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A review of feeding interventions for children with disabilities: Implications for institutionalised settings

Paula Rabaey



Paula Rabaey

*PhD Candidate Nova
Southeastern University,
Fort Lauderdale, FL;
Assistant professor,
Occupational Therapy
Department, St Catherine
University, St Paul, MN,
USA*

Email: parabaey@stkate.edu

Feeding practices in the United States and other developed countries have established best practices for feeding children with disabilities. However, the observed practice in developing countries shows that they are often not following best practices for a variety of reasons, including low ratio of caregivers to children, decreased economic resources, and lack of education for both caregivers and health workers (Adams et al, 2011; Johnson and Gunnar, 2011; Colodny et al, 2015;). The purpose of this article is to critically review evidence for best practice in feeding children with moderate to severe neuromotor disabilities. This review will serve as the initial step in establishing the validity of a new observational feeding tool that can be used to assess caregiver practices of feeding in institutionalised settings, such as orphanages, in developing countries.

Developmental disabilities refer to a large and diverse group of chronic conditions that consist of both mental and physical impairments, and include diagnoses such as cerebral palsy, intellectual disability, and chromosomal abnormalities (Brown and Patel, 2005). Approximately 30–90% of children with significant motor and/or cognitive disabilities also have feeding difficulties, which include dysphagia, swallowing disorders, oral motor

coordination problems, and aversive feeding behaviours (Arts-Rodas and Benoit, 1998; Sullivan et al, 2000; Dusick, 2003; Schwarz, 2003; Calis et al, 2008; Andrew and Sullivan, 2010). Children with more generalised severe cerebral palsy and intellectual disabilities are especially at risk for dysphagia, which has significant health consequences including malnutrition, aspiration, and aversive mealtime experiences (Dusick, 2003; Schwarz, 2003; Calis et al, 2008). Sullivan et al (2000) in their Oxford feeding study, found that children with moderate to severe neurodevelopmental disabilities exhibited consistent feeding difficulties, including: 56% choking with feeds, 28% with prolonged feeding times, and 89% needed help with the feeding process. Mealtimes were reported by caregivers as stressful and unenjoyable (Sullivan et al, 2000).

The consequences of such feeding difficulties can impair development and quality of life in children with moderate to severe motor impairments (Sullivan et al, 2002; Schwarz, 2003). Growth and nutrition intake problems are prevalent in children with moderate to severe cerebral palsy, which leads to chronic under nutrition or malnutrition; particularly in non-ambulatory and immobile children (Sullivan et al, 2002; Andrew and Sullivan, 2010). Repercussions of poor nutrition not only affect physical growth, but brain growth and development, cognition, cardiac function, immunity and healing ability as well (Andrew and Sullivan, 2010). These children are also at risk of micronutrient deficiencies, including calcium, iron, and vitamin C, as well as insufficient energy intake (Sullivan et al, 2002).

Children with disabilities make up a large percentage of institutionalised residents throughout the world, and often have significant neuromotor problems

that interfere with the ability to eat and participate successfully in mealtimes (Johnson and Gunnar, 2011; Hearst et al, 2014). Children who reside in institutional care settings, especially those in developing countries, often experience significant global growth suppression and growth failure (Dobrova-Krol et al, 2008; Johnson et al, 2010; Johnson and Gunnar, 2011; Hearst et al, 2014; Kroupina et al, 2015). This is exacerbated in individuals with disabilities who already have a baseline risk of growth impairment (i.e. children with cerebral palsy and other developmental disabilities) (Johnson and Gunnar, 2011).

Psychosocial growth failure is an added problem in institutionalised children due to chronic social deprivation and high child to caregiver ratios. This phenomenon is caused by a combination of nutritional insufficiencies and social deprivation leading to stunted growth and delays in motor, cognitive, social, and language development, as well as decreased health and wellbeing (Adams et al, 2011; Johnson and Gunnar, 2011; Hearst et al, 2014; Kroupina et al, 2015). All of these symptoms further intensify the current feeding problems in children with disabilities (Adams et al, 2011).

