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A service evaluation of parent adherence with dysphagia management therapy guidelines: Reports from family carers supporting children with complex needs in Greece

Article category: Research paper

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Abstract

Purpose: Many children with complex needs exhibit eating, drinking and/or swallowing disorders (dysphagia). These children often have associated learning needs, and require assistance from carers for daily tasks such as eating and drinking. The aim of this study was to identify which strategies to manage dysphagia were challenging for family carers, and reasons for any non-adherence.

Method: In this service evaluation researchers observed carers during mealtimes, and investigated carer opinions of strategies used to minimise the risks of dysphagia. Eight children with complex needs aged 3.4 - 7.5 years and their primary family caregiver participated.

Results: Adherence with speech and language pathologists' dysphagia recommendations overall was over 50% in all but one case. For specific strategies, the highest adherence was observed for diet modifications of foods (89%), communication during the mealtime (83%), amount of food to present (81%) and the pacing of fluids and foods (81%). Lower levels of adherence were identified in relation to postural management (58%), environmental changes (58%), utensils (56%) and preparatory strategies (49%).

Conclusion: Adherence with use of strategies to support mealtimes was over 50% in all but one case. Findings suggest that support is essential in order to promote safe mealtimes, reduce family carers' stress and increase knowledge, confidence and adherence in implementing dysphagia guidelines in the family home.

Key words:

Feeding difficulties; carer adherence; complex needs; mealtime strategies; dysphagia

Introduction

Many children with complex needs exhibit eating and drinking difficulties and/or swallowing disorders (dysphagia) (1). These children often have physical disabilities and associated learning needs, requiring assistance from carers for daily tasks such as eating and drinking. Mealtimes present challenges for family carers and can be stressful and unpleasant (2).Despite the life-threatening consequences related to non-adherence with speech and language pathology (SLP) dysphagia recommendations, carer practices supporting children with neurological impairments during mealtimes has been an understudied area.

Within the population of children with complex needs, the prevalence of dysphagia is variable. For children with specific disorders such as cerebral palsy, aspiration difficulties have been identified in 31% - 99% of participants in the populations studied (3; 4; 5; 6). For general neurodevelopmental difficulties, the prevalence of swallowing problems has been identified in 34% of participants in a group studied (7). It is acknowledged that there is variation in both the interpretation of and definition of eating and drinking difficulties in these studies, with variability in reporting oral preparatory, oral phase and pharyngeal phase problems. Feeding and/or swallowing disorders are associated with significant poor health outcomes such as aspiration, under-nutrition, growth failure, gastroesophageal reflux and constipation (8). Health difficulties, along with challenging mealtime interactions can have a negative impact on a child's daily mealtime (9; 10).

As many as 89% of children with complex needs are likely to require some assistance during mealtimes (8). Difficulties associated with providing support include the stress experienced by family carers (9; 11). Family carers' lack of knowledge of eating and drinking safety and nutritional needs have also been found to be factors leading to variable feeding practices when assisting children with complex needs (11; 12; 13).

To help reduce risks associated with dysphagia, SLPs develop programmes to support safe mealtimes and promote a positive eating and communication environment (1). The selection of appropriate strategies depends on the child's nutritional needs, feeding and swallowing skills, specific medical conditions, intellectual abilities, as well as the family environment (14; 15). Strategies may include postural / positioning changes, diet modification, equipment / utensil use, biofeedback, oral-motor treatments, pacing and feeding strategies, sensory stimulation techniques and environmental changes (1).

Intervention success is inextricably linked to the level of consistency of use of the strategies recommended. Non - adherence with dysphagia strategies by adult patients with acquired and progressive neurological problems has been associated with negative clinical outcomes, among which aspiration pneumonia was reported as the primary cause of death (18). Family carers comply significantly less with strategies to support those they care for compared with professional carers assisting patients within the medical setting (19). Family carers have been reported to be less responsive and often underestimate the need to follow recommendations to support eating and drinking recommended by a speech and language pathologist (20). Adherence in this context may be related to confidence in developing the competence to carry out the strategy, and Ray et al (21) comment that it can take up to six months for families to feel comfortable using necessary skills needed to provide adequate care. Some strategies have been reported by carers as being simpler and easier to carry out (e.g. posture and positioning, use of specialised equipment/utensils), or alternatively, more challenging to follow and comply with (e.g. consistency and food preparation, monitoring and prompting, pacing, time and resource limitations) (19). However, these findings cannot be generalised in relation to family carers supporting children with complex needs and highlights the need for further research.

