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An evaluation of an intensive desensitisation, oral tolerance therapy and hunger provocation programme for children who have had prolonged periods of tube feeds.

Introduction.

Feeding, eating and drinking problems within a paediatric population are complex and varied, and many children with such difficulties require intervention from healthcare professionals to overcome these issues, (Puntis, 2008). Some children may have a more serious difficulty with eating and drinking that impacts on swallow safety. The inability to cope with eating and drinking safely is referred to as "dysphagia". Problems in this area could include the following; inability to manage food effectively in the oral cavity to create a bolus pre-swallow, difficulties triggering a swallow, and problems with the mechanics of the swallow action itself. These difficulties can be as a result of a congenital condition, such as cerebral palsy, or Duchenne's muscular dystrophy or an acquired condition. Infants and young children may also have gastroesophageal reflux, (GORD) and this can have an impact on weight gain, safe swallowing and feeding development, (Mathisen et al, 2002; Vakil et al, 2006; Bhatia et al, 2009).

Eating, drinking and swallowing difficulties can have severe and adverse health effects on children and in some cases can lead to alternative methods such as tube feeding, (Cook et al, 1999). All the conditions mentioned may create long term problems that require the need for alternative feeding such as gastrostomy insertion to ensure that risk of aspiration is reduced and adequate nutrition can be taken.

There is a small cohort of children who have a gastrostomy tube inserted early in their life, but who make progress, (such as children who have had chronic reflux), but who no longer require the tube. These children can be highly resistant to developing oral feeding skills.

This paper seeks to explore an Intensive Approach within a Paediatric Gastroenterology Team that developed oral feeding tolerance with children who had had prolonged periods of tube feeding. All children who participated had an early history of persistent infant reflux that impacted on feeding development and the safety of the swallow. This study will also attempt to consider the rationale for working with this population.

Prevalence.

Some studies have attempted to quantify the types and range of difficulties that children may have. Predictions vary, but Babbitt et al, (1994) report that there are up to 25% of children within a normal population who experience some eating aversions, and up to 33% within a developmental disability group. Food aversions can have a serious impact on a child's oral motor development, (Senez et al, 1996; Hawden et al, 2000; Mathisen et al, 2002), and consequently, early monitoring and intervention is highly recommended, (Puntis, 2008).

A UK study explored early feeding with 9,360 mothers of infants born in 1991/1992, (Northstone et al, 2001). Questions were asked about infant feeding behaviour at 6 months and at 15 months. Up to 40% of the sample reported some degree of feeding difficulties by the time the infant was 15 months of age. Other

studies reflect that the number of children with feeding aversions within a normal population may be around 4%, (Skuse et al, 1994; Wilensky et al, 1996).

There appear to be key clinical areas where there are increased chances of dysphagia. For example, children who were born prematurely or those with developmental delay with an early history of severe reflux can have difficulties establishing successful feeding, (Douglas et al, 1996). Infants who have GORD are likely to have lower energy intake, a significant increase in food refusal behaviours, be difficult and more demanding feeders and have challenging mother-child interaction during mealtimes, (Mathisen et al, 2002).

Infants and children who receive tube feeds because of complex needs are at risk of developing oral hypersensitivities due to prolonged tube feeding, (Hawden et al, 2000). Consequently, these children are highly likely to develop significant difficulties in learning to tolerate eating orally. This may have an impact on the child's social and emotional development.

Multidisciplinary working.

It is suggested that a multidisciplinary approach to feeding disorders where there are a range of skilled professionals can help to minimise long term and persistent problems, (Puntis, 2008). An effective team for children with feeding difficulties is recommended as comprising of a paediatrician, clinical psychologist, dietitian, speech and language therapist and clinical nurse specialist, (Harris et al, 1992). Other researchers suggest that a team approach to diagnosing and treating complex feeding needs has to occur to enable progress to be made, (Wolke et al, 1992). Specialist Feeding Clinics provide a team approach to managing these disorders, although few studies have established the efficacy of such teams, (Puntis, 2008).

Approaches to working with children who have long term feeding needs.

Due to the wide range of feeding problems that can occur and the persistent nature of some of these difficulties, behavioural issues can develop and delay progress. Some parents feel that tube feeding can enable both themselves and their child to have an improved quality of life, (Manhant et al, 2009).However, children who have needed tube feeding for a significant amount of time, but who do not require this any longer may have difficulties weaning off their tube dependence. Senez (1996) suggests that therapists should work on the tactile, taste and olfactory aspects of development for tube feeders, whereas Bazyk (1990) stresses the importance of allowing tube fed children who are planning to wean off feeds the opportunity to experience hunger through changing the timing of tube feeds. This may act as an important trigger in developing opportunities to tolerate oral feeding.