In well-resourced countries, best practice for children with moderate to severe feeding difficulties who are experiencing poor nutrition and growth is to provide professional expertise and/or supplement with alternative feeding methods (Calis et al, 2008; Adams et al, 2011). In many resource-poor countries, however, alternative feeding methods are very scarce, expensive, or simply not available (Adams et al, 2011). In these impoverished situations, children with moderate to severe disabilities who need extra time to feed cause added stress for the caregiver, which in turn promotes

unresponsive feeding practices, and leads to stressful mealtimes for both caregiver and child (Adams et al, 2011).

Feeding practices in institutionalised settings also contribute to the child's risk of aspiration and oral aversion by techniques such as: enlarging the hole in the tip of the bottle nipple, putting a lot of food in to the child's mouth while the child is on their back, or standing behind the child while feeding them (Johnson and Gunnar, 2011). Such practices are prevalent in institutions due to high child to caregiver ratios and the need to complete tasks in efficient and expedient ways that are not based on child cues (Johnson and Gunnar, 2011).

In developing countries, limited attention is often paid to persons with disabilities; especially in the area of rehabilitation (Gallagher et al, 2008; Adams et al, 2011). Because caregivers in institutionalised environments are not health care professionals, they typically lack the knowledge, skills, and resources to adequately address the feeding problems that they see. Caregivers may not even be aware that the practices that they are using are detrimental to the child. Feeding assessments exist for children with feeding difficulties that are designed for educated and trained professionals to use. Unfortunately, caregivers in institutionalised settings are not equipped to administer these technical and complicated assessments without extensive training and resources.

According to Gallagher et al (2008), only 68 of 194 countries have recognised occupational therapy services. As occupational therapists and other health care professionals expand their work in developing countries, sustainable models of assessment and intervention need to be developed and implemented in order to sustain lasting change; particularly in institutionalised settings. Occupational therapists play a major role in supporting the development and engagement of young children in their daily occupations and routines, including feeding and mealtime and are often asked to intervene when a child has difficulty with the processes of feeding and eating (American Occupational Therapy Association, 2007; 2011).

A critical need exists for health care professionals to train caregivers of children with disabilities in institutionalised settings to feed children as safely as possible to

prevent problems such as choking, coughing, and aspiration, which can lead to long-term health consequences and even death. This literature review looks at the most current interventions on safe feeding practices for children with neuromotor disabilities who cannot feed themselves. The results will be used to create a tool to guide caregiver feeding practices in institutions. This tool could then assist professionals and caregivers working in institutions to identify and modify feeding practices that are potentially detrimental to a child's health. In order to develop this observational tool that can be used internationally in a broad range of institutionalised settings, current evidence on interventions used to improve safe feeding and swallowing in these children needs to be reviewed.

METHODS

The search strategy included CINAHL, PubMed, PsychINFO, and Cochrane Systematic Reviews databases, as well as hand searching references from selected articles. The following key words were used in combination with the words 'developmental disabilities' or 'cerebral palsy':

- Feeding
- Dysphagia
- Positioning
- Jaw support
- Food texture
- Postural alignment
- Jaw control.

Key terms were also used in combination with each other. The following criteria were used to select articles:

- Published in a peer-reviewed journal
- Available in the English language
- Encompassing children ages 0–19 years who met criteria for moderate to severe developmental disability and have feeding and swallowing problems
- Interventions fit within the domain of occupational and speech therapy practice (although intervention does not need to have been carried out by occupational therapist or speech-language pathologist),
- Dealt with effectiveness of the intervention
- Included quantitative or qualitative peer-reviewed studies, case studies, and systematic reviews.

Articles were accessed from 1990 to 2015. Initially, the search was limited to the last 15 years, but it became apparent that earlier pertinent literature was available; therefore, the start date emerged from the literature rather than being set by the author. All articles that potentially met the inclusion criteria were screened and reference lists from pertinent articles were checked and cross-referenced.

Articles were excluded if they included alternate feeding methods such as feeding tubes, oral motor stimulation techniques, use of oral devices, and behavioural treatments. Most of these methods are high tech or high cost options that are not often available in developing countries. Behavioural treatments were excluded as most of the literature regarding this intervention focused on children with autism, which was not the intended population of this review. After the exclusion criteria were applied, 10 articles remained for analysis. The selected articles were categorised using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) quality of evidence assessment tool (Schunemann et al, 2002) (*Table 1*). The GRADE tool adopts a consistent approach to rating the quality of evidence around predefined and prioritised outcomes of interest into four categories:

- High (4)
- Moderate (3)
- Low (2)
- Very low (1).