To date, no study has investigated implementation of and adherence to SLP dysphagia management guidelines by family carers supporting children with complex needs. The aim of this service review of practice was to combine observational data from home-based mealtimes with carers' experiences in order to explore rates of adherence and to identify reasons for non-adherence. It was hypothesised that carers would find some strategies easier (e.g. positioning) to implement compared with others (e.g. preparatory strategies such as oral motor exercises).

Materials and methods

In this service evaluation family carers' use of and opinions of the strategies recommended to support their child's eating and drinking difficulties was observed. The primary investigator of the study was a highly experienced speech and language pathologist in Greece (bilingual in English and Greek) who had not been working with the participants. Ethics approval was granted by City, University of London Ethics Committee, (MSc/14-15/07) and by the Hellenic Society for the Disabled in Athens, Greece (letter of approval issued). Quantitative and qualitative data were collected via direct observations and semi-structured interviews. Participants were dyads of preschool and school aged children with complex needs and their primary family carer in the home setting during mealtimes. The participants were recruited via a local society for children with disabilities. Parents received information about the service review, inviting them to participate. Inclusion criteria for children included: i) a diagnosis of a neurological condition; ii) a minimum of 6 months participation of the local society's rehabilitation services; iii) feeding and/or swallowing difficulties, as reported by the local society's medical team and, vi) a need for a high level of assistance during mealtimes as reported by the local society's rehabilitation services.

Inclusion criteria for family carers included: i) Being the primary person supporting the child during mealtimes at home; ii) being willing to give consent to be video-recorded during one home-based mealtime observation and to participate to an audio-recorded semi-structured interview; and, iii) attend with his/her child one 30-minute SLP session, during which the dysphagia management strategies devised for the child would be reviewed at least two weeks before onset of the study's video recordings.

Following recruitment, background information was collected on each child participant from the rehabilitation service including: aetiology, the types of eating and drinking problems the children had (oral, pharyngeal and/or oesophageal stages), if a videofluoroscopic swallow study (VFSS) had been performed and aspiration had been detected, epilepsy, descriptions of mobility (mobile, limited mobility, not mobile, spastic quadriplegia, spastic diplegia), and level of Gross Motor Function Classification System (GMFCS) (I to V) (22) for children with a diagnosis of Cerebral Palsy (CP), and finally, level of Eating and Drinking Ability Classification System (EDACS) (I to V) and level of assistance during mealtimes (I to III) (23) (Table 1). For the GMFCS, EDACS and levels of assistance measures, a higher numeric classification is associated with a greater need for supports. No measure of feeding was available for participants without CP, as the possible assessments are not translated into Greek.

The first part of the study consisted of a home-based video-recorded observation of one meal and one drink for each child - family caregiver dyad. When evaluating the video recordings, the primary researcher observed features as indicated in Table 1. The strategies observed (Table 1) were based on the range of approaches typically used by SLPs in the team.

- ***Put Table 1 about here –***

The second part of the study involved a brief semi-structured interview of the family carer with the primary researcher. All interviews were conducted in Greek, and translated into English by a Greek SLP. The translations were completed by the primary investigator. Another Greek and English speaking SLP also translated the interviews separately to check for accuracy. There was a high level of agreement between the two SLPs, but this was not statistically analysed. The interviews used the questions in Table 2, to collect information about difficulties carers were experiencing with the guidelines. Additionally, reports about potential reasons for failing to adhere with the recommended strategies were recorded. The carers were allowed enough time to reply to every question and were free to discuss as many difficulties as they wished.

