

Insights into Pediatric Tube Feeding Dependency – A Speech Language Pathology
Perspective

Abstract

Aim: To identify factors that contribute to pediatric tube dependency from the Speech Language Pathology (SLP) perspective. Tube dependency is characterised by the need to remain tube fed after the need for enteral feeding has ended. Most research relates to intervention programmes for tube withdrawal/weaning. However, there is limited research into factors contributing to tube feeding dependency. SLP perspectives about this morbidity have yet to be explored.

Method: A sequential mixed methodology was utilised. In the quantitative phase, 43 SLPs completed an online survey. Ten participants were then interviewed for the quantitative phase. Findings from both phases were integrated at the final analysis.

Result: There was four clear factors that contributed to tube dependency from the survey; medical condition, the tube fed child's negative reaction to oral feeding, limited appetite, and insufficient clinical time to transition children to oral feeding. The interview data further explained the survey results. In addition, participants perceived the prolonged use of nasogastric tube (NGT) feeding; parental influence; service delivery issues and the challenges of school transition as contributing factors to tube dependency.

Conclusion: SLPs identified that there were often multiple and often competing factors that resulted in tube dependency. Early and ongoing biomedical focus on weight gain continued to affect long-term goals for transitioning to oral feeding. Team goals were not shared or consistent in terms of priorities for the child. This lack of a shared vision led to parents receiving competing and conflicting messages prolonging tube feeding.

Key words

Tube feeding dependency

Enteral feeding

pediatric

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Due to medical advances, more infants who are preterm, and with other medical complications, require tube feeding. Tube feeding, also known as enteral or gavage feeding, is used to increase nutritional intake (Phillips, 2006). After a tube is inserted an important final goal should be to commence oral intake as soon as possible. Tube feeding dependency is the unintended result of long term tube feeding in infants and young children. Dunitz-Scheer, Levine, Roth, Kratky, Beckenbach, Braegger et al. (2009) defined tube feeding dependency as the active refusal to eat and drink; lack of will to learn or the inability; lack of motivation to show any kind of precursors of eating development and eating and drinking skills after a period of enteral feeding.

Tube feeding dependency can cause negative associations with oral feeding such as fatigue, vomiting, or being unable to control food and fluid in the mouth (Mason Harris & Blisset, 2005). Negative reactions to oral feeding can cause family stress, decreased parent-child interaction at mealtimes and undesired behaviours, such as fighting, crying, gagging, coughing and vomiting. These behaviours may in turn cause parents to be reluctant to stop

tube feeding (Davis, Bruce, Cocjin, Mousa & Hyman, 2010; Mason et al. 2005). In order to reduce these difficulties associated with tube feeding and transition children onto oral feeding, research in the last two decades had focused on single discipline behavioural interventions to increase appropriate feeding behaviours and decrease maladaptive feeding/eating behaviours to reduce tube feeding dependence (Sharp, Jaquess, Morton & Herzinger, 2010). In recent years the focus has changed to multidisciplinary interventions as research has begun to recognise the contribution of approaches from across professional groups due to the multifactorial nature of tube feeding dependency. The multidisciplinary approach promotes that successful transition from tube to oral feeding must include practitioners from a range of disciplines working together to address the underlying factors that maintain tube dependence (Edwards, Lyman, Cocjin, Dean, Ernst, Davis, Hyman et al. 2015; Sharp, Volkert, Scahill, McCracken & Mc Elharon, 2017; Wright, 2013a).

The most effective multidisciplinary approach appears to be rapid weaning in the inpatient/onsite and community settings (Trabi, Dunitz-Scheer, Kratky, Beckenbach & Scheer 2010). In rapid weaning, hunger provocation is the primary intervention strategy, involving the reduction of tube feeds over the first five days of intervention to induce hunger (Kindermann, Kneepkens, Stok, Vvan Dijk, Engels & Douwes, 2008). This success is generally attributed to the short transition time children take from tube to oral feeding. Researchers reported the majority of children transitioned to oral feeding after approximately three weeks of intervention (Brown, Kim, Lim et al., 2013; Ishizaki, Hironaka, Tatsuni, & Mukai, 2013; Kindermann et al., 2008; Trabi et al., 2010).

Although this type of intervention has traditionally been done in an inpatient hospital environment; in the last few years rapid weaning has been achieved in the outpatient and homecare settings (Harding, Faiman & Wright, 2010; Marinschek, Dunitz-Scheer, Pahsini, Geher & Scheer, 2014; Nowark-Cooperman & Quinn-Shea, 2013; Wilken, Cremer, Berry, &

Bartmann, 2013). Rapid weaning in both the inpatient and home-based programmes are more successful in terms of faster transition time and higher success rates than other interventions (Ishizaki et al., 2013; Kindermann et al.; Marinschek et al.; Trabi et al. 2010; Wilken et al., 2013).