The tool classifies recommendations into two categories: strong or weak (Brown et al, 2013). The GRADE approach involves upgrading or downgrading evidence quality based on an appraisal of criteria including: study design, quality, consistency, potential bias, and rigour of findings (Brown et al, 2013).

RESULTS

The 10 studies comprised:

- One group comparison
- One single subject case design
- Two pre-post studies
- One case study
- Three systematic reviews
- Two narrative reviews (see *Table 1*).

The majority of participants were aged from 6 months to 19 years, with the

exception of one systematic review that included studies of both children and adults. All studies were published in either rehabilitation, developmental disabilities, or paediatric peer-reviewed journals. The studies were categorised according to the type of intervention used to improve safe feeding and swallowing in children with moderate to severe disabilities being described. This categorisation yielded three main categories:

- Positioning
- Jaw control techniques
- Food and liquid consistency.

The critical review suggests that, although some evidence is available to support the use of positioning, jaw and cheek control techniques, and altering the food consistency for increased safety in feeding with children with moderate to severe disabilities, the GRADE level of evidence ranged from low quality to moderate quality; therefore, there is a continued need for higher quality and well-controlled studies in this area. Many methodological issues and biases were present across articles including:

- Studies were small with varied methodological rigour
- There were no randomised control trials
- A lack of detail in procedures or lack of specific treatment protocols described.

Positioning

It is well documented that many children with moderate to severe cerebral palsy or other neuromotor conditions are at high risk for aspiration due to poor oral motor and swallowing coordination (Larnert and Eckberg, 1995; Rogers, 2004). The presence of abnormal muscle tone and reflexes further contributes to poor alignment of the head, neck, and trunk, which can interfere with the swallowing process (Redstone and West, 2004). The most supported position for feeding in the literature includes an upright seated position with back supported, head aligned with the trunk, chin slightly flexed in a chin-tuck position, and hips, knees, and ankles at 90° of flexion (West and Redstone, 2004). However, it has been unclear if this proper alignment actually reduces the risk of aspiration or improves nutritional intake.

Larnert and Eckberg (1995) examined five children with severe cerebral palsy using video fluoroscopy. All children were given puree and liquid in their regular upright feeding position and then again in a 30° reclined position with the neck slightly flexed. When the neck was flexed, aspiration decreased in all five children when swallowing liquid and in four of the five children when swallowing puree (Larnert and Eckberg, 1995).

Gisel et al (2003) found similar results in an exploratory case study with three children with severe cerebral palsy. One child fed best in a 30° reclined position, and overall results indicated that pulmonary function could be improved over a period of 1 year by maintaining the best position that minimised aspiration according to video fluoroscopy (Gisel et al, 2003). While these results are encouraging, it should be noted that tube feedings were recommended for two of the three children due to the severity of aspiration (Gisel et al, 2003). Morton et al (1993) concluded that children with feeding difficulties and cerebral palsy fed

Table 1. Articles listed by type of intervention and level of evidence using GRADE tool

Study	N	Design	Intervention approach	GRADE level of evidence
Adams et al (2011)	37 child-caregiver pairs	Pre-post, no control group	Training programme for caregivers	Strong recommendation, moderate quality evidence
Benoit and Dahl Reeves (2001)	1	Single subject case design	Technique of oral support	Weak recommendation, moderate quality evidence
Croft (1992)	71	Pre-post, non-randomised	Food consistency	Strong recommendation, low quality evidence
Gisel et al (2003)	3	Case study	One full year of optimal positioning and feeding appropriate food textures	Strong recommendation, low quality evidence
Howe and Wang (2013)	NA	Systematic review	Systematic review of feeding interventions used by occupational therapists with children 0–5 years	Strong recommendation, moderate quality evidence
Larnert and Ekberg (1995)	6	Pre-post, non-randomised, no control group	Investigation of trunk and neck position on five children with feeding problems and cerebral palsy	Strong recommendation, moderate quality evidence
Rogers (2004)	NA	Narrative review	Evidence-based review article	Weak recommendation, low quality evidence
Snider et al (2011)	NA	Systematic review	Review of evidence of feeding techniques currently used with children with cerebral palsy	Strong recommendation, moderate quality evidence
Steele et al (2015)	NA	Systematic review	Review of evidence of the influence of food texture on swallowing physiology and function	Strong recommendation, moderate quality evidence
West and Redstone (2004)	NA	Narrative review	Review of evidence pertaining to alignment during feeding	Strong recommendation, low quality evidence

best in an erect to semi-reclined position based on which phase of the swallow was most difficult (oral or pharyngeal); however, the seating recommendations did not have a significant change in weight gain of the children.

