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Managing eating and drinking difficulties (dysphagia) with children who have learning disabilities: What is effective?

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Abstract

People who work with children who have neurological and learning disabilities frequently need to manage the health and emotional risks associated with eating, drinking and swallowing (dysphagia). Some approaches can support children to develop oral feeding competence or to maximise their ability to maintain some oral intake supplemented with tube feeding. However, some clinicians feel that oral-motor exercises can support eating and drinking skills as well as speech and language development, whereas there is little evidence to support this.

The implied "beneficial" association between oral-motor exercises, speech and swallowing skills gives a false impression in terms of future outcomes for parents and carers of children with learning disabilities. This paper considers oral-motor approaches in the remediation of dysphagia and the need for a cultural shift away from this view. Realistic and useful outcomes for people with learning disabilities need to be an essential part of therapeutic intervention.

Keywords

Developing dysphagia intervention, intellectual disabilities, oral-motor interventions, paediatrics, therapy practice

Introduction

Many paediatric health care professionals, in particular speech and language therapists (SLTs), focus on managing the needs of infants and children who have eating and drinking difficulties (dysphagia) in acute and community settings. A typical caseload would include infants and children with neurological disorders such as cerebral palsy, acquired difficulties including traumatic brain injuries or brain tumours, developmental delays, (e.g. Down's syndrome), gastro-intestinal disorders, renal diseases, heart conditions and anatomical anomalies that potentially could impact on nutritional intake and therefore the development of eating and drinking (Field, Garland, & Williams, 2003; Sullivan, Lambert & Rose, 2000). Alongside eating and drinking difficulties, these children are likely to have significant cognitive needs as well as receptive

and expressive communication difficulties. This paper reflects on the current philosophy underpinning approaches to remediate dysphagia, particularly the use of oral-motor exercises in relation to the needs of children with learning disabilities. In addition, it considers the importance of learning benefits and opportunities for children with learning disabilities when there are the perceived requirements to "manage" a particular difficulty through a programme which may sit uneasily within the regime of a learning environment (Clark, 2003).

The environment plays an important part in learning, and the provision of learning opportunities. This occurs right from birth, where the stimulation from interaction between infants and carers supports early learning (Als et al, 2004; Bowlby, 1969; Rutter, 1979). Communication also has its greatest meaning, and therefore learning in functional contexts (Tomasello, Carpenter, & Liszkowski, 2007). Many education practitioners work with children who have complex needs, including dysphagia, where the mealtime is a part of the learning experience (Harding, Faiman, & Wright, 2010). Strategies tend to fall into two groups: 1) goals to manage eating and drinking difficulties which are integrated into the mealtime environment; and 2) goals that involve oral-motor work completed outside of the mealtime context and possibly within a situation that has no obvious learning outcome for the child. SLTs have mentioned the perceived conflict between the demands of a medically based intervention to meet the needs of a child with dysphagia and the integration of these goals within an educational context (Bailey, Storner, Angell, & Fetzer, 2008; Kurjan, 2000; Lefton-Grief & Arvedson, 2008). The potential conflict in management between healthcare practitioners, carers and education staff can be considered to be a barrier to implementing goals to enhance the child's best interests within the education context (Huffman & Owre, 2008). Conflict can be more challenging when the child's health and safety is considered to be at risk because of inconsistent, minimal or non-compliance with goals to manage eating and drinking, even though the school is ultimately responsible for the child's safety and well-being within the education environment (Huffman & Owre, 2008; Lefton-Grief & Arvedson, 2008). SLTs who have less experience, or who see fewer children with these needs on a regular basis, raise concerns about the management of such cases, if they have the competence to manage such cases, and also argue that the dysphagia needs should be met elsewhere; "Dysphagia management isn't supposed to be in a school" (Bailey et al., 2008, p 445). Concerns are strong when the child's safety is a priority along with infection control; "It's a scary thing to know that if you are doing therapy with a child, and then the child starts choking on you, you don't have any back up". (Bailey et al., 2008, p 445). This is in sharp contrast to Lefton-Grief & Arvedson (2008), who discuss the importance of giving children the opportunity to be active participants in their education goal setting so that goals about how to manage their own needs and skills can be embedded across the school day within a range of functional and academic activities.