Douglas (2002) critiqued various approaches used that deal with food refusal. This paper attempts to identify and discuss underpinning principles in therapy approaches for this population and suggests that due to the complex nature of feeding problems and the various aetiologies involved, it is important to reflect on a range of theoretical models linked to each child's individual needs. Learning Theory, Developmental Approaches and Attachment Theories are discussed in relation to children's persistent behavioural needs around mealtimes. Douglas recognises the fact that parental support and a mixture of psychological and therapy approaches,

(e.g. messy play), are essential aspects in intervention with this population. Parental support may involve specific coaching and feedback during mealtimes to provide confidence to ensure appropriate strategies are implemented.

Because of the assumption that food aversion is largely a behavioural issue, some researchers have chosen behavioural approaches to remediate food refusal eating disorders. These studies have looked at behavioural approaches to attempt to improve a child's oral intake. Approaches may include stimulus fading, giving contingent positive reinforcement and making food refusal behaviour non-functional, (Freeman et al, 1998). Single case studies, (Markell et al, 2001; Kelley et al, 2003),focus on specific shaping behaviours and training to encourage children to eat more, but results are not clear as to maintenance effects. Ahearn et al, (1996) developed an in-patient programme for three children with a range of food aversions. All made improvements with *physical guidance* and *non-removal of the spoon* (the two key approaches focused on) to above 80%. Clear definitions of mealtime behaviours were given, e.g. *acceptance, negative vocalisations, expulsion, disruptions, and self-injurious behaviour* and these behaviours decreased as the intervention progressed. Follow up improvements were noted for two children up to10 months. Some of the principles defined in these papers have been used when weaning children off tube feeding.

A few studies have attempted to evaluate interventions to wean children onto oral feeding from prolonged tube feeding. Eleven children with mild to severe learning disabilities participated in a programme to reduce dependence on tube feeding, (Blackman et al, 1987). Children were required to have; 1)a stable medical condition; 2) a minimal developmental level of 6 months; 3) no dysphagia or aspiration ; 4)family involvement ; and 5)a history of prolonged tube feeding. Staff were reported as carrying out the intervention with no additional parent coaching whilst the children received the intervention. A basic description of the intervention was included. It was not clear as to what the level of parental support was during and post the process. The range of children within the group had with very different feeding disorders and needs, and therefore it is difficult to draw specific conclusions and possible strategy management skills needed from this study to be able to replicate it. In addition, it was stated in the study that two of the children had significant swallowing issues post the study, (one of whom died due to a choking episode during eating).Consequently, the results need to be treated with caution because of the types of disorders the children within this group had, and the reality of implementing a tube weaning programme with such a population.

Two studies have attempted to define in more detail their approaches. Burmucic et al, (2006) evaluated tube weaning with two children with Alagille syndrome, (2 years and 4.5 years), and in addition, this paper described the intervention schedule, (an in-patient approach), and the role of each professional, including developmental psychology and speech and language therapy, (e.g. oral – motor stimulation). Interestingly, both children lost weight when beginning the programme, but gained weight as they progressed. One child weaned successfully in 7 days, the other in 13 days. Kindermann et al, (2008) worked with ten children, aged 9 – 21 months over a period of 12 days where children were admitted as in-patients. This study also included specific inclusion criteria as did the Burmucic et al,

(2006) study. These criteria included the following; team agreement that the child would benefit; exclusion of significant organic issues and stable oral motor skills with no aspiration. Exclusion guidelines were clear, in particular, excluding children who were still at risk of aspiration. Outcomes for the Burmucic study stated that "normal feeding behaviour and stabilization of body weight were established" for both children, (p935), but there is little information on parental feedback and longer term outcomes. Kindermann et al, (2008) demonstrated success with nine out of ten of the children eating orally. All children were eating post 1 week of intervention with a mean of 9.1 days, (range 4 – 24) to wean off tube. The children were re-evaluated at 3 months and six months. At 3 months children maintained their skills. At 6 months post the intervention, eight out of ten remained on full oral feeding.

Other studies have also attempted to define a specific approach and have also highlighted the importance of the multidisciplinary team when dealing with this population, (Byers et al, 2003; McGrath Davies et al, 2009). Byers et al, (2003), recruited 9 children with a mean age of 3.1 years, (range 1.8 – 5.5 years), on an in-patient programme which lasted an average time of 11.4 days. The programme involved largely behavioural therapists and psychologists coaching parents using behavioural approaches. On discharge from the programme, 44% of the population had weaned completely from gastrostomy feeding with maintenance effects noted. McGrath Davies et al, (2009) also carried out a tube weaning programme with nine children with a mean age of 27.3 months; (range; 7 months to 52 months). Careful assessment of oral motor skills was carried out to eliminate aspiration risk. Some of the population did have mild developmental delay. Unlike other studies, this paper clearly defined the team involvement. As part of the intervention, pain rehabilitation was implemented with use of medication, the rationale being that early feelings of pain during feeding may have caused a strong association with mealtimes, and therefore contributed to significant food aversions. This was an out-patient study lasting 14 weeks, with eight out of the nine participants feeding orally at the end of the programme.

Background and rationale to the study.