- ***Put Table 2 about here -***

Analysis

All analyses of the quantitative data were carried out using the IBM Statistical Package for the Social Sciences (SPSS) (Version 22). The video – recordings were analysed using the same methods as reported in the Chadwick et al., (19) study:

1. **Discrete behaviours** were scored dichotomously (yes/no), for example "Caregiver presents mashed food – pureed homogenous consistency".
2. Programme advice that involved a **particular behaviour throughout the mealtime** was scored on a 5-point scale (whole meal = 1; most of the meal = 0.75; half of the meal = 0.5; a little during the meal = 0.25; none of the meal = 0).
3. Programme advice that was **opportunity-dependent** was scored only if it was hypothesised that the particular management strategy was necessary to be implemented, for example

> “Provide verbal guidance in order to slow down the speed of drinking liquids and swallowing mouthfuls / small pieces of solid food”. If the guideline was not assumed to be necessary, it was marked “*not observed*” and was not counted in the total number of guidelines.

A framework approach was used and analysis was completed according to the five stages recommended by Pope et al., (24): *Familiarisation; identifying a thematic framework; indexing; sorting; mapping and interpretation.*

Reliability

To ensure reliability of the primary researcher’s observations when evaluating the video recordings, an independent assessment was made for all 8 observations by a second researcher, who was also an experienced paediatric SLP. Kendall's rank correlation (τ) suggested statistically significant agreement between raters, with the sole exception of the “Supervision and Prompting during the mealtime” strategy (Table 3).

- **Insert Table 3 here –**

Inter-rater reliability was calculated on 30% of the parent interview analyses. Inter-rater agreement was found to be excellent (kappa range 0.61-1.0, mean agreement) between rater 1 and rater 2 (see table 3).

Results

Nine families volunteered to participate in the study, whereas one dyad subsequently declined to continue with the study for personal reasons, forming a total sample of eight child-carer dyads (Table 1). The mean age of the children was 5.30 (SD = 1.32, range = 4.10), with an equal number of boys (n = 4) and girls (n = 4) with complex needs. All family carers were female and in seven cases the mother of the child with complex needs. The remaining carer was a grand-mother (Table 4).

- ***Put Table 4 about here -***

PART 1: Quantitative data analysis of mealtime video recordings

Adherence with dysphagia programme recommendations

Carers demonstrated variability with how they followed the meal time therapy plan (Table 5; range of adherence observed was from 24% - 88%). The number of observed strategies differed between participants, ranging from 24% to 88%. Two participants (participant 5 and participant 6) showed the highest percentages (88% and 87%, respectively) of observed strategies. Five participants ranged from 64% to 78% in their usage of dysphagia strategies recommended in their programmes (Participants: 1, 2, 3, 7, 8), whereas Participant 4 showed the lowest percentage of observed recommended strategies (24%).

For specific strategies within the guideline categories (Table 6), higher mean percentage scores were observed for carers using strategies for “Diet modifications of foods” (89%), “Communication with caregiver during the mealtime” (83%), “Amounts” (81%) and “Pacing” (81%). Lower levels of adherence were observed for “Postural changes & Equipment for positional support during the mealtime” (58%), “Environmental changes” (58%), “Utensils” (56%) and “Preparatory strategies” (49%).

- ***Put Table 5 about here –***

PART 2: Carer Interviews

Carers highlighted difficulties with managing the majority of strategies within categories, with the exception of “Diet modifications of foods” and “Communication with caregiver”.

Preparatory strategies

"Preparatory strategies" caused the most concerns for carers. In particular, "vibrations" (participant 5), "brushing" (participant 5) and "deep pressures" (participant 7), were reported as difficult to apply. Participant 5 reported that "*Vibrations scare her [child] a lot (...)".*

Diet modification of fluids

"Diet modifications of fluids" was reported only by one carer (8) as being difficult to comply with; "*I was always very scared he would choke*".

Diet modification of foods

No concern was reported by any of the eight carers about "Diet modification of foods" as being a difficult strategy to implement.