A summary of approaches to dysphagia management

Evidence to support treatment for dysphagia is variable; for children with learning disabilities, the evidence base is developing but remains small (Arvedson, Clark, Lazarus, Schooling, & Frymark, 2010a, 2010b). In the absence of studies to support interventions for feeding and swallowing, SLTs have used strategies developed for adults with acquired disorders as there is a perception that there is more research in this area. In reality this is not appropriate, as the strategies developed for this population rely on a past history of normal eating and drinking plus some level of cognition and receptive language ability that enables a person to understand and carry out a specific strategy thatwill reduce risk. For children with learning disabilities, or for those who are not yet cognitively able to initiate strategies for themselves, this is not an option.

The following paragraphs summarise briefly the main types of approaches used.

Modification of food textures. Using specific textures to make food more manageable to eat is frequently implemented to help compensate for motor difficulties. The type of food texture required is dependent upon assessment findings as to the oral-motor and swallowing needs of the client, and which texture is best in terms of reducing aspiration risk. Thin fluids can be difficult to manage and thus be the cause of aspiration or penetration, so thickeners may be used. Altering the texture and temperature of food as well as thickening fluids may help someone create a better food bolus, gain better oropharyngeal control, alter transit time in the pharynx and therefore reduce any risks of aspiration (Sciortino, Liss, & Case, 2001; Steele & Van Lieshout, 2009; Taniguchi, Tsukada, Ootaki, Yamanda, & Makoto, 2008). Although thickening fluids and modifying food textures can help manage eating and drinking needs, there are a number of issues related to use of thickeners that are controversial with poor outcomes. Thickeners are often mixed incorrectly, as carers do not understand the rationale of why fluids need to be thickened or the properties of how the thickener may react when mixed with other fluids (Smith, Logemann, Burghardt, Zecker, & Rademaker, 2006). Changes with thickeners can contribute to alterations in sensory characteristics, as they change temperature or alter in viscosity over time during the course of a meal (Dewar & Joyce, 2006; Garcia, Chambers, Matta, & Clark, 2008; Matta, Chambers, Garcia, & Helverson, 2006). People on thickened diets do not always meet the hydration targets necessary for good health, and still have a higher incidence of pneumonia compared with other groups of people with other health needs (Finestone, Foley, Woodbury, & Greene-Finestone, 2001; Vivanti, Campbell, Suter, Hannan-Jones, & Hulcombe, 2009; Whelan, 2001). This suggests that although thickeners may provide some benefit in reducing risk from aspiration there are still other problems in relation to health that a thickened diet fails to support.

The importance of posture. Providing appropriate head control and ensuring that there is whole body stability, in particular the pelvis and hips, trunk, shoulder girdle and legs, during mealtimes will reduce some aspects of risk during eating and drinking (Morton, Bonas, & Fourie, 1993). Limited motor skills may impact on the following: i) initiation of effective oral-motor skills; ii) appropriate breathing pattern required for eating and drinking; iii) effective swallow mechanism; and iv) effective gut motility (Morton et al., 1993). Using other postural strategies such as jaw support or side-lying during a mealtime with a client can enable better oral preparatory and oral phase stability and is effective (Boiron, Da Nobrega, Roux, Henrot, & Saliba, 2007; Clark, Kennedy, Pring, & Hird, 2007). Children with learning disabilities find it challenging to use postural strategies such as a chin tuck, as these require cognitive and receptive language abilities to carry out (Okada et al., 2007). However, caregivers may focus on supporting the client physically, verbally and visually to have a specific head posture, for example, and therefore use some of the biomechanical principles outlined in the postural techniques described to aid bolus transit.

Penetration: Food that remains at the back of the throat above the vocal cords.

Aspiration: Food that passes blow the vocal cords and ends up in the lungs rather than in the stomach.

Independence during mealtimes can enable children with learning disabilities to control the speed and pace of the meal; importantly, by setting the pace themselves, a bolus of food can be more effectively managed before taking the next mouthful (Pinnington & Hegarty, 2000). Hand-over-hand prompting when using utensils may maximise opportunities for independent eating and drinking.

Some practitioners may implement specific oral-motor exercises such as oral stimulation to increase tone, tongue strengthening, tongue movement, tongue placement and jaw movement (Ganz, 1987; Harden & Rydell, 1984; Korbmacher, Schwan, Berndsen, Bull, & Kahl-Nieke, 2004; Lamm, DeFelice, & Cargan, 2005). Culturally, it is assumed that such exercises will have dual benefits for both eating skills and speech development (Beckman, 2001; Rosenfeld-Johnson, 1999).These exercises would probably be completed outside of a mealtime context. The use

of oral-motor exercises outside of a functional setting probably does not have significant benefits as the neurological sites for activating nutritive and non-nutritive oral-motor movements are different (Martin et al., 2001). Further research needs to clarify clearly the underlying neurology of these differences. In addition, oral-motor exercises or stimulation to increase or reduce oral sensitivity may be invasive for a child with learning disabilities. Making sure that strategies to support eating and drinking are embedded within the learning framework of the mealtime context may have more impact in terms of successful outcomes. Non-nutritive sucking (NNS), for example, is a strategy used with premature infants who have no neurodisability issues. It does appear to have some benefits in hastening the time taken to achieve oral feeding; however, the reason for this is unclear and it is unlikely that the use of NNS actually improves nutritive sucking skills; it is more likely that there are significant physiological and sensory benefits for the baby (Harding, 2009).