Despite the success of rapid weaning it is not appropriate for every child. Children with neurodevelopmental disabilities and older children may take longer to acquire the oral motor skills required to consume an age-appropriate diet or to take enough nutrition orally. For children with complex medical aetiologies the transition process needs to progress slowly to allow for oral skills to become age-appropriate (Wright, 2013b). Putting these children through a rapid weaning programme when feeding skills need time to develop may result in significant weight loss and difficulty for children regaining weight during the maintenance phase (Wright, Smith & Morrison, 2011). This weight loss may lead to the resumption of tube feeding due to risks to growth. Regular monitoring over a longer period appears most beneficial to this group of children (Wright, 2013b; Wright et al., 2011).

An alternative to rapid weaning is gradual weaning, which seems a better alternative for these children who are older and/or have neurodevelopmental disabilities. Studies highlight success with gradual weaning interventions, which involve transition over a longer time without using hunger provocation as the main intervention. Successful outcomes have occurred in the outpatient and school setting (Davis, Bruce, Mangiaracina, Schulz et al, 2009; McKirdy, Sheppard, Osborne & Payne, 2008; Wright et al., 2011). Two case studies of children with neurodevelopmental difficulties who had failed previous rapid weaning interventions were successful in the school and home setting with a gradual weaning protocol (McKirdy et al., 2008).

Factors influencing weaning success

Age

Age and degree of exposure to oral feeding experiences may affect success with weaning of tube feeding. Age of the child affects success transitioning to oral feeding (Ishizaki et al., 2013; Marinshek et al., 2014; Wright et al., 2011). Ishizaki and colleagues concluded that children referred for tube weaning over three years of age had a markedly longer treatment time, compared to younger children. Similarly, Wright identified that slow or failed weaning often occurred for children five years and over.

Feeding readiness

Feeding readiness refers to children who are tolerating some foods and fluids prior to tube weaning. Studies have reported transition success due to the children's oral feeding readiness before their treatment (Davis et al., 2009; Nowark-Copperman & Quinn Shea, 2013). Wright (2013a) reported that feeding readiness strategies by SLPs is significant prior to transition, in order to increase the likelihood of success. SLPs typically take the lead in managing swallowing and feeding difficulties and use specific strategies to minimise risk of aspiration and assist infants and children for oral feeding readiness (Dodrill, 2016; Edwards et al. 2015; Sheppard, 2008).

Professional assistance

Tube weaning requires a team approach to support parents through what is often a demanding and at times frightening process. Jolleyman (2013a) suggested difficulty transitioning from tube to oral feeding might be related to the lack of assistance by professionals who can support families. Wright (2013a) reported that health professionals did not assist many parents even though the principles of tube weaning were relatively straightforward. Dunitz-Scheer et al. (2011) argued that many children with feeding disorders do not learn to eat because of lack of professional assistance and lack of information, diagnostic definition, clear guidelines, and clinical expertise.

In summary, although tube feeding is life-saving and an excellent short-term solution to sustain nutrition and growth, it can lead to tube feeding dependency (Dunitz-Scheer et al., 2009). Dependency can occur even though clinically a child's medical condition and developmental potential should allow them to transition easily to eating and drinking by mouth (Dunitz-Scheer et al., 2011).

Rationale for the study

In Australia and New Zealand, SLPs are involved in children's transition to oral feeding (Gardiner, Fuller & Vuillermin, 2014; Jolleyman, 2013) and are considered an essential part of the multidisciplinary team for tube weaning (Edwards et al., 2015; Gardiner et al., 2014; Sharp et al., 2017). Due to their significant role in assessment and management of feeding and swallowing difficulties their perspectives seem important to understand better the context in which tube dependency occurs (Dodrill, 2016). According to Dunitz-Scheer et al. (2009) tube feeding dependency can have a destructive impact on the child's development even in cases when the nutritional benefits might be beneficial. The SLP perspectives on tube dependency appear to have had little attention in the literature and may throw further light on why tube dependency occurs and what is necessary to reduce it.

This study aimed to capture the perspectives of SLPs about key issues around tube feeding dependency in children. This study collected and analysed survey and interview data about tube feeding from SLPs in New Zealand across the health setting and education setting in urban and rural settings. The research question for the study was "What are the factors contributing to tube feeding dependency in children from the SLP perspective?"

