaning* will be discussed in reference to the transition from *tube dependency* to oral eating. Oral eating in this context is simply a child meeting all of their nutritional needs through consuming a functional, age-appropriate, diet. The process of moving from tube dependency to oral eating is frequently termed *tube weaning*. In order to provide a definitive definition of the term *tube weaning*, references will be made to trachea-tube weaning, neonatal weaning and a deconstruction of all of the important variables that make up oral eating.

In the absence of any definition specific to nasogastric/gastrostomy tube weaning, the emphasis must turn to explanations of terms found in similar fields of research. The lack of definition is not specific to the nasogastric/gastrostomy field. Specifically, the trachea tube weaning literature also reported problems with a lack of definition of the term ‘weaning’ [42]. Principally, the field of trachea tube weaning suggested that the lack of universal definition prohibited comparisons between different techniques. A similar problem currently exists in feeding tube weaning too. In an attempt to resolve these issues, international consensus on the definition of trachea tube

weaning concluded it was the gradual reduction of ventilatory support and its replacement for spontaneous ventilation [39]. Cross-application of Giménez et al's [43]definition within gastroenterological *tube weaning* would suggest that the process could be summed up as all of the factors that are involved in transitioning a child from *tube dependency* to spontaneous oral eating.

Conundrums remain however, as eating behaviour has a developmental component to it and therefore, age appropriate skill mastery need to be considered. Within the typically developing literature, the term weaning is defined as the introduction of solid food into an infant's diet and is used to define the transition to oral eating in preterm infants (e.g. [44]). One addition to this simple definition would be the inclusion of the term functionally appropriate foods. For example, nasogastric/gastrostomy tube weaning a baby onto solid food would not be appropriate; neither should professionals discount some semi-solid (e.g. mash potato, stews and casseroles) and liquid-state foods (e.g. soups, yoghurts and milkshakes) that are consumed by the general population from a useful working definition. Indeed, the incorporation of these foods into the transition to oral eating provides the professional with a process of graduated texture exposure [31] and provides the child with a functionally and socially appropriate addition to their diet.

The combination of the two trachea-tube and neonatal weaning definitions still does not provide a definitive definition with effective clinical outcomes. In order to satisfy this last criterion, it would be appropriate to accept the DSM-V criteria for diagnosing avoidant and restrictive food intake disorder (ARFID) [17]. The reason for the appropriateness of the inclusion of this diagnostic component allows several

additional operational criteria to emerge that can both aid in measurement within a given intervention and allow the professional to ascribe a successful outcome to the intervention. Without adding in these last components, the endeavours of any team that attempts to nasogastric/gastrostomy tube wean children will effectively be making additional work for allied health professionals.

In sum, an appropriate definition for tube weaning would be:

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 their nutritional requirements without disproportionately impacting on the their development, social environment and family.

Defining Success of Transitioning to Oral Eating

Children who cannot physically achieve a full wean due to a lack of sufficient oral motor skills would benefit from a partial transition within the bounds of safety [45]. Eating food is not a simple process of hand to mouth to sustain the individual's energy needs [46]. Eating is a complex biopsychosocial experience that has developmental value by simply being involved in mealtimes [47, 48]. . Wolf & Glass [49] offers moderation to the definition of full oral eating by suggesting that an appropriate target for a specific child was that they achieve their expected outcomes. This additional explicit caveat to the definition of tube weaning would temper expectations for individuals that cannot achieve a full oral diet, while providing the

professionals with the impetus to intervene with an individually derived exit criterion. However, including this explicit caveat within the actual definition would not be appropriate. Specifically, the inter-disciplinary tube weaning team should strive to allow the child to achieve their best possible outcome rather than their expected one. To avoid subjectivity in the success of tube weaning protocols, an appropriate scale to measure success in the transition between supplementation and oral eating is needed. An appropriate scale would be the amount of functionally useful and age appropriate food that the target child orally consumed [50]. Therefore, a child that meets their nutritional needs without the need for supplementation through either the tube or a liquid meal replacement would be termed a child that has achieved an effective one hundred percent transition from tube dependency.

Transitioning a child from tube feeds to a series of liquid meal replacements would not be considered as a suitable objective under the current definition proposed. Preference for products added to functionally appropriate foods rather than products that replace oral eating completely would also be preferred. Adding calorie enhancing products to foods also encourages experience with food while receiving the liquid supplements. Dietetic expertise should arbitrate what processes/products would be most appropriate for each child. Products that replace mealtimes function to prohibit transition to oral eating in the same manner as tube feeding [15], and potentially create another form of psychological dependency.