The studies mentioned have small samples by nature of the specific population of children who have long term gastrostomy tubes and oral aversions. Also, the wide range of aetiologies within the populations studied makes it difficult to draw specific conclusions about how to approach these cases successfully, and with minimum risk. Due to the wide range of factors involved within the learning disabled population, it was felt appropriate to explore an approach with children who did not have significant learning and physical needs first. This study attempts to define a rationale for this population that could be a discussion point in providing a more consistent approach to these children and parents, and hopefully lead to further studies and investigations to explore key themes more rigorously. At present, there is no specific recommended package of care prescribed that demonstrates the most effective intervention for children who have prolonged tube feeds and who have the oral and pharyngeal capability to take an oral diet.

This pilot project has attempted to evaluate an intensive five day group intervention where children with food aversions who need to wean off tube feeds

received a multi-disciplinary out-patient therapy package of intervention at an inner city hospital. This was compared with a parent and child who opted for the traditional feeding clinic approach that involved individual consultations.

Method.

Participants.

This study recruited five children aged from 3 years 9 months – 4 years 8 months from the paediatric gastroenterology caseload at an Inner City Hospital. Given the highly specific nature of the difficulties these children have, gaining a large sample was challenging, hence the small sample size. Two of the children were excluded from the study as both were unwell at the time of the interventions being offered.

Two children and their parents / carers elected to receive an Intensive Approach, (Child A and Child B), whilst one child and her parents/carers elected to receive the Traditional Approach, (Child C). All children and their parents / carers were offered both approaches. The mean age of the participants was 4 years 4 months, (range 3 years 9 months – 4 years 8 months).The mean age of the surgical placement of the tube was 8.3 months, (range 8 months – 9 months).

Table 1: Child characteristics and medical history.

Child:	**Age at onset of study:**	**Age of gastrostomy tube insertion:**	**Gender:**	**Medical history:**
Child A:	4 years, 4 months.	8 months.	Female.	IUGR; GORD; premature, born at 34 weeks. Displays some mild texture aversions.
Child B:	3 years, 9 months.	9 months.	Male.	GORD; born at 41 weeks; uncoordinated sucking and swallowing pattern; “floppy larynx”. Displays some severe food texture aversions.
Child C:	4 years, 8 months.	8 months.	Female.	GORD; motor delay – floppy baby; liver disorder; premature, born at 36 weeks.

				Displays some moderate texture aversions.

Key:
IUGR = Intrauterine growth retardation.
GORD = Gastroesophageal reflux disease.

Ethical approval was gained form the local NHS Committee and City University, London.

Inclusion Criteria.
Inclusion criteria were as follows:

1. Children participating had to be known to the hospital gastroenterology team, and aged between 6 months – 5 years of age.
2. Children participating should not have had any illnesses relating to aspiration over the last year, and have highly competent oral motor skills as assessed using the Paediatric Oral Skills Package – POSP ,(Brindley et al 1996 ; Table 2).
3. Children participating would have had clear evidence such as videoflouroscopy data to indicate that they had a safe swallow and no other significant risk factors that would effect the development of full oral feeding.
4. General health with participating children would be judged by doctors involved to be robust enough to sustain a progression to full oral feeding.
5. Maintenance of adequate weight during tube feeds for the past year.
6. Children participating would have competent cognitive and language skills that did not fall below the first standard deviation in assessments.

Table 2: Summary of oral motor function before the intervention.

Child:	01 - 02	03 -05	06 – 08	09 - 011	012 - 014
Child A:	0	0	0	0	0
Child B:	0	1	1	0	0
Child C:	0	1	1	0	0

POSP Categories	**Key:**
01 Facial features / symmetry. 02 Symmetry of the smile. 03 Jaw: habitual posture. 04 Jaw: ability to open mouth. 05 Ability to close mouth. 06 Lips: habitual posture. 07 Lips: tone of upper lip. 08 Lips: tone of lower lip.	0 = no oral motor difficulties. 1 = mild oral motor difficulties. 2 = moderate oral motor difficulties. 3 = severe oral motor difficulties.

09 Tongue: habitual position. 010 Tongue: status at rest. 011 Tongue: habitual posture. 012 Palate: structure of the hard palate. 013 Palate: structure of the soft palate. 014 Palate: movement of the soft palate.	

Setting and materials.

The interventions offered were as follows:

1. Traditional Approach.

The child and her parent who elected this approach received an individual monthly 30 minute multidisciplinary feeding clinic appointment (dietitian, speech and language therapist, consultant gastroenterologist, psychotherapist). Information collected included growth assessment, monitoring of tolerance to enteral feeding and dietary assessment as well as a review of medications. This approach does not always involve direct intervention with the child, but may involve some demonstration and discussion of strategies to facilitate eating and drinking skills outside of a functional context. Some individual sessions may take place outside of the clinic and arranged by individuals in the team as appropriate.