Method

Participants

Participants in the online survey, included 43 practising SLPs recruited through a professional email network, National Children's Feeding & Swallowing Special Interest Group. We received completed survey responses from 43 of a possible 110 participants. All participants had undergraduate or graduate qualifications. The majority of participants who fully completed the survey had been practising for more than five years (63%), worked full time (72%) worked in urban (58%) or mixed urban/rural (35%) locations, and for the public health sector (67%).

Participants in the interviews were a sample of 10 SLPs from the 26 respondents in the survey who had volunteered to be interviewed. The 10 interview respondents were all female. The mean number of years of experience for the interview group was 19.50 (SD = 12.82), ranging from seven years to more than 20 years. All worked in either urban or rural/urban settings. Seven SLPs were from the health sector and three from education. Seven worked full time and three were part time.

Measures

Survey

In the quantitative part of the study, the online survey, questions asked about characteristics of respondents including qualifications and years of experience, whether they were currently practising, the nature of their employment contract, work location, and the ages of children worked with. The remaining questions used a 5-point Likert format to ask respondents about their beliefs relating to tube feeding and tube feeding dependency.

Interviews

In the qualitative part of the study, interviewees answered a series of semi-structured questions about tube dependency. All participants were interviewed face-to-face, three in their homes and the rest at their workplaces. Interview questions were semi- structured open-

ended questions. The study was approved by a University Human Subjects Ethics Committee.

Data Analysis

The reporting of the quantitative survey data used simple descriptive statistics (raw scores and percentages) and chi square statistical analyses for some items. Qualitative data were transcribed and then analysed using a general inductive approach as described by Thomas (2006).

Results

The research question was ‘What are the factors contributing to pediatric tube feeding dependency in children from the SLP perspective’. In order to answer the question the survey items were put into categories for the results section. These were: child factors, age factors, parent factors, multidisciplinary team (MDT) factors and SLP factors. Survey responses were put into three levels of response (e.g., agree, undecided, disagree).

Child factors related to tube feeding dependence

Practitioners’ perceptions of issues medical and issues related to the tube feeding and the tube itself affected transitioning. Five questions in the survey asked SLPs to comment on aspects of the tube that may affect the child specifically in terms of influencing transitioning from the tube to oral feeding. Survey respondents agreed that tube dependency was due to medical conditions (58.1%), negative reaction to oral feeding (85.7%), limited appetite (88.4%), fatigue during oral feeding (55.8%) and reflux (51.2%). There was less agreement that vomiting was a cause of tube dependency (48.8%).

The interview data from the 10 SLPs supported the survey results. Most spoke about the impact of children not eating enough at mealtimes/limited appetite, the negative aspects

of prolonged nasogastric tube feeding including sensory defensiveness and aversion associated with the NGT. In addition, some commented on the vomiting and pain associated with the tube feeding. From their practice experience they discerned these were factors contributing to persistent tube feeding.

Interviewees' highlighted children not eating enough or limited appetite as an obstacle to oral feeding, particularly for infants born preterm for example:

I find with ex-prems [infants born preterm but now discharged home] if the tube's been in... like if it doesn't get out in that first six months post discharge, it seems to be really hard to ever get out... Like one of the ex-prems that I've got, she's never had a hunger drive. (p5)

Interviewees stressed the difficulties of scheduled feeding in the Neonatal Intensive Care Unit (NICU) environment impacting the infants' appetite. They reported that there seemed to be no longer term developmental plan to encourage oral feeding. They expressed that these scheduled feeds did not assist in developing the hunger drive in infants. Their concern was that the focus of care in the acute hospital setting is on growth and weight gain even when their medical condition is stable. This medical focus marginalises attention to longer-term developmental goals. For example one interviewee said:

..but even from our newborn intensive care unit it is very much we follow this algorithm and we are not planning for getting them off this tube or.... Yeah, it is kind of crisis care all the way along and then it stops. (p8)

Three interviewees, who worked in a NICU emphasised their concern for prolonged NGT feeding, as this could lead to oral sensory defensiveness or aversion, which is the emotional response by the child to sensory input to the oral facial region. This aversion affects their ability to accept foods orally, and in addition, the volumes needed to sustain

nutrition. Some said that wherever possible there is the need to work proactively to minimise this risk. For example, one interviewee remarked that for a child on her case load having the NGT in for a prolonged period seemed to lead to sensory aversion for the child:

So, she left the ward with a nasogastric tube because she was having difficulty with tolerating volumes and subsequently became unwell multiple times. ... Was nil by mouth for a period of time and now is extremely averse and.., sensory averse to anything around her face. (p5)

The type of feeding tube may be significant in terms of transitioning to oral feeding. One interviewee described a child on her caseload who was discharged home with a percutaneous enteral gastrostomy (PEG) tube instead of a NGT. This infant transitioned to oral feeding quickly. The interviewee speculated that it was possible that the type of feeding tube played a part in this rapid transition to oral feeding. She noted that the insertion of the PEG might have limited the prolonged negative oral and sensory experiences of the NGT:

She actually came out with a gastrostomy tube because she didn't tolerate the nasogastric tube so they had to the gastrostomy while she was in hospital...I do wonder if the fact that she had a gastrostomy rather than a NGT played a part because there is some evidence to suggest that children are more likely to develop an oral aversion if they've had a NGT.. with things going in and out of their noses and nasty experiences around their face, tape causing rashes on their face and having a tube down the back of their throat, all of that I think plays a part. (p4)

A possible problem with NGT feeding is that it may cause recurrent vomiting. Vomiting could possibly prolong tube feeding for these children. One interviewee commented:

I know all the medical team will say that the tube does not cause vomiting but so many families tell me about the vomiting with tube feeds and multiple families see it resolved when the tube comes out. And we've just got to the point now where we call it a functional vomiting issue because there's no anatomical cause, there's no medical cause but we've got these tube fed kids that vomit all the time...I've seen it with all types of tubes.. (p7)

In summary, the participants stressed that they saw correlations between tube dependence and negative oral and sensory experiences associated with the type of tube; lack of appetite; the timing of the intervention; vomiting; and inadequate pain management strategies.

Age factors related to tube dependency

Participants perceived that age was not a factor affecting tube feeding dependency on the two Likert scale questions in the survey. Survey respondents disagreed that children were too old (72%) to transition to oral feeding. In direct contrast, 50% of interviewees did think age was a contributing factor to tube dependency of children, particularly when a tube dependent child reached school age. Interviewees observed that by school age tube feeding had become normalised. They described a plethora of complex, competing demands that resulted in the normalisation and persistence of tube feeding for school age children. These demands included family acceptance of the tube; difficulty with implementing intervention to children with tube feeding issues before they go to school; lack of funding and pressure to service a large caseload. These were some of the factors mentioned to be associated with older children remaining tube dependent.

The following interviewee noted that when tube feeding is first broached with the family of an infant or preschool child it is difficult for families to accept. However, when those children reach school-age, tube feeding has become part of the family routine:

At pre-school it's much harder to get them on tube feeding... Then they are not interested in getting them off anymore, like no one is jumping, there are not many people jumping at school age to get their child off tube feeding. (p1)

Another interviewee reported a similar experience of tube feeding becoming normalised:

And I think as well when kids get to five, six or eight.. I've seen these tubes at eight, and families by that point have really normalised stuff and they reach a point of acceptance of this is the way it is.. (p6)

The SLPs responses above highlighted the limited capacity of families to adapt to the different needs of their children, as they get older. This results in SLPs having little influence about tube weaning once the child reaches school age.

Parent factors related to tube feeding dependency

SLP perceptions of parental influence on tube feeding dependency revealed a dichotomy for parents. SLPs perceived parents, although motivated for their child to be eating orally, had major concerns for their child's nutritional safety. The survey results found the majority of parents were motivated to transition their child from the tube onto oral feeding (76.7%). Only a small minority agreed with the statement that parents relied on tube feeding (20.9%). Half of the participants agreed with the statement that parents were concerned about their child's nutrition (51.2%). Only 32.6% agreed that parents were reluctant to transition their child from tube to oral feeding. In contrast, the interviewees recounted numerous instances when parent concerns did strongly relate to tube dependency.

Most of the interviewees commented that transitioning the child from being tube fed to oral feeding was difficult because of parental concerns about their child losing weight. For example, one interviewee commented that the constant weighing of the tube fed child,

ordered by medical team members creates an anxiety cycle for parents about possible weight loss. This interviewee questioned the frequency of it due to the anxiety it causes:

Because the constant weighing I think, is also a very stressful factor for parents. And I wonder sometimes whether it's necessary....She was happy that he was gaining weight. For some families just a child losing a few ounces of weight is hugely stressful. (p3)