Amounts

Two participants (participant 4, participant 7) reported difficulties with strategies on the dysphagia programme relating to "Amounts". Participant 4 expressed concerns about the child's rejection of fluids leading to limited hydration, whereas participant 7 acknowledged giving larger than recommended mouthfuls of food during mealtimes.

Postural changes & equipment for positional support

Positioning and equipment guidelines were reported as difficult to comply with by three carers (participant 1, participant 2 and participant 6). Two carers reported their child's refusal to be fed on the special seat thus, having to feed them on their lap. Interestingly, Participant 6 reported another clinician in the child's care as having advised the caregiver to feed the child on her lap, which contradicts the SLPs individualised dysphagia programme. Another carer reported not using the specialised equipment for postural support during mealtimes (participant 2).

Utensils

Only one carer (participant 1) reported difficulties relating to the feeding equipment and specifically, independent use of a cup when drinking.

Communication with caregiver

No concern was reported by any of the eight carers about "Communication with caregiver" as a mealtime strategy.

Supervision and prompting

"Supervision and prompting" recommendations were reported as challenging by three participants. Difficulties with monitoring and prompting throughout the mealtime were reported by one carer (participant 2).

> *"But sometimes, if I haven't noticed that she has a lot of food in her mouth and I give her water, then she may choke a bit but nothing really happens."* (Participant 2)

Two carers (participant 3, participant 5) reported concerns with monitoring during mealtimes due to their child's physical (participant 5) and oral-motor difficulties (participant 3).

> "*Also, sometimes when she is sleepy, I prefer to let her sleep and feed her later, because when she wants to sleep she may keep the mouthful in her mouth and it's quite dangerous."* (Participant 5)
>
> *"(…) chewing is not continuous, I mean she chews a little bit and then she stops and she might just swallow it the way it is."* (Participant 3)

Environmental changes

One carer (participant 4) reported that “Environmental changes” recommendations could be time consuming. Specifically, the carer described the safety measures and environmental modifications they had to make at home and at school, in order to manage the child’s challenging behaviour and inability to focus on eating during mealtimes.

Pacing

Only one carer (Participant 7) acknowledged conducting the mealtime more quickly than recommended.

Behaviour

Managing challenging behaviour during mealtimes was highlighted by two carers (Participant 4; Participant 6). As discussed earlier, for Participant 4, the child’s challenging behaviour was also associated with the caregiver’s difficulty in following recommendations related to environmental changes. A child’s refusal to eat during mealtimes was discussed by one caregiver as follows (participant 6); *“If he wants to (eat), it’s very easy to feed him (eat and drink)... “IF” he wants to, of course ... the difficulty lies more in his behaviour*” (participant 6).

The findings highlight that the highest adherence was noted for diet modification and communication during the mealtime, with no carers reporting these two forms of strategy hard to implement during a mealtime.

Why dysphagia strategies are hard to implement

Caregiver difficulties

Two carers (participant 3, participant 7) expressed feelings of insecurity during mealtimes and their need to be offered training for the adequate application of the dysphagia strategies. Specifically, carers pointed out that despite being able to understand the theory behind the recommendations, difficulties arose with the practical implementation.

"*I feel insecure and need guidance…when you are not an expert you feel insecure*" (participant 3).

"*Of course, as I've said to X (SLP), we are not always exactly following the instructions we have been given*" (participant 6).

*"Also, I find it a bit difficult to make the preparatory strategies in order to prepare him for the mealtime with the deep pressures and the movements with the sponges... but it's just because I have never done this before. …..It was something new for me, I did it for the first time there. That's an area we could say that I need to be trained"(*participant 7).

The child

Children's physical (participant 1), behavioural (participant 4) and oral-motor difficulties (participant 5) were reported by carers as affecting the mealtime process, leading to difficulties complying with recommended dysphagia strategies.