Several systematic reviews also supported positioning as an intervention to reduce the risk of aspiration in children with moderate to severe neuromotor disabilities. West and Redstone (2004) found several studies that demonstrated that misalignment with an extended neck results in greater aspiration and a lessened protective function of the epiglottis. They referenced Ekberg's (1986) pioneering study that demonstrated that changes in neck alignment affected one's ability to protect the airway during swallowing and that the best protection was with the neck flexed. It has also been noted that safety and efficiency can be enhanced with upright positioning and the use of a chin tuck posture, thus directing food away from the airway when swallowing (Redstone and West, 2004).

Snider et al (2011), in their systematic review, found limited evidence that positioning had a positive effect on feeding safety and efficiency due to the fact that no RCTs could be found on the effects of positioning on feeding safety. While this is true, the majority of the literature supports proper positioning and alignment of the head and neck; particularly an upright to 30° reclined trunk position and neck flexion in order to decrease the risk of aspiration and improve the ability to swallow. Positioning interventions did not appear to make significant differences in weight gain, but rather helped with oral control and swallow ability (Snider et al, 2011).

Jaw support and control

While only one study was found that addressed jaw and cheek support as an intervention for feeding children with moderate to severe neuromotor difficulties, a few articles referenced jaw support as part of an overall intervention plan for difficult feeders. Jaw and cheek support techniques have been widely used by therapists and nurses for preterm infants to enhance feeding efficiency of poor feeders (Hwang et al, 2010).

Oral support has been defined as support on the cheeks (buccal pads) and under the base of the tongue, midway between the

throat and chin (Case-Smith and Humphry, 1996). This technique is said to compensate for 'inadequate buccal compression' and can help inhibit wide jaw excursions (Case-Smith and Humphry, 1996; Benoit and Reeves, 2001). There is previous literature support for using these techniques with preterm infants to improve oral motor performance, increased nutritional intake, and feeding efficiency (Einarsson-Backes, et al, 1994; Hwang et al, 2010).

Benoit and Reeves (2001) conducted a single subject ABAB design with a 32-month-old with brainstem stroke and feeding difficulties. Oral support under the base of the tongue was provided once a day for a period of 4 days every other week, which was found to have increased nutritional intake versus the days without oral support (Benoit and Reeves, 2001). While the participant had more control with the spoon, it was noted that feeding times were not less messy and the same amount of food loss was noted with oral support and non-oral support. Results are also difficult to generalise due to single subject design and restricted number of feeding sessions (Benoit and Reeves, 2001).

While studies are limited regarding oral jaw support, jaw stability techniques remain a recommendation in the literature for feeding children with moderate to severe neuromotor disabilities and feeding problems. Adams et al (2011) looked at the effectiveness of a low-cost, low-technology intervention to improve the feeding practices of children with moderate to severe cerebral palsy in Bangladesh, which included providing oral jaw support when necessary to reduce the amount of spillage and assist in chewing and the overall management of food in the mouth. They found positive outcomes in a number of variables, including: reduction in risk of aspiration during feeding, improved or maintained nutritional status in 13 of 22 children, and reduction of caregiver stress during feeding times (Adams et al, 2011).

Howe and Wang (2013) also found moderate evidence in their systematic review for therapeutic techniques including oral support for young children with feeding problems. This suggests that oral techniques such as jaw support for children with moderate to severe neuromotor disabilities and feeding problems can have positive effects on nutritional intake and decreased stress during mealtimes.