Interviewees reported that for many of the families of tube fed children, reliance on tube feeding and measuring calories and weight started in infancy. This medical role of watching weight gain and counting calories made it hard for parents to let go of the tube and start transition to oral feeding. For example, one interviewee reflected on her experiences with families where the parents were reluctant to transition their child to oral feeding. Tube feeding became normalised and relied on even if their child was developing well. A consequence of the parents' experiences in infancy and the medicalisation of the parental role had led to this reliance on the tube even when their child could be an oral feeder:

I've definitely had families that, it's really hard to get rid of the tube even when the child's doing quite well it's really hard...for them to step away from it because they always have that backup., ...It's the parachute of always having to be able to give a tube feed if needed. And I think when parents have that initial stress and anxiety of, especially a neonatal experience and becoming so focused on weight gains that they lose sight of typical children and normal development and normal weight fluctuations. (p7)

Interviewees highlighted that for many families, the predictability of tube feeding was preferable to revisiting any of the traumas and uncertainties associated with experimenting with oral feeding.

Multidisciplinary team and workplace factors related to tube feeding dependency

SLP perceptions revealed differing opinions on workplace issues affecting tube feeding dependence. The survey results found a clear split with almost half (41.9%), of the respondents thought it was due to team reluctance and the other half, (39.5%) did not think team reluctance was a factor. There was also a split of opinion as to whether tube dependency was due to lack of team confidence to transition to oral feeding (41.9% agreed; 37.2% disagreed). Most agreed that there was not enough clinical time to address transitioning (53.5%).

The interview data indicated that workplace issues were the reasons for prolonged tube feeding. The main issues were lack of funding, increasing caseloads and lack of joint team planning. In regard to increasing caseloads, one interviewee highlighted that service delivery becomes fragmented because of historical policies and increased referrals especially for children with complex needs:

Yes, so I certainly struggle with having a large case load.. We're kind of getting squeezed more and more to try and provide a greater service for a larger population and a more intensive service as well. But yeah, it's really hard to provide that. (p5)

In terms of funding constraints, interviewees perceived that social services were not keeping abreast of medical advancements. Although more children are surviving the funding for complex medical issues has stayed static. This affects the tube fed child's long-term quality of life due to compromised service provision as described below:

You know, a lot of children are surviving with more complex medical issues.., I think it's great that these children, are surviving and they're able to go home with these feeding

tubes but it has had a big impact on service provision and unfortunately there hasn't been any extra funding to support these children in the community which is a real... a real problem.

(p4)

Interviewees commented on the lack of integrated planning and communication among the MDT members affecting feeding plans. The following interviewee worked in a NICU ward and spoke about an incident when her feeding plan was changed by a night nurse. The infant subsequently had a negative feeding experience due to being given a faster flow bottle teat:

The frustrating thing is that when you start off feeding, and you say 'ok I don't want you to do more than 10 minutes because they're getting tired', and then you'll get somebody who comes in on the nightshift and decides well you know this is taking far too long, we'll just put it on a faster flow teat and the whole thing goes to custard.. Instead of people following the plan. People don't read, the notes or the feeding plan, it is frustrating. (p10)

In addition, SLPs thought that MDT members being located in different departments subsequently affected clear goal setting between professionals. An example of this is seen in the next interviewee quote. Below, an interviewee commented about communication gaps due to the separation of the MDT within the same health service. She commented that as the nursing and child development team were not located close to each other in their hospital setting, this physical separation caused limited communication between health professionals. The interviewee perceived that the need to transition takes second place because of the compartmentalisation of care where each professional is advising within their scope of practice rather than being team, family and child focused. The opportunity to transition a child gets lost:

And because we don't all work in one team so anyone who is tube fed will have a dietitian and home care nursing but they are in a separate department and we meet together every 2 weeks and do as much as we can to work together but we are all so busy and so stretched that things do fall over sometimes....we come at things from different perspectives. ..So I come very much from a developmental perspective and they come very much from a medical perspective and sometimes it lines up really well and other times it just doesn't. ... I mean only in my experience, it feels less related to medical conditions and more related to planning. (p8)

Interviewees' comments highlighted a number of issues in with dealing with these complex children. The impact of historical policies not keeping abreast of changing status of children; members of the MDT not working cohesively and the challenges of geography and professional scopes of practice. The most concerning point being the communication breakdowns in the MDT impacting the child's potential to be weaned.

SLP factors related to tube dependency

Practitioners' perceptions of their ability and entitlement to advocate and influence clinical care impacted on weaning decisions. Six questions in the online survey asked SLPs to comment on their own attitudes and experiences about tube dependency. Survey respondents mostly agreed that managing the child's feeding was a significant part of their work (67.4%); that transitioning to oral feeding was a high priority (83.7%); and they frequently addressed tube feeding issues including dependency (69.8%). They believed they were prepared to address this (62.8%) and judged that experienced with working with tube dependent children (65.1%). They expressed confidence to advocate for transition to oral feeding (67.4%).