2. Intensive Approach (intervention).

Children and parents who elected to receive this approach were offered a five day intensive programme of daily group intervention. This involved Monday to Friday outpatient attendance at an inner city hospital, but was based within the hospital playroom and school room. These sessions were 1.5 hours long and involved multidisciplinary assessment and intervention. Mealtime observations occurred daily combined with direct speech and language therapy intervention to reduce oral aversion. Parents received verbal coaching in addition to the therapy the children received, and this assisted parents in identifying challenges and areas to develop. This is an approach where goals were discussed and agreed with parents on a daily basis with psychology support being a key part of the multidisciplinary team based on direct observation of child feeding behaviour. Parents were asked to keep a 7 day Food Diary one week pre-intervention, during the intervention and a further 7 days 3months post intervention. Each child's diet was analysed by a dietitian using Dietplan to inform levels of current oral intake and levels of tube feed.

Three days prior to day one of the intervention week each of the children in the intervention group were individually assessed for a reduction in tube feeds prior to the commencement of interventions. This was designed to stimulate hunger in the children by the start of the five day intervention. Child A already met over 50% of her total energy EAR (Estimated average requirement) with oral nutrition so A's tube feeds were stopped prior to the intervention week and instead the same volume of water was given via PEG to limit the risk of dehydration for three days pre-intervention. Child B's tube feeds were reduced by 30% (400kcal) only as pre intervention less than 10% of his total nutrition came from oral intake. The reduction in tube feeds was supplemented by an increase in water (400ml) via tube pre intervention to remove risk of dehydration.

The general routine of each session was as follows:

1. **Greeting time:** Children would arrive with their parents /carers and lunch boxes/picnics would be placed unpacked on a trolley.
2. **Mat time:** Children would be informed of the routine of the session with a visual timetable, and would also be introduced to basic oral stimulation work through "vegetable of the day". This involved exploring the texture and tastes of raw vegetables. The children would have their attention drawn back to the visual timetable throughout the session, (speech and language therapist and dietitian present to provide support).
Rationale: Some researchers suggest that children experience tastes and textures and gain sensory stability and development from these experiences around 6 -9 month level, and that should they miss these experiences, then sensory integration and development will not take place. (Illingworth et al, 1964; Clark et al; 1990; Lawless, 1985;Senez et al,1996). This task is rooted in this assumption, and enables children to become desensitised to and experience tastes and textures in a fun, non-threatening activity.

3. **Drink time:** Water only, (50 – 100 mls in a cup, no bottles or cartons).
Rationale: Water can have an impact on satiation, so amounts were limited pre-eating so that children could potentially take in more solid food, (Lappalainen et al, 1993).

4. **Cooking / messy play activity:** Children would have a specific play task around messy play e.g. making fruit kebabs, fruit trifle, etc, to enable them the opportunity to experience positive feelings about food through play. During this time, parents /carers would leave the room and spend time discussing concerns/clear goals, etc with the psychology, speech and language therapy and dietetics staff. Use of information from the video recordings such as e.g. specific language to use with the children, (not using reprimands when food is not eaten), amounts of food to target, etc. was shared.(One speech and language therapist and play specialist remained with the children for messy play, and one speech and language therapist joined the dietitian and clinical psychologist with the parents for discussion of goals).

Rationale: This activity allows adults working with the child to focus on oral desensitisation and practice functional movements such as chewing in a play context. Due to prolonged periods with no or minimal oral feeding, children often develop challenging behaviours associated with eating as well as oral hypersensitivities. Oral desensitisation therapy is rooted in the acquired oral-motor disorders literature. However, the assumption that the alignment and integration of motor and sensory skills is an important aspect considered within paediatric therapy approaches, and as such forms the foundation for activities such as this one, (Winsten, 1983; Langmore, 1994; Gilmore, 2003; Senez et al, 1996).

5. Washing hands.

6. Plating Up: Parents/ carers re-entered the room at this point and prepared the child's meal. They were expected to eat with their child. Team members made sure that parents did not put on how much they *wanted* child to eat, but how much is

realistic and achievable. The goal was for children to have experiences of success, i.e. finishing a plate, and having the opportunity to go back for more if they wanted to. In addition, to reduce children becoming too full, only ¼ of a cup of water was allowed during the meal. If more was requested, then they would have to have finished their plate of food first. Children would be given specific coaching and modelling from their parents, (speech and language therapist and dietitian present to provide support).

7. Washing hands.
8. Good-bye. Children were invited to play and wait in the playroom with play / support staff if there were any final specific issues pre-the next session to be discussed with parents.

Design.

This study is a comparison of two approaches for children who have had long term tube feeding, and who have the capacity to take their nutrition orally. It is a before and after measures study that seeks to explore a current management approach with an intensive approach for these children.

It is hypothesised that those children receiving the intensive direct therapy and multi-disciplinary group intervention initially are likely to receive more satisfactory outcomes with maintenance effects as well as quicker transition to full oral feeding compared to the traditional/individual therapy approach.

Data collection and agreement.

At the beginning of the intervention, baseline assessments were carried out. These involved height, weight and amount of oral versus tube feeding the children experienced, and number of days taken to achieve full oral feeding. A food diary was also completed by the parents and carers at each stage of the process. All children participating had their oral motor skills evaluated using the Paediatric Oral Skills Package (POSP), (Brindley et al 1996) to ensure they met the inclusion criteria.