The environment. Mealtimes are a daily event and communication should be a central part of the management for children with learning disabilities. Given the high incidence of eating and drinking problems within a paediatric caseload of children with learning disabilities, parents and caregivers are likely to experience a high level of stress and this can impact on a child's eating and drinking management (Cass, Wallis, Ryan, Reilly, & McHugh, 2005; Field et al., 2003; Hewetson & Singh, 2009; Peterson, Kedia, Davis, Newman, & Temple, 2006; Sleigh, 2005). Using appropriate communication strategies can support both their receptive and expressive skills and can help prepare the child to manage liquid and food effectively. This contributes to risk reduction as well as enhancing the quality of life within the routine context (Harding & Halai, 2009; Harding et al., 2010). Children may have reduced communication competence and have to rely on others to interpret their non-verbal or idiosyncratic communication when indicating that they are having difficulties; this is important especially when monitoring risk within a vulnerable population (Lace & Ouvry, 1998).

Case study: This case of an infant born at 31 weeks illustrates the range of approaches that could be used, supported by examples from the current evidence base. The baby has a diagnosis of Trisomy 21, (Down's syndrome), reflux, and a congenital heart condition that potentially may require surgery. Both reflux and the heart condition could seriously impact on the baby's ability to develop feeding skills (Field et al., 2003). The infant initially would receive the bulk of his nutritional intake via a nasogastric tube. At approximately 33 weeks this baby has started to show signs of oral readiness. Assessment would involve observation of the infant at rest and an evaluation of his non-verbal cues during different activities, including responses to more familiar people. Early reflexes such as the rooting reflex would be stimulated and observed, the non-nutritive suck pattern would be assessed as well as the swallow using a small amount of milk or water. Non-nutritive sucking might be employed before or during tube feeding to facilitate either transition to oral feeding (Boiron et al., 2007; Fucile, Gisel, McFarland, & Lau, 2011) or to promote oral readiness skills as well as enabling parents to develop skills in interpreting infant communication (Harding, 2009). Positioning the infant in a prone position to facilitate a forward tongue posture when beginning breast feeding might also be encouraged so that the pharyngeal area, and therefore the airway, is not occluded during the feeding process. A variety of strategies could be used that look at maximising oral feeding effectiveness such as nipple manipulation during breast feeding, teats and flow rates with bottle teats and maintaining the suck-swallow-breathe cycle through pacing. These approaches would be encouraged to develop a positive feeding experience and reduce any potential risks of aspiration. Given that the baby has a heart condition and is probably waiting for surgery, tiring during feeding would be inevitable, and in a case such as this he may well go home with a naso-gastric tube as a short-term measure. A focus on early communication during feeding times would still be encouraged.

Trisomy 21 infants are at higher risk of hypotonia, and therefore some speech and language therapists may suggest increasing muscle tone by tapping and/or stroking the muscle fibres to improve tone prior to feeding. Another strategy may be to provide jaw and chin support to help maintenance of a more stable sucking pattern (Boiron et al., 2007). As the baby develops, these combined strategies of managing the environment, positioning, moving onto weaning and looking at texture modification to ensure textures are manageable and providing oral stimulation through tongue and facial muscle exercises (Beckman, 2001; Rosenfeld-Johnson, 1999) as well sensory development through exploring food and developing the use of utensils (Senez et al., 1996) are likely to be an ongoing part of this infant's management.

Summary of relevant issues

(i) Clinicians need to be clear about why they may be examining oral structures at rest, then when eating and drinking. As indicated, the activation of key components of the oral motor mechanism varies according to non-nutritive or nutritive activity. The suggestion is not to stop carrying out such observations, but to be clear about the differences so that appropriate judgments can be formulated relevant to the child's care (Bennett, Pascal, Van Lieshout, & Steele, 2007; Kent, 2004; Murray, Larson, & Logemann, 1998; Perry, Anderson, Lean, & Cotton, 2002).