In contrast to the strong agreement that came up in the survey, the interviewees commented on the complexities facing SLPs working with tube fed children. Interviewees thought there were three main issues that influence tube feeding dependency. Firstly, SLPs having a small voice in the larger MDT, negatively influencing their ability to advocate for tube fed children. Second, the reluctance of parents and school staff to change what they are used to. Thirdly, the SLPs interviewed reported a lack of confidence in their own skill set to convince all the stakeholders in this complex situation that children should move towards their oral feeding potential.

An interviewee in the inpatient (health) setting described the challenges advocating for tube fed children, as they were often the only SLP on the MDT. When they tried to voice their professional views they believed that they were not acknowledged:

...We have a very small voice on the teams and it also means that when we are saying but what about this, but what about this, but what about this then you become the annoying person, because there is only one voice quite often. (p8)

An interviewee working in education had a similar experience of feeling that they were the only professional wanting to advocate to encourage oral feeding in children. She experienced professional isolation. This interviewee said that it was very hard to convince members of the team that the child's situation could change and to encourage oral feeding:

And people then just start accepting things that they are the way they are and then if you go in and try and change them it's like, well this is the way it is and it works so why would we change it.....And I used to feel very lonely in the school. (p6)

Similarly to the survey results another interviewee expressed that she felt that some SLPs were hindered in doing tube weaning work due to a lack of confidence in their own skill set and not being supported by the wider team to try and work on oral feeding potential:

Sometimes the risks I think are being..., hyped up more than they need to be and then people are just getting scared to go there. It's not just the funding, it's also the culture, it's the fear of touching it (tube feeding) it is the environment, the people in the environment, families or team members who are just not that keen on change. (p1)

To summarise, in contrast to the overall survey results, the SLPs who were interviewed perceived professional disempowerment and isolation in both the health and education settings, impacting their confidence to advocate and effectively support tube fed children to reach their oral feeding potential. Some felt they were a small voice in relation to the wider team working with the tube fed child.

A possible reason for the discrepancy between survey results and interview results relating to SLP confidence in managing dysphagia might be differences in confidence between SLPs in the health sector and those not in the health sector. To determine if there was a difference between these two groups a series of chi square analyses of the survey items was carried out. The chi square results were checked using the Fishers Exact Test which takes into account small sample sizes and the results were the same. For most items, there was no statistical difference between the two groups but there were some differences.

The results in Table 1 show significant statistical differences between the two groups on four of the survey items. First, in terms of the extent to which tube-feeding management was a major part of their work, those in the health sector saw it as more significant ($p < .001$) than did those in the non-health sector. Second, those in the health sector more frequently addressed tube feeding issues than did those not in the health sector ($p = .001$). They were also more likely than those in in non-health sector to see transitioning as a high priority ($p = .021$) and perceive that their team and workplace prioritised transitioning ($p = .001$). Those in the health sector were also more confident to advocate for transition ($p = .007$) compared with those in the non-health sector. These statistical differences indicated that SLPs in the

health sector were more competent and confident to deal with tube dependency than those not in the health sector.

Insert Table 1 here

Discussion

The aim of this study was to obtain the SLP perspective about the factors that contributed to pediatric tube feeding dependency. To assist in understanding why children with developmental potential and no medical reason remain tube fed. The discussion will focus on two main themes derived from the data. The first theme is *medicalisation being a root cause of tube feeding dependency*. This leads to the second theme of the *fragmentation of the tube fed child's continuity of care*.

Medicalisation as a root cause of tube feeding dependency

Medicalisation is a powerful 'lens' through which health professionals and lay people make sense of health, illness, and embodiment. Medicalisation can also mean that perspectives of medical staff may take precedence over the views of other health professionals (Kanieski, 2010) and that all practitioners tend to prioritise the immediate, narrow biomedical outcomes over broader quality of life goals. Often from the beginning of their child's life, parents are 'schooled' in the life-saving value of biomedical interventions and so they too learn to defer to biomedical conceptualisations of their child's health and wellbeing. In this study, this medical perspective often focused on the medical condition of the child rather than their developmental potential and persisted beyond the initial crisis time when the tube was first inserted. The parental concern about their child's potential weight loss and the security provided by long-term tube feeding was evident.