Employing calories as the continuous measurement to define success discounts the additional need of essential vitamins and minerals in the patients' diet. Not meeting the child's nutritional needs would indicate the diagnosis of avoidant/restrictive food

intake disorder [17]. Although blood metabolite tests would be the definitive arbitrator of nutrient deficiency, the presence of low levels of essential vitamins and minerals are not without comparisons within the typically developing literature. It has been frequently shown that the population is deficient in zinc, iron and vitamin D [51, 52]. Therefore, assuming that a child transitioning onto an oral diet within current environmental and cultural constraints would be nutrient replete would be ambitious. Within these constraints, a socially appropriate outcome should be sought and a child that maintains their micronutrient levels through supplementation of vitamins and minerals [53] would still meet the criteria of being fully and successfully weaned from the tube..

Predicting Successful Outcomes in Tube Weaning

Miller et al [54] has offered a detailed discourse on the composition of the multidisciplinary team for feeding tube weaning in children. Interested readers wanting to create a multidisciplinary team to offer tube weaning are referred to this source. Miller et al's team would be considered best possible practice for any service, but it would neither be prudent nor appropriate to define necessity by the composition of a particular service. Each child referred to a feeding service requires a unique tailor-made intervention [31]; although, some services advocate 'off the peg' interventions [15, 27]. Due to the variability in the reason for fitting a nasogastric/gastrostomy tube, and the characteristics of the children referred for tube-weaning, it may be possible to transition children without the need of all professionals outlined by Miller et al [54].

TABLE 1 GOES ABOUT HERE.

Professionals attempting to tube wean children without the full multidisciplinary team advocated as the ‘gold standard’ should be aware of the minimum requirements in the assessment phase to ensure that the attempted wean is safe. Table 1 outlines the components that require assessment. Schauster & Dwyer [29] offer criteria for readiness to tube wean defined through five headings. These were: the medical problem has stabilised; nutritional status was good; oral-motor skills were appropriate; swallowing was observed as safe; and caregivers were ready. In addition to Schauster & Dwyer’s criteria, professionals must also provide the criteria for discontinuing the attempt. Generally, the reason for discontinuing a tube-weaning protocol is that the child has lost too much weight too quickly. Recognising failure should constitute a clinical decision in the context of the child’s specific aetiology/symptoms and the professionals’ opinion of what would be safe weight loss. Failure to wean indicates that the child does not have the capabilities, for whatever reason, to transition from being tube dependent at this moment in time. Therefore, the criteria to start the tube wean must be continually (re)assessed throughout the weaning protocol. Continual and accurate assessment should allow the professional some certainty in predicting the potential outcome of the attempted tube weaning protocol (see figure 1).

Figure 1 GOES ABOUT HERE

To date, no data has been published that compares programmes of different durations to explore the impact of duration on outcomes. The distinction between

different tube weaning programme durations are popularly termed *fast* or *slow* weans. Specifically, these programmes refer to the duration of the intervention to instil oral eating. The overwhelming evidence base has been for fast weaning [15, 31, 50, 55-58]; purportedly transitioning the child in less than three weeks. In contrast to the fast wean method, there are at least three studies that show effective outcomes following a slow wean procedure [59-61]. These approaches have the added benefit of avoiding an unnecessary stay in hospital and allow the child to progress at a relaxed rate suitable for them [50].

Efficacy rates comparing fast versus slow tube weaning procedures show little variation. Employing only the quantitative studies of follow-up durations of at least a year, the percentage of children who achieve full oral eating are between 74% [31] in fast weaning protocols and 78% in slow weaning protocols [61]. Taken together, the data suggests that there were no differences between fast or slow weaning procedures based on efficacy rates. Therefore, the decision to implement fast over slow weaning protocols is dependent upon the composition of local services.

In addition to effective and continual assessment, there is also a need to assess any problem behaviours that occur beyond those defined by their absence (i.e. inability to chew/swallow). Typically, these problem behaviours are termed as persistent food refusal or feeding disorder (now termed ARFID). In effect, the child wilfully refuses to eat food orally. The definition of problem behaviour in this context would be any wilful action by the child that interferes with the process of eating orally. Although the exact topographies of behaviour differ by age, and child, typically, this manifests as head shaking, hand batting (knocking the food away or onto the floor), induced vomiting in

the presence of food, teeth clenching, screaming, crying and running away [62]. Appropriate interventions strategies are available from both a psychoanalytic [63] and applied behavioural [64] perspective. It must be noted however, that for those dependent on evidence-based practice, there is a difference in the quantity of evidence between the two approaches. In general, the quantity of evidence favours behavioural interventions. The reported fundamental disagreements between the two schools of thought, the psychoanalytic and applied behavioural, lie in their respective definitions of food refusal. Applied behavioural psychologists define food refusal as a problem behaviour under environmental control [65, 66]. Alternative interpretations of the same food refusal behaviour by the psychanalytic school are deemed to be the child's internally-motivated wishes [27]. . Irrespective of the approach the professional adheres to, the need to have an effective strategy to tackle problem behaviours that interfere with the mealtime are of paramount concern within the tube weaning protocol.