(ii) Non-nutritive sucking before and/or during tube feeding to promote oral feeding still has an unclear underlying philosophy. There are undoubted benefits, particularly in relation into oral readiness and learning to interpret an infant's communication. However, these changes are likely to be due to the physiological and sensory changes that emerge from preparing the infant for a state suitable for feeding, and the development of parent ability to interpret early infant communication (Harding, 2009).

(iii) Positioning provides stable head and neck alignment to ensure the infant has the safest possible feeding opportunities (Clark et al., 2007; Morton et al., 1993). More specific strategies such as providing chin support do appear to give sensory feedback and support the development of tongue and jaw movement (Boiron et al., 2007).

(iv) Some evidence implies that enabling children to engage with food in a more relaxed context can help remove psychological barriers to eating. The rationale also relates to the developmental aspect of independent feeding and how children naturally explore and play with food; it suggests that children with early feeding difficulties may miss out on these early opportunities, and that this can potentially impact on their eating development as well as early learning opportunities (Byars et al., 2003; Harding et al., 2010; Senez et al., 1996).

(v) Use of oral-motor exercises outside of a functional context and providing sensory stimulation in the oral-facial region remain controversial. It is uncertain that oral-motor exercises can always stimulate better oral movements for feeding or help speech development. The reason for this is because the underlying neurological mechanisms for speech and swallowing are different and distinct. Cognitive ability also has an important part to play when implementing any therapy programmes, and with an infant of the age in the case described, all intervention will need to be integrated into a functional context to ensure that there will be learning benefits. Undoubtedly, further research is needed in this area to suggest more clearly what is happening and why.

The issues related to the evidence base

The case cited includes many different approaches including the option of using oral-motor exercises to promote speech and oral skills to help with feeding. Work on oral-motor skills outside of a functional context is considered by some SLTs to be a method of improving oral-motor function both for speech and swallowing (Beckman, 2001; Rosenfeld-Johnson, 1999).This idea about the relationship between eating and drinking skills and speech ability will now be considered.

Swallowing activity involves three distinct areas of the nervous system: i) the peripheral aspect, where all the peripheral sensory and motor events occur; ii) the medullary swallowing centre situated in the nucleus tractus solitarius and the nucleus ambiguous (known as the central pattern generator); and iii) the cerebral cortex and some subcortical structures connected to the brainstem central pattern generator via corticobulbar pathways (Jean, 1984, 2001; Martin, Goodyear, Gati, & Menon, 2001; Mosier & Brenznaya, 2001). The system is complex, with cortical activation of swallowing for voluntary and involuntary swallowing being different (Martin et al., 2001). This has implications for when we ask a child to swallow their saliva or attempt a dry swallow, as opposed to observing sequential swallowing during a meal. Already it is known that there are key differences with movements within and aside from eating and drinking; tongue movements in swallowing are slower and more variable than in speech (Bennett et al., 2007). Differences in labial muscle force are noted between cup, straw and non-nutritive labial muscle movement (Murray et al., 1998). Palatal elevation varies for swallowing and for speech, thus highlighting a contrast in movement types, so use of "ah" to check palatal movement during an oral-motor assessment has a questionable value (Perry et al., 2002). In contrast, language and speech areas are largely within the left hemisphere of the brain (Sciote, Horton, Rowlerson, & Link, 2003). This information suggests that programmes that claim to support both speech, eating and drinking skills by working on tongue movement and exercises need careful considerations about their rationales, as these movements have different neurological origins which may not necessarily lead to a transfer of skills.

Differentiation between which areas of the brain are activated in relation to speech, language and swallowing is important in understanding and developing more effective therapy for children with swallowing difficulties that can have meaning for the child and can be integrated effectively with a beneficial learning environment. Speech, language and swallowing are linked in that they have sequential processes involved in planning, but despite the shared pathways, activation and outcomes are different.