At the end of the intervention, the same assessments were completed with a further follow up at one month and 3 months to evaluate maintenance effects. Assessments were video recorded at each stage. Independent blind-rating of the video recordings took place and was carried out by a health care professional who did not participate on the intervention to validate the results. The inter-rater agreement was 89%, (Agreement/Agreement x Disagreement x 100). Discussion took place where some of the meanings were unclear.

Video analysis was undertaken for each child pre-the intervention, at one month and at three months post the group and involved distinct areas of observation linked to papers reviewed within the literature review. The responses observed for the children included: ***Initiation of language;****(hypothesis; a child may initiate more language when more relaxed during a mealtime, therefore those in the Intensive Approach may initiate more after the intervention);* ***ignoring of parent;****(hypothesis; the child may ignore the parent less once he/she has received some intervention to support feeding);* ***leaving the table;****(hypothesis ; children*

receiving the Intensive Approach may leave the table less as they become more confident with eating).
The responses observed and recorded for parents /carers included:
Reprimands;*(hypothesis ; with coaching, the parents may use fewer reprimands over time during mealtimes);* ***coaxing;****(hypothesis; post training, the parents would use less coaxing to encourage their child to eat);* ***commenting*** *(hypothesis; parents should reduce their feelings of anxiety and therefore make more positive general comments about their child's mealtime behaviour).*

Descriptive data was collected for weight and height for all children. Changes in oral versus gastrostomy tube intake were calculated. Child and parent language and behaviours during mealtimes were analysed descriptively. Children's nutritional requirements were calculated using dietary nutrient RNIs (Reference Nutrient Intakes).

Results.

The results summarising outcomes for the children include weight and height measures, changes in oral and gastrostomy tube feeding, and changes in the use of language by children and parents during mealtimes.

Table 3: Estimated Average Requirement / intake before and after the intervention.

Time	Total oral nutrition intake (kcal)		Nutrition from PEG (kcal)		Total (kcal)		EAR (estimated average requirement)*	% of EAR from oral intake
Pre-intervention (one week)	A	750	A	500	A	1250	1140	66
	B	0	B	1200	B	1200	1050	0
	C	600	C	800	C	1400	1140	53
6 weeks post intervention	A	1100	A	0	A	1100	1140	96
	B	750	A	540	A	1290	1050	71
	C	650	C	600	C	1450	1140	57
3 months post intervention	A	1300	A	0	A	1300	1140	100
	B	800	B	500	B	1300	1050	76
	C	600	C	600	C	1300	1140	53

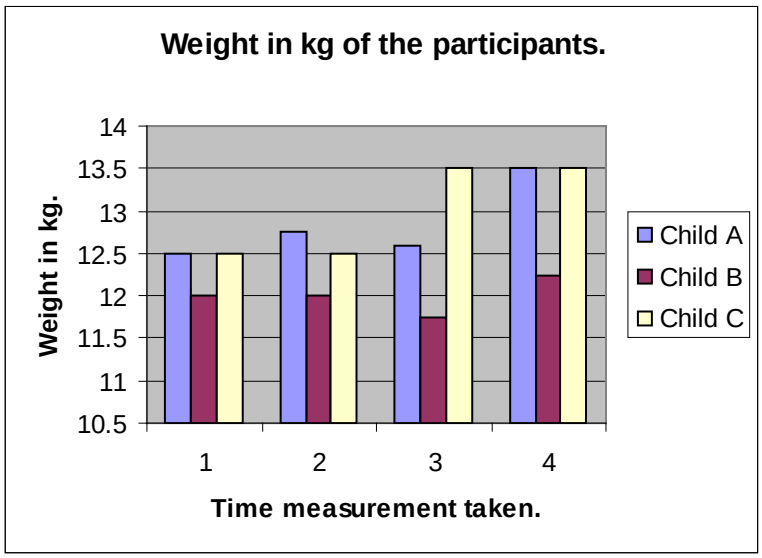
*EAR (estimated average requirement)
Girls 4-6 years of age 95kcal/kg
Boys 4-6 years of age 90kcal/kg

Intensive Approach:
Child A
Child B
Traditional Approach:
Child C

These results show that the children who received the Intensive Approach, (Child A and Child B), demonstrated increases in percentage of estimated average requirement orally over three months. Child A's progress was such, that she did not

require any gastrostomy feeds at 3 months. Child A did not restart tube feeds and supplementary water via the tube was discontinued. Child B had a further reduction in tube feeds mid-way through the intervention week as oral intake increased. Child C, who elected to receive the Traditional Approach, did not demonstrate any significant changes in percentage of estimated average requirement orally over three months.

Table 4: Weight before and after the intervention.