Ensuring Successful Outcomes in Tube Weaning

The current paper has proposed a successful tube weaning outcome as the child achieving full oral intake. Minimum standards of intervention for transitioning a child from tube dependency must include an extended period of follow-up. The length of follow-up varies significantly between studies from no-follow-up to 2 years (e.g. [41, 61]). This wide range in follow-up suggests that guidance for duration of assessment after intervention would be necessary. Two potential exit criterions could be implemented. The first would consider an assessment within weeks of the initial intervention to ensure stability, as well as a discharge interview at six months;

although this may vary dependent on the type of tube weaning protocol (fast or slow) implemented. The second criteria would be if the child has maintained their eating behaviour during adversity. For example, if the child continues to eat while suffering from an illness (e.g. flu, respiratory infection or gastrointestinal infection), then it could be appropriate to assume that the child's eating behaviour was robust.

Better tube weaning protocols should include the teaching of self-regulatory and generalisable skills under the control of the child's internal motivations [67-70]. Children's energy intake has been shown to be variable across the day [71]; however, they will compensate their energy intake accordingly in the short- to medium-term [72]. This ability remains intact even after long periods of tube feeding [73], suggesting that the child can readily adapt. Integral to this adaptable response is the ability to self-regulate and understand the biological determinates of hunger, as well as have the behavioural repertoire to alleviate these internal feedings. In effect, the child must know what hunger is and what to do about it when it occurs. Self-regulation for the child is the ability to request food and to eat freely when food is available in their environment without the need for external motivation. Without explicitly teaching these skills and associated internal feelings, there would be a higher likelihood for failure in the medium- to long-term.

Being able to self-regulate is extremely important for the child to gain control of their energy security. However, implicit to self-regulation would be that the child has adaptive rather than mal-adaptive eating behaviour [74]. A child that consumes a single item or very limited repertoire of foods would be at risk of relapse, as they reach sensory-specific satiety sooner [75] and as the diet becomes monotonous [76].

Therefore, children that transition to oral eating without at least some variety in their diet cannot be considered as being successfully weaned. Any form of negative emotional association that the child makes (e.g. disgust) with the limited number of foods that they consume can effectively lead to under-consumption and dramatic weight loss. Moreover, a child that eats only a few items of food that are not ubiquitously available outside of their home environment will not become exposed to new environments and social situations (e.g. eating the same foods as their family, eating at restaurants, eating at peers' birthday parties etc…). Therefore, the act of eating for them is not socially appropriate. A programme of increasing dietary variety [77-79] after the intensive intervention would be required for an adaptive and successful long-term outcome.

Conclusion

To aid in creating appropriate interventions, the aim of the paper was to offer important definitions of the terms *tube dependency*, oral eating and *tube weaning*. Based on these definitions, we have offered recommendations to facilitate successful long-term outcomes for tube weaning interventions and service provision. By measuring the type (oral eating, enteral feeds and tube feeds) and quantity of calories the child consumes potentially allows cross-comparison between children at presentation, attending different clinics and engaging in different interventions. Under the simple definition of 'eating orally' suggests that even simple transition to take any food orally was a one hundred percent successful outcome. However, such criteria actively ignore the underlying principle of instilling a functional and adaptable diet that does not impact on the children's family and social groups. Modifying social

environments to include the child may be appropriate in situations where there was a medical ailment resulting in inability, but to assume that all children who are tube fed cannot progress onto the same diet as their families would not be adopting the most positive outlook for the child.

The advice for the varied health and allied health professionals involved in transitioning children from tube dependency to oral eating would be the following series of five statements. (i) To define success by caloric intake in the short-term and by weight status in the medium- to long-term. (ii) To aim to instil a varied diet to allow the child to adapt to different environments where food is eaten and social circumstances where food is a central feature of the gathering. (iii)To tailor interventions to the individual child and deliver it specifically for them. (iv) To meet the minimum standards of assessment and follow-up. (v) Finally, to ensure that the intervention teaches the child generalisable and adaptable set of skills so that they may eat in multiple environments. This approach would then open up a variety of new environments previously inaccessible to the child. This will inevitably enrich the child's personal and social development and lead to a more harmonious and less stressful family mealtime.

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