Oral-motor approaches appear to have been developed from limb rehabilitation therapy with adult-acquired disorders populations (Clark, 2003; Martin et al., 2001; Robbins et al., 2008). What has not transferred effectively into discussions and evaluations of oral-motor approaches is that the muscles involved in speech and swallowing are different to limb muscles (Clark, 2003; Kent, 2004). The muscle fibres relevant for eating and drinking are clearly different, in that they have different muscle fibre properties compared with joint muscles (Sheppard & Fletcher, 2007; Stal, Mraklund, Thornell, De Paul, & Eriksson, 2003). Consequently, if oral-motor and swallowing exercises are largely based on limb function rehabilitation approaches, then the outcomes are likely to be variable. In addition to this, many therapy approaches are based on people who have an acquired neurology, and do not differentiate clearly between an immature, developing neurology, a congenital condition and normal neurological status which has been impaired by an acquired disorder (Clark, 2003; Ruscello, 2008). Despite these differences, oral-motor exercises are used with children. Babies may receive NNS to help them make the transition to oral feeding: "Non-nutritive sucking promotes the coordination of sucking and swallowing, accelerates the maturation of the sucking reflex improves the initiation and duration of the first nutritive sucking," (Boiron et al., 2007 pp. 439). The notion that NNS enhances sucking maturation as in nutritive sucking development is also supported by other researchers, (Fucile et al., 2011; Hill, 2005), although this approach using NNS to develop nutritive sucking does not always help infants who have disabilities (Harding et al., 2012).

Arvedson et al. (2010a, 2010b) completed two systematic reviews of the benefits of oral-motor exercises on swallowing skills for preterm infants and children. For preterm infants, 12 studies were reviewed (Arvedson et al., 2010b); the authors concluded that there were some effects beneficial for the development of oral feeding when NNS programmes are used. In the review of children, 16 papers were reviewed; outcomes revealed that none of the studies demonstrated any benefits in improving pulmonary health in relation to swallowing after completing a programme of oral-motor exercises. However, limitations were noted in methodology and wide variations in interpretation of results, and the

results themselves suggest that conclusions about the benefits of therapy exercises to manage oral-motor skills for feeding are inconclusive for both infants and children. The evidence to support oral-motor exercises and the perceived link to speech development is also limited (Lof & Watson, 2008).

Given the complex learning needs of children with learning disability and dysphagia, it is suggested that both education and health care practitioners need to consider a way forward to accommodate meeting daily care needs in a realistic and learning-focused way, rather than separating an approach from a meaningful situation. For example, if oral-motor exercises are deemed to be necessary, and there is new and substantial evidence to support their use, then they need to be completed within a task familiar to the child such as oral care and tooth-brushing after a meal. In addition, greater consideration needs to be given to the learning and communication benefits for daily activities for children with learning disabilities. One suggestion for consideration could be the Milieu Approach (Yoder & Warren, 2001), which is based on Transactional Theory in which a participant has the potential to develop through interaction with his or her environment (MacLean & Snyder-MacLean, 1987.) This approach states that the agents of change within the environment are the usual interactive partners: parents, siblings, teachers, learning support assistants and care staff. To accommodate this change the environment is altered to increase the probability that a particular communicative function will be used, and that responses to spontaneous attempts to communicate are responded to. Targets could be selected to enable a child to develop and confidence-build skills with their communication as well as their oral-motor skills within a learning environment. Joint attention is an important part of the approach so that acquisition opportunities and positive principles of good interaction are maximised (Tomasello et al., 2007). Such a method could be employed with activities that are perceived to be more “medical”, and such a cultural change in a child’s learning environment to create a wider range of learning opportunities can only be perceived to be a positive addition to learning within a home and school context.

Summary

The evidence supporting approaches to eating, drinking and swallowing disorders is polarised and variable in content. For oral-motor exercises used outside of a functional setting, and their assumed links to both eating skills and speech development, the evidence base is weak. It is likely that this is the case, as different neurological sites are being activated during speech, swallowing and when carrying out oral-motor exercises. There appear to be learning benefits for approaches that integrate goals into functional settings, but studies need to differentiate between congenital and acquired disorders more clearly so that the clinical applications can have maximum efficacy. Clinical groups have a wide range of ability within each area; so for example, the range of difficulties within a population of children who have cerebral palsy is going to vary considerably. Information on the participant’s communicative and cognitive capacity is an important issue, and some research is suggesting that considering communicative interactions during mealtimes of people who have complex eating and drinking needs is an area that requires further exploration, with research that explores intervention (Harding & Halai, 2009).

It is important that congenital neurological disorders are further researched so that more effective and realistic therapy approaches can be established for children with learning disabilities and additional feeding, eating and drinking needs. These need to be meaningful, useful and easily integrated into daily activities, so that communication and learning opportunities are increased. A Milieu Approach (Yoder & Warren, 2001) may provide an important framework to consider how to structure learning and communication whilst managing complex eating and

drinking needs in an integrated way throughout a child's day. In addition, it is important that therapy focuses on the child's immediate needs, with appropriate goals that do not give parents and carers false assumptions about the potential outcomes.