"I don't know if there is a reason, I cannot say that something bothers her on the special seat, I guess she doesn't like it. But that's how my older daughter was, she didn't like the chair and she was eating with me on the couch"(Participant 1)

"During the last months, he has become extremely naughty, very mischievous, although before he was quiet ... he constantly needs someone to chase him and watch him. (…) But he is no longer quiet as he used to be… he is restless! *"*(Participant 4)

- ***Put Table 6 about here –***

Discussion

This service evaluation observed family carers' levels of adherence with mealtime eating and drinking strategies in the home setting as recommended by a speech and language pathologist. It also investigated carer opinions of strategies used to minimise the risks of dysphagia. It was hypothesised that some recommendations for each child such as "Equipment for positional support" would be easier to implement than other recommendations such as "Diet modifications of fluids". Results showed that with the exception of one child-caregiver dyad (Participant 4), all carers were able to carry out more than half of the SLP dysphagia strategies recommended on their individual programmes, indicating a good level of adherence (Table 5 and Table 6). It was noted that Participant 4 had significant needs, with a GMFCS (22) score of 5 and an EDACS (23) level of IV, and was totally dependent on carer support. As many strategies are opportunity dependent, it could be that the child's responses to strategies vary from day to day, indicating that the results gained from the observations undertaken are not fully representative of the daily experience of supporting mealtimes for children with complex needs.

When evaluating specific strategies within the defined categories (Table 2), it was found that all strategies, with the exception of "Preparatory Strategies" (49%) were adhered to more than 50% of the time during observations (56% – 89% Table 6). This is encouraging, indicating that family carers supporting children with complex needs at home demonstrated good levels of adherence with SLP dysphagia programme recommendations. Preparatory strategies and postural changes and equipment were discussed by some carers as being difficult. Interestingly, although environmental strategies and use of utensils were two areas of management with the lowest levels of observed adherence, only one participant reported difficulties in these areas. The high level of adherence observed in this service evaluation contradicts previously cited studies which highlighted poor adherence of both family carers and paid carers of people with learning disabilities and adults with acquired and progressive neurological difficulties (18; 19). Carers often reported difficulties in carrying out preparatory strategies before the mealtime, in particular, strategies for oral sensory stimulation, e.g. brushing. The invasive nature of these strategies potentially highlights the need for SLPs to provide more demonstrations when training carers as well as verbal and written information. Two carers admitted not completing the advised preparatory strategies, whereas another carer mentioned that vibrations as a sensory stimulus were not beneficial for the child. It may be that carers do not view these approaches as functional, and therefore they are not seen to be helpful in the way that other strategies are. A lack of evidence in the literature related to preparatory strategies reflects the current debate about the effectiveness of sensory integration and oral - motor strategies in children with complex needs. Arvedson et al (29) completed a systematic review evaluating the effects of oral motor exercises for children with sensorimotor and swallowing problems and found insufficient evidence to indicate that they were beneficial. In this service evaluation, adherence with preparatory strategies gained the lowest levels of observed strategies (49%), with participants reporting that these were hard to implement.

The level of observed recommended strategies was high for diet modifications of foods, caregiver communication with the child during the mealtime, amount of food / fluid to be consumed, duration of mealtime and average speed of given mouthfuls to child (pacing). High levels of adherence to food preparation strategies have also been identified in other studies. Chadwick et al., (20) and Rosenvinge & Starke (25) found that the concrete nature of food preparation guidelines appears to facilitate recalling and promotes appropriate implementation of what is expected. This is important as texture modification strategies can compensate for motor difficulties and reduce aspiration risk (2). Previously, findings regarding adherence to pacing of food and drink have been unclear. Pacing has only been exclusively assessed in Chadwick et al., (20), showing moderate levels of adherence. However, in this study adherence was assessed only after providing training to carers. Interestingly, in this service evaluation carers were found to implement an appropriate speed during mealtimes for more than 75% (most of the mealtime). It may be that this was successful as the SLP involved with the families could spend time providing hands – on training when supporting the carers and children's mealtimes at home.