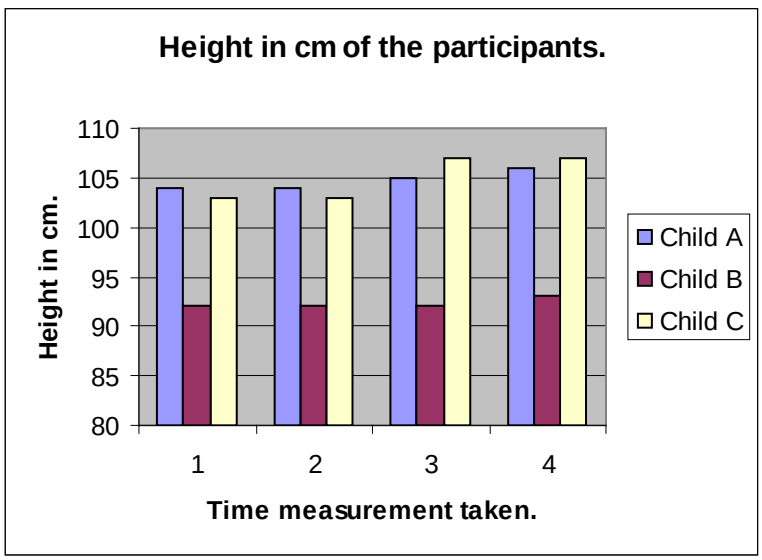


Time 1 = Pre-intervention, (one week).
Time 2 = Post-intervention , (final day).
Time 3 = 6 weeks post-intervention.
Time 4 = 3 months post-intervention.

All three children demonstrated changes in weight during the intervention period. Child A increased her weight by 0.2 kg during the Intensive Approach week. She had a loss of 0.1kg at the 6 week review which coincided with a drastic reduction in gastrostomy tube feeds. At 3 months post the Intensive Intervention, Child A's weight increased to 13.5kg. At this stage, she was taking all of her nutrition orally.

Child B maintained weight during the intervention period at 12kg. He lost weight at 11.7kg and this was attributed to an illness that he had had at the time. At Time 4, his weight had increased above the Time 1 level to 12.02kg.

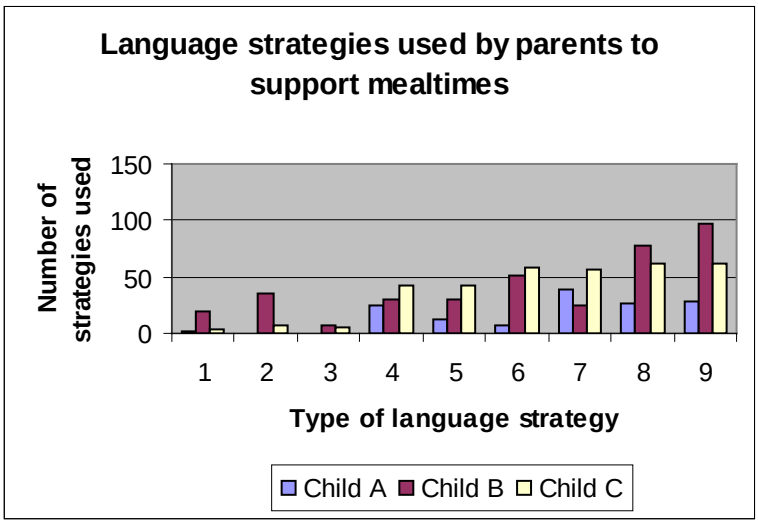
Table 5: Height before and after the intervention.



Time 1 = Pre-intervention, (one week).
Time 2 = Post-intervention, (final day).
Time 3 = 6 weeks post-intervention.
Time 4 = 3 months post-intervention.

All children showed changes in height over the three month period.

Table 6: Language strategies used by parents before and after the intervention.



1 = Reprimands used during time of Time 1, (assessment pre- Intensive or Traditional Approach).
2 = Reprimands used during mealtimes at 6 weeks post Time 1.
3 = Reprimands used during mealtimes at 3 months post Time 1.

4 = Use of coaxing during time of Time 1, (assessment pre- Intensive or Traditional Approach).
5 = Use of coaxing during mealtimes at 6 weeks post Time 1.
6 = Use of coaxing during mealtimes at 3 months post Time 1.

7 = Use of commenting during time of Time 1, (assessment pre- Intensive or Traditional Approach).
8 = Use of commenting during mealtimes at 6 weeks post Time 1.
9 = Use of commenting during mealtimes at 3 months post Time 1.