The results indicated that SLPs considered parental concern about their child's potential weight loss substantially affected tube weaning. The study's findings support parental concern

regarding weight loss is reported in the literature and has ramifications for the child transitioning to oral feeding in the future (Dunitz-Scheer et al., 2011; Edwards et al., 2015; Wright, 2013b; Wright et al., 2011).

This parental anxiety and subsequent reliance on the tube appear to stem from the volume-driven culture of the NICU unit (Shaker, 2013), where weight gain is prioritised over the broader development of the child. This medical prioritisation of weight gain beginning in the NICU environment appears to affect the potential for weaning from the tube to oral feeding. The prioritisation of weight can consequently impact the child in terms of appetite-loss and insufficient oral motor skills. The survey results showed that the SLTs perceived reduced oral intake of food at mealtimes as a cause of tube feeding dependency. This finding was supported by the comments from the interview participants. A possible reason for the reduced oral intake of food was the inability of tube fed infants and children to establish appetites due to rigid tube feeding schedules (Mason et al., 2005). This lack of connection between oral feeding and satiety is concerning because researchers have found that children who have limited oral intake have difficulty developing the oral sensorimotor skills needed for eating (Edwards, Ernst, Sitzmann, Keeler, Davis, Bruce & Hyman, 2015; Shepperd, 2008). Shepperd (2008) comments further that if sufficient practice time, task repetitions, and appropriate environmental supports are not provided for oral feeding, the child may have delayed development or acquire dysfunctional movement patterns for feeding. This impact on development may lead to persistent tube feeding and consequently tube feeding dependence.

Another aspect of the medicalisation of tube feeding dependency is long term NGT feeding. This practice was a factor preventing efficient and successful transition to oral feeding. The SLTs perceived that children with NGTs inserted for prolonged periods, a duration greater than six weeks, were more likely to become tube feeding dependent. Current European guidelines recommend if the duration of enteral nutrition exceeds four to six weeks

then gastrostomy, particularly percutaneous enteral gastrostomy (PEG) is indicated for infants and children (Braegger, Decsi, Dias, Hartman, Koletzko et al., 2010). The concern with prolonged NGT feeding, according to the SLPs, were the symptoms the children acquired. For example, the development of oral aversion to food, exacerbated vomiting, and pain in the nasopharyngeal region when NGTs were used for prolonged periods. These negative experiences are consistent with findings in the literature regarding the negative side effects of prolonged NGT feeding. Often leading to the tube fed child refusing oral intake as they get older (Avitsland, Birketvedt, Bjornland & Emblem, 2013; Babl, Mandrawa, O'Sullivan and Crellin, 2008; Mason et al., 2005).

The SLTs in this study perceived that medicalisation was possibly a root cause for tube feeding dependency. This biomedical focus on the child starts in the NICU environment and progresses through the child's care. As a result, goal planning and care plans are influenced, affecting the child and family's continuity of care as they transition through different services. This leads to the second theme to be discussed, where medicalisation leads to *fragmentation of the care pathway for the tube fed child*

Fragmentation of the care pathway for the tube fed child

The influence of medicalisation leads to fragmentation of the care pathway for the tube dependent child. The results of the study suggested that the continuity of care for tube fed child was fragmented. The absence of a cohesive approach was highlighted across the data, including a lack of planning and integration amongst the MDT working within and across services, insufficient clinical time with increasing caseloads and lack of resourcing despite the increasing numbers of tube fed children. The results also indicated that there was decreased clinician confidence to intervene and the lack of cohesion of the MDT may have contributed to the normalisation of tube feeding once children are in school. Ideally, according to Reid, Haggerty and McKendry (2002), the care pathway should be coherent, connected, and

consistent with the patient's needs over time. The ineffective ways of working caused by service constraints highlighted in both health and non-health settings by the participants were found to contribute to lack of cohesion and vision by the MDT.

Similarities to what these SLPs experienced were also found in the health literature. Researchers found ineffective communication pathways, restricted information transfer and limited collaboration between professionals in health settings. Resulting in the discontinuity of care for children with complex needs (Jeyendra, Rajadurai, Cajnmugam, Trieu, Nair et al., 2013; Psaila, Schmied, Fowler & Kruske, 2014).

Resourcing issues appear to influence the transition rate of school age children. Jelleyman (2013) and Wright (2013a) found that shortages of SLPs in New Zealand and the United Kingdom meant that the practice of tube weaning was limited. Research is needed to find ways to assist tube fed children reach to their oral feeding potential, despite resourcing constraints.