With postural changes, two carers admitted feeding the child in their lap and not in the special seat when the child appeared upset. Chadwick et al., (20) found fewer barriers with positioning and postural guidelines when supporting adults with learning disabilities. Only nine participants out of forty six reported that maintaining an upright position was difficult, and these carers specifically looked after people who had cerebral palsy (20). Poor adherence with guidelines regarding posture & equipment has also been identified (25) prior to carers' training, whereas Chadwick et al., (19) identified extremely high levels of adherence after providing training. Potentially, difficulties with postural changes during mealtimes underline the physical nature of this particular strategy and the need for providing hands-on demonstration. Considering the direct relationship between postural stability, mobility and function of oral - facial structures, the collaboration of the physiotherapist, OT and SLP is essential for establishing appropriate head control and whole body stability (pelvis, hips, trunk, shoulder girdle and legs) in order to promote safety of mealtimes (26).

In this service evaluation, carers found it difficult to monitor, observe and prompt children during the mealtime. Specifically, two carers mentioned not checking for any oral food debris and one mother reported difficulties monitoring if the child had sufficiently chewed mouthfuls of food before swallowing. As in the case of the preparatory strategies, the effective use of supervision and monitoring skills requires carers to have an adequate level of knowledge and experience in order to properly identify and manage these difficulties. Thus, as has been emphasized by Chadwick et al., (27), appropriate description and demonstration of the dysphagia guidelines is essential in order to establish safe mealtimes for the child and reduce caregiver's anxiety. Aside from preparation, one carer had concerns about the child's refusal to drink enough water, whereas another acknowledged giving larger mouthfuls of food due to concerns about growth failure. As has been demonstrated in the Oxford Feeding Study (9)**,** carers of children with neurological impairments are concerned about the nutritional problems associated with dysphagia, which in turn heightens stress during the mealtime.

A high number of successful communication events, between carers and the children (83%) were observed as recommended on the therapy plan. This is important as parents can support eating development by using specific types of language (17). In contrast, there were fewer observed examples of supervision and prompting strategies (67%). In Chadwick et al., (19), communication and supervision were incorporated into the same guideline category, which was perceived by carers to be complex, specifically pacing and supervision strategies, even after training. Rosenvinge & Starke (25) did not assess communication between patient-carer dyads, but these authors identified that professional carers in the adult medical setting demonstrate poor adherence when implementing supervision and monitoring dysphagia guidelines. Positive results observed for the carer-child dyad communication levels may reflect the difficulties of managing mealtime dynamics for children with eating and drinking difficulties. Notably, as children with eating and drinking difficulties experience more disruptive mealtimes, carers have been found to adopt a more controlling role and make use of a directive, rather than an interactive communication style (17; 28). This assumption may be further supported considering that family carers of children with neurological impairments have been reported to experience stressful and unpleasant mealtimes (12; 13). Additionally, Veness & Reilly (17) identified a relationship between a child's level of severity of eating and drinking difficulty and the pattern of carer interaction. Harding et al (16) highlight the problems of using augmentative and alternative communication. Considering that all children in this study were non-verbal, it is reasonable to assume that the levels of communication between child and carer were largely carer – led, with carers using language to encourage and prompt the child during the mealtime.

The main methodological limitation of this study is that it is a descriptive service evaluation that did not compare the strategies observed with comparisons. Other services may create recommendations which do not incorporate all of the strategies mentioned which therefore makes generalisation of the findings from this service evaluation difficult. It is also a limitation that no measure of feeding was available for participants without CP.

In addition, being observed may have influenced caregiver behaviour. Specifically, awareness of being observed may have prompted carers to follow more rigorously the dysphagia guidelines and strategies recommended; thus, potentially observations may not have highlighted practices carers usually apply in their daily setting. However, observation of practices in the home setting, including mealtime observation, is a common process for assessment and intervention in SLP practice. During the day of the pre-arranged home meeting, after the initial discussion with the caregiver, the primary researcher remained discreet, filming in a location that was non-visible to the child and caregiver. On the other hand, knowledge of being video-recorded may have caused anxiety and nervousness to carers, therefore having a negative impact on adherence. Another important limitation also mentioned in Chadwick et al., (19), is that the caregiver sample included participants who had self – selected for the service evaluation; thus, the sample may have been biased towards carers who were more responsive and aware of the guidelines and the necessity for implementing these strategies to children with neurological impairments and dysphagia. It is also acknowledged that there may be cultural considerations that could not be investigated within the scope of this study. Finally, as observations included only one meal and one drink, caution should be taken in the generalisability of the findings.