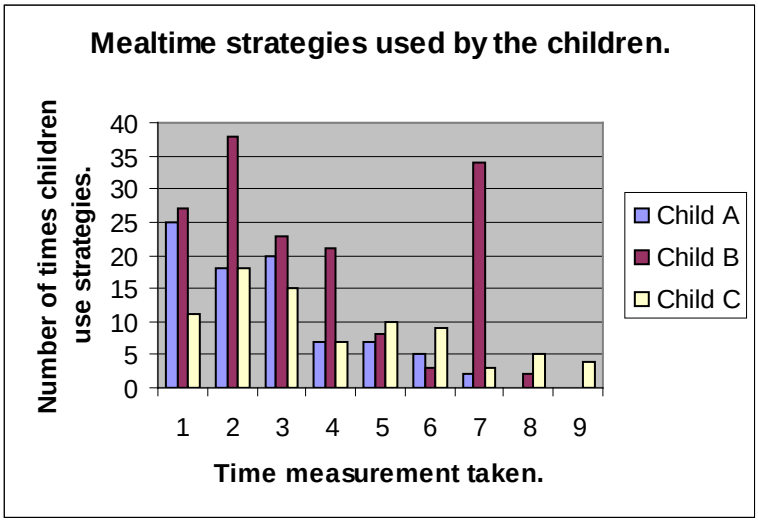
It was hypothesised that the number of reprimands would decrease with coaching. Few *Reprimands* were used by Child A's parents. Child B's parent demonstrated an increase, then a final decrease in *Reprimands* during the 3 month period. Child C showed an even pattern of parental use of *Reprimands* during the meal with no major changes. The original hypothesis speculated that there would be greater changes with use of *Reprimands*, although this has not been indicated in this study.

Coaxing a child to eat food verbally was considered to be a communication aspect that would decrease during and after the intervention. This occurred with

Child A's parents, although Child C's parent demonstrated less change. Child B's parent showed an increase in *Coaxing*, an opposite effect to the hypothesis.

Commenting, i.e. making positive comments about the child's mealtime experience, or how they were functioning, e.g. "Good chewing", was considered something that would increase during and post the intervention. Interestingly, *Commenting* decreased for Child A, increased for Child B and was an equal pattern for Child C.

Table 7: Mealtime strategies used by participant children before and after the intervention.



1 = Language initiated with parent during time of Time 1, (assessment pre- Intensive or Traditional Approach).
2 = Language initiated with parent during mealtimes at 6 weeks post Time 1.
3 = Language initiated with parent during mealtimes at 3 months post Time 1.

4 = Ignoring of parent's communication about the meal during time of Time 1, (assessment pre - Intensive or Traditional Approach).
5 = Ignoring of parent's communication about the meal during mealtimes at 6 weeks post Time 1.
6 = Ignoring of parent's communication about the meal during mealtimes at 3 months post Time 1.

7 = Leaving the table during mealtime at Time 1, (assessment pre- Intensive or Traditional Approach).
8 = Leaving the table during mealtimes at 6 weeks post Time 1.
9 = Leaving the table during mealtimes at 3 months post Time 1.

It was hypothesised that during and post the intervention, children would *Initiate* more language with their parents. All children demonstrated variable levels of *Initiation*, with no distinct pattern being evident.

An assumption was made that children receiving the Intensive Approach would *Ignore* their parents less and engage with them more during the meal. Child A and Child B showed a decrease in the number of times they *Ignored* their parents. Child C who received the Traditional Approach showed a more even pattern of *Ignoring*.

It was thought that after the intervention, children would leave the table less. This was the case for Child A and particularly for Child B who both received the Intensive Approach. There was no specific change throughout the three month period of the study in the number of times Child C left the table, (Traditional Approach).

Discussion.

This study has attempted to define a clear treatment plan and care pathway with a robust rationale for a small group of children who have long term and persistent difficulties in weaning off tube use. Whereas authors have highlighted the essential importance of multi-disciplinary working for children who receive support from Feeding Clinic Teams, (Puntis ,2008), few studies have attempted to evaluate the component parts that create positive outcomes for children and their parents with long term tube dependency. This particular pilot project supports the use of specific strategies to enable change to occur: clear components of parent coaching based around language use to encourage the child; parents' perception of the food amount the child could manage orally and how to deal with this practically and emotionally; involving the children in strategy management through visual prompting and learning from others; modelling and support as well as clear role definition within the team.

The results indicate that weight and height were stable throughout the three months for all three children. Child A had an increase in weight at the end of the Intensive Approach, (from 12.5kg to 12.7kg), but at 6 weeks, (Time 3), displayed a slight loss of 0.1kg. However, at Time 4, three months post the Intervention, Child A's weight had increased to 13.5kg. At Time 3, Child A had recently moved onto taking all of her nutrition orally, and the slight drop in weight at that time was attributed to this. Child B did increase his weight from 12.0kg at Time 1 to 12.02kg at Time 4. A weight loss to 11.7kg at Time 3 was attributed to a cold virus he had had just before follow up, and his mother reported that his appetite had been affected. Child C showed a high increase in weight, from 12.5 kg at Time 1 to 13.5kg at Time 4. Child C was still receiving 50% of her nutrition by tube, 600kcal, with 600kcal orally. Her increase in weight and the fact that she displayed no weight loss was attributed to her ongoing use of the tube. Child C's mother did report that her daughter had started to eat more of her packed lunch at school although if she felt that C had not eaten enough orally, then she still altered how much was taken via the tube.