The results also indicated that there was decreased SLP confidence to advocate for the transition to oral feeding for children. Fragmentation of the MDT may be a reason why the interviewees perceived lack of confidence in advocating for tube fed children in the school setting. The study found significant differences between SLPs that worked in health and SLPs in non-health settings in terms of their perceptions on the management of tube dependent children including confidence in treating and to advocate for them in the wider team environment. Their difficulty in managing tube fed children in schools, as reported by this study's results is consistent with other research findings. In the United States researchers also found a lack of confidence in SLPs that work in an education setting to deal with the challenges adapting dysphagia and feeding practices traditionally used in a health setting (Bailey, Stoner, Angell, Fetzer, 2008). SLPs in their study worried about safety and health, e.g., choking. They felt they lacked sufficient training and administrative support especially from those in

medical settings. The results of the present study showed similar concerns from SLPs not in the health sector about whether they had sufficient support, training, and confidence to treat dysphagia.

Current ASHA guidelines state that clinicians and other professionals in the school system must be prepared to recognise signs and symptoms of dysphagia and be prepared to provide appropriate interventions for dysphagia, including assistance with the transition to oral feedings if appropriate (ASHA, 2007a; Lefton-Grief & Arvedson, 2008). For SLPs and members of the MDT, however changing practice to focus on dysphagia and feeding when historically the focus has been on communication difficulties may be a major challenge. Particularly, if their work setting cannot yet provide them with adequate support in this expanded scope of practice. A concerning finding of this study was the SLPs perception of the normalisation of tube feeding by school age. This highlights the need for a change of culture with more leadership from managers and professional leads and not just focusing training on frontline staff.

Limitations and directions for future research

This study has provided the perspective of SLPs only regarding tube feeding dependency. Further investigation to gather information from children and families is warranted on how to best empower them with encouraging oral feeding and tube withdrawal. Interventional quality improvement studies focused on MDT collaboration may be worthwhile.

Although tube weaning is developmentally ideal, an early and ongoing biomedical focus on weight gain disrupts long-term goals for transitioning to oral feeding. The emphasis of health care professionals on the medicalisation of tube feeding may result in prolonged dependence. Furthermore, the goals of the members of the MDT were not seen to be shared

or consistent in terms of priorities for the child. This lack of a shared vision by MDTs could also be a major reason for prolonged tube feeding. Most importantly, there is a need for SLPs to take up greater advocacy for these children; to bring about change in service delivery and training of diverse professional groups to enable them to move away from medicalisation to a developmental potential.

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Conflict of Interest Statement

The authors declare that there is no conflict of interest.

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INSIGHTS INTO PEDIATRIC TUBE FEEDING DEPENDENCY: A SPEECH-LANGUAGE PATHOLOGY PERSPECTIVE

Table 1

Raw scores, percent scores, and chi square comparisons between Health Sector and Non-Health Sector SLPs in relation to tube dependency

| Questions | Ratings | Health Sector | Non-Health Sector | χ^2 (N=43) | Fisher's Exact Test (p values) |
|--|--------------|---------------|-------------------|-----------------|--------------------------------|
| How significant is the management of the child's tube feeding in relation to your overall management of the child? | Low | 0 (0%) | 0 (0%) | 14.28*** | <.001 |
| | Moderate | 4 (14%) | 10 (71%) | | |
| | High | 25 (86%) | 4 (29%) | | |
| How frequently would you spend addressing tube feeding issues with your client and the client's family? | Never/rarely | 0 (0%) | 3 (21.4%) | 13.09** | .001 |
| | Occasionally | 4 (14%) | 6 (42.9%) | | |
| | Frequently | 25 (86.2%) | 5 (35.7%) | | |
| Transitioning tube dependent infants and children from tube feeding to oral feeding is a high priority | Agree | 27 (93.1%) | 9 (64.3%) | 7.71* | .017 |
| | Undecided | 2 (6.9%) | 2 (14.3%) | | |
| | Disagree | 0 (0%) | 3 (21.4%) | | |
| My team sees transitioning as a high priority | Agree | 22 (75.9%) | 5 (35.7%) | 7.82* | .017 |
| | Undecided | 5 (17.2%) | 4 (28.6%) | | |
| | Disagree | 2 (6.9%) | 5 (35.7%) | | |
| I am confident to advocate transition from tube to oral feeding for my clients in my workplace | Agree | 24 (82.8%) | 5 (35.7%) | 9.84** | .009 |
| | Undecided | 3 (10.3%) | 4 (28.6%) | | |
| | Disagree | 2 (6.9%) | 5 (35.7%) | | |

Note: * = p<.05; ** = p<.01; *** = p<.001