For the second part of this study (caregiver interview), limitations include the small sample size and the limited number of interview questions; replication of this study with a larger sample size including broader interviews about carers reports supporting children with complex needs and dysphagia would be valuable in SLP research and clinical practice. Furthermore, considering this was a time-limited project, the questionnaire was not validated on a group of carers prior to the interviews, but was developed by the primary researcher according to the literature reviewed (20). In addition, limited time for analysis allowed inter-rater reliability to be assessed only for a 30% of the participants (three out of the eight participants).

Conclusions

Findings of this study support previous research and contribute new information about the various difficulties family carers supporting children with neurological impairments and complex needs experience in the family home. The implications of the results suggest SLPs should consider carefully which particular dysphagia strategies to recommend in order to improve carer adherence. Notably, as pointed out by Chadwick et al., (19), as adherence varied between strategies to manage dysphagia, SLPs should analyze the specific nature and requirements of each therapy strategy and carefully select the appropriate method for how to support effective implementation (e.g. concrete written recommendations, examples, scenarios, photos, etc.) using an individualised approach for each family. Undoubtedly, replication of this study with a larger sample size and investigation of adherence at home with health outcomes in children with complex needs would be valuable, as has been demonstrated by Adams et al., (11) in a low-cost caregiver training in Bangladesh. It is interesting to note that carers also found that completing specific oral – motor exercises and oral desensitisation work pre- meals was unhelpful. It is recognised that this is an approach used by SLPs where this service evaluation took place. However, it is possible that carers may value therapy approaches which have an understandable rationale and which appear to have a functional application. Given that the benefits of oral – motor exercises to support the management of dysphagia have yet to be proved, further research on these types of therapy approaches is certainly warranted (29).

Families who care for children with complex needs may have to additionally manage their child's eating and drinking difficulties through use of equipment, or through use of specific therapy strategies. Some methods used to support children to eat safely and effectively are easier to implement than others. Research needs to continue to investigate efficacy of these strategies and also methods of supporting parents to undertake these approaches confidently, so that the stress of mealtimes can be reduced, and so safe eating and drinking can be maximised.

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Table 1: Strategies observed during mealtimes

Type of strategy	Description of strategy
Preparatory strategies	Oral - sensory techniques to improve muscle tone and sensation, e.g. stroking and tapping the oral – facial muscles; relaxation and concentration (verbal and physical cues, including reassurance before starting the meal).
Diet modifications of fluids	Texture/consistency; taste; temperature; type of thickener, if used.
Diet modifications of foods	Size of mouthful; texture/consistency; taste; temperature.
Amounts	Amount of food and fluid to be consumed within one meal and one drink.
Postural changes & equipment for positional support during the mealtime	Postural changes of the trunk, limbs, shoulders, head, jaw; equipment for positional support including: chairs, cushions, headrests, etc.
Utensils	Cutlery, cups, non-slip mats, etc.
Communication with caregiver during the mealtime	Means of communication (verbal or augmentative and alternative communication (AAC)); eye contact; verbal & physical cues.
Supervision and prompting during the mealtime	Monitor for signs of aspiration, choking alertness, discomfort, injury; speed of drinking/ swallowing, etc.; check person’s mouth was clear of food debris.
Environmental changes	Changes to minimize distractions/ noise; lighting; enhance social interaction.
Pacing	Average duration of meal; rating of pacing (much too fast; somewhat fast; slow; appropriate).