All children had their average estimated calorific requirement via tube and orally measured before and during the study period. Child A had an estimated average frequency of 750kcal orally at Time 1, and 500kcal by tube, (total = 1250kcal). At Time 4, Child A was able to take her 1300 kcal required intake per day orally with no additional tube feeding necessary. This has been maintained, and Child A no longer has a gastrostomy tube. Child B still has some tube feeding, at Time 4 his total oral intake was 800kcal with 500kcal received via his tube, (total = 1300kcal). However, although he still has some tube feeding requirements, he did not receive any nutrition orally at Time 1. Child C's tube requirements continued to be necessary throughout the 3 month project period, (Time 1; 800kcal, and Time 4; 600kcal). McGrath Davis et al, (2009) reported a time period of 14 weeks for 8 out of 10 children to receive full oral feeding. Within this study, Child A took 12 weeks, and Child B took 12 weeks to take 800kcals orally from previously taking nothing.

It is difficult to make an assumption about which strategies enabled the children to make progress. All children displayed varying levels of texture aversions to food. The strategy used by the speech and language therapists of working with food textures to reduce food phobias was beneficial in this study as with Senez et al, (1996).The consultant and dietitian with support from the clinical psychologists coached the parents to enable them to allow children to experience hunger between meals as suggested by Bazyk, (1990),and Child A and Child B certainly made progress in changing their oral intake.

Parents who received the Intensive Approach coaching used fewer *Reprimands* at Time 4.There was no change for Child C. *Coaxing* and *Commenting* were considered strategies that parents would used differently to support their child's eating development. However, Child A's parents increased rather than decreased their use of this as a strategy, and no specific pattern was noted with Child B, or Child C. Child B's mother increased in *coaxing* and *commenting* when encouraging B to eat; this could be because he was not really eating orally at all at the beginning of the study, and that B's mother was keen that he maintained oral feeding and therefore continued to prompt him and verbally motivate him. He also had mild oral motor difficulties, preferring not to chew foods. B's mother found that reminding B to chew verbally and *commenting* on this has successful outcomes for him in terms of food eaten orally. Child C's mother did not display any specific differences in *Reprimands, Coaxing* or *Commenting* during the project period. A tentative suggestion is that discussion during parental coaching about reducing negative comments such as *Reprimands* during mealtimes can have beneficial outcomes in terms of the amounts children will attempt to make orally.

The parental coaching used by all professionals to support the parents in this project has had benefits, and this is supported in the literature, (Douglas, 2002).Here, a mix of psychology and therapy approaches in the areas outlined, (language use, parent confidence in amounts and types of foods given to the child, etc), has positive outcomes, (Douglas, 2002).

Children who received the Intensive Approach showed differences in leaving the table. Both Child A and Child B showed improvements in this area, especially Child B. Child B attempted to avoid mealtimes initially, leaving the table 34 times at

Time 1 ,but did not do so at Time 4. Child C, (Traditional Approach), showed no specific change in avoiding the meal and attempting to leave from Time 1 to Time 4.

Strategies for *Initiated* language and *Ignoring* the parents' language were also evaluated. No distinct pattern was noted with *Initiating* throughout the project, although with *Ignoring*, Child A and Child B did show a decrease in the number of time they ignored their parents' communication during the meal, (Child A at time 1 ignored her parent 7 times, and at Time 4 5 times; Child B ignored his parent 22 times at Time 1 and 3 times at Time 4. This suggests that the parental prompting did have some value for the children.

The literature quoted does discuss some specific parent strategies, although it has already been stated that these approaches are behavioural in origin, (Ahearn et al, 1996; Freeman et al, 1998; Markell et al, 2001; Kelley et al, 2003).Such strategies included supporting parents to use hand over hand prompting with utensils to help their child participate in the meal, as well as ignoring negative vocalisations. Benefits in the quoted studies from supporting parents in this way have been beneficial.

Conclusion.

This study was different because it attempted to define a range of strategies used by members of the team to facilitate change within an out-patient, non-acute context. In particular, specific methods were used with success. These included; parental coaching in specific areas; working with food textures; enabling children and their parents to deal with changes in their eating behaviours and describing therapy approaches by using a rationale.

This study does support the fact that good outcomes were obtained by close multi-disciplinary working. This study also has value in that it describes component parts of the treatment regime. Such aspects need to be explored further. Of particular interest is the use of language and communication during mealtimes and the impact this can have on the child's ability to engage with the eating and drinking process. It was hypothesised that an Intensive Approach using specific strategies would improve outcomes, and enable children able to feed orally to reduce or wean off tube feeding totally. Success was achieved, but as the sample size was small, it is difficult to generalise these findings to a larger group. In addition, the types of children in the literature who have received interventions to reduce tube feeds have included those with a range of learning disabilities. Future studies do need to focus on specific patterns within clinical groups, but within this pilot project it is interesting to note that all three children had had an early history of GORD, all three had had early oral-sensory issues, and all three had had significant difficulties establishing feeding as infants. The impact of early infant feeding difficulties can chewing be highly pervasive, whilst further research is needed to replicate the findings in this project it is also clear that the initial stages of early feeding require further investigation and exploration in an attempt to prevent the need for long and unnecessary use of tube feeds.

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