Table 2: Carer interview questions

Interview questions	
Question 1	Are there particular management strategies from the SLP mealtime guidelines you found difficult to follow?
Question 2	*If the person's answer was "YES" in Question 1, ask separately for each SLP management strategy reported as difficult to comply with:* "Could you explain to me, with more details, what kind of difficulties do you experience with this particular management strategy (e.g. pacing, positioning or other SLP management strategy reported in Question 1 as difficult to comply with)?"
Question 3	*Ask separately for each SLP management strategy reported as difficult to comply with in Question 1:* "Could you think of any possible reasons or factors that make this particular management strategy (e.g. pacing, positioning or other SLP management strategy reported in Question 1 as difficult to comply with) difficult for you to implement?"

Table 3: Rater levels of agreement.

Kendall's rank correlation (τ) among raters

Guideline categories	Kendall's tau-a	Kendall's tau-b	SD	Mean	Lower	Upper	p-value
Preparatory strategies	0.57	0.79	0.286	0.528	0.242	0.814	0.02
Diet modifications of fluids	0.53	1	0.518	0.625	0.107	1.143	0.01
Diet modifications of foods	0.61	1	0.155	0.892	0.737	1.047	0.01
Amounts	0.61	1	0.372	0.813	0.441	1.185	0.01
Postural changes & Equipment for positional support during the mealtime	0.75	0.95	0.393	0.575	0.182	0.968	0.01
Utensils	0.75	1	0.417	0.563	0.146	0.98	0.001
Communication with caregiver during the mealtime	0.54	0.83	0.372	0.813	0.597	1.069	0.02
Supervision and Prompting during the mealtime	0.32	0.4	0.162	0.673	0.311	0.835	0.26
Environmental changes	0.75	1	0.496	0.583	0.087	1.07	0.001
Pacing	0.6	1	0.372	0.813	0.441	1.185	0.01

Note. Kendall's coefficient of agreement suggests agreement between rater 1 and rater 2 for all observed guideline categories in a statistically significant manner, except from "Supervision and Prompting during the mealtime" (p = 0.26). The significance level was set to 5% (0.05).

Table 4: Participant characteristics

Participant's code	Child's gender	Child's age	Diagnosis	Stage at which dysphagia problems presents	VFSS	Aspiration	Epilepsy	Mobility	GMFCS (C.P)	EDACS (C.P)	EDACS Level of Assistance (C.P)
P1	F	3.4	Learning Disabilities -Hypertonicity of upper and lower muscle extremities	Oral	NO	NO	NO	Not mobile	-	-	-
P2	F	5.11	Learning Disabilities – Possible Genetic Syndrome	Oral	NO	NO	NO	Mobile	-	-	-
P3	F	4.8	C.P Dystonic	Oral	NO	NO	YES	Dystonic Quadriplegia	5	Level IV	Totally Dependent
P4	M	6.5	C.P Spastic	Oral	NO	NO	YES	Spastic Quadriplegia	5	Level IV	Totally Dependent
P5	F	4.1	Learning Disabilities – Possible Genetic Syndrome	Oral and Pharyngeal	NO	YES	NO	Mobile	-	-	-
P6	M	5.0	C.P Spastic	Oral	NO	NO	YES	Spastic Quadriplegia	5	Level II	Totally Dependent
P7	M	6.0	C.P Spastic	Oral	NO	NO	YES	Spastic Quadriplegia	5	Level IV	Totally Dependent
P8	M	7.5	C.P Spastic	Oral and Pharyngeal	NO	YES	YES	Spastic Quadriplegia	5	Level IV	Totally Dependent

Table 5. Overall carer adherence with individual guidelines observed

Participant	% of observed strategies complied with
1	67
2	64
3	66
4	24
5	88
6	87
7	78
8	75

Table 6. Proportions of observed specific strategies complied with across therapy guideline categories

Guideline categories	% of observed strategies complied with
Preparatory strategies	49
Diet modifications of fluids	63
Diet modifications of foods	89
Amounts	81
Postural changes & Equipment for positional support during the mealtime	58
Utensils	56
Communication with caregiver during the mealtime	83
Supervision and Prompting during the mealtime	67
Environmental changes	58
Pacing	81