Food texture and consistency

Children with moderate to severe neuromotor difficulties and oral feeding problems often have problems with chewing and swallowing solid food, which can lead to aspiration (Trier and Thomas, 1998; Steele et al, 2015). Recommendations for feeding children who have chewing and swallowing deficits often include altering the texture and consistency of the food by mashing or puréeing. It has been found that altering the food consistency can help reduce the risks of aspiration by enabling more effective oral and pharyngeal management of the food (Adams et al, 2011; Steele et al, 2015). It can also assist in increasing the nutritional intake of food by decreasing the effort required to chew and swallow, which can lead to improved oral manipulation of the food and increased child cooperation in the feeding process (Adams et al, 2011).

While the literature supports altering the food texture and consistency, only one experimental study involving 67 children with cerebral palsy could be found (Croft, 1992). This study also had a control group of 64 children and demonstrated that children with cerebral palsy (especially more severe with no speech) benefited from eating mashed rather than solid foods, as results in the group with mashed versus non-mashed food were statistically significant in the area of reduced time and reduced coughing and sputtering (Croft, 1992; Snider et al, 2011).

Steele et al (2015) conducted a systematic review to describe the impact of liquid consistency and food texture on swallowing behaviour. This comprehensive review analysed 36 articles, although only three of them described swallowing or oral processing in children and all of them had identified bias including participant selection, measurement of behaviours, and missing data (Steele et al, 2015). The authors concluded through their analysis that the studies did provide sufficient information to show a reduction in the rate of 'penetration aspiration' with liquids as they progressed from 'thin' to the 'very thick' end of the viscosity continuum. While this suggests that thicker liquid and food textures are safer for children with moderate to severe cerebral palsy in regards to decreasing aspiration, evidence is still lacking in this area. Additional and higher-quality studies involving food consistencies need to be conducted; especially with children.

DISCUSSION

As a result of this evidence review, there is moderate support that an assessment of safe feeding practices in children with moderate to severe neuromotor disability and feeding difficulties should include positioning, type of oral support given during feeding, and texture/consistency of food presented during feedings. Evidence for positioning that was individualised was the strongest and should be a high priority when evaluating children with feeding difficulties and neuromotor conditions. Literature on best practices in feeding supports that positioning techniques demonstrated moderate evidence that a flexed neck and partially reclined trunk minimized or eliminated aspiration (Redstone and West, 2004; Howe and Wang, 2013). This same recommendation was found in Snider and colleagues' (2011) review of feeding interventions of children with cerebral palsy. Alignment of the head and neck appears to be a crucial factor for decreasing risk of aspiration and increasing nutritional intake. This is consistent with the recommendations of experienced clinicians from a variety of disciplines who contend that positioning with correct body alignment is a necessity for feeding children with moderate to severe neuromotor disorders (Dusick, 2003; Redstone and West, 2004).

While the evidence is more prevalent for positioning, it is also apparent that other factors need to be considered when assessing safe feeding practices. Adams et al (2011) found that a training programme for children with moderate to severe cerebral palsy and their caregivers in Bangladesh that included recommendations for positioning, food consistency, and adapted feeding methods such as jaw support and control, was effective in reducing the risk of aspiration and chest-related illnesses, improved nutritional status, increase in child cooperation during mealtimes, and a reduction in caregiver stress during mealtimes.

A combination of positioning and altering food textures has also been reported in the literature to be effective in minimising aspiration risk in children with severe cerebral palsy (Gisel et al, 2003). Dusick (2003) reported that in some cases, thickened liquids and purees may be the only intervention needed for aspiration as the smooth, thickened solid is easier to

safely swallow. Literature on best practices in feeding has emphasised that safety and efficiency are enhanced with an upright sitting position and that the addition of oral control can aid in mouth closure and facilitate jaw, tongue, and lip movements needed for effective feeding (Redstone and West, 2004).

Children residing in institutionalised settings in developing countries are unique in that they often experience significant global growth suppression and growth failure (Dobrova-Krol et al, 2008; Johnson et al, 2010; Johnson and Gunnar, 2011; Hearst et al, 2014; Kroupina et al, 2015). This is further exacerbated in children with moderate to severe disabilities who already have a known risk for aspiration, dysphagia, and other health complications such as dehydration, malnutrition, and pneumonia (Colodny et al, 2015).

Many limitations exist in the studies reviewed. There is clearly a paucity of rigorously designed studies within the last 10 years involving feeding interventions with children with moderate to severe disabilities and no studies existed involving children in institutionalised settings. Most studies had a very small sample size and no control group, making it very difficult to generalise the results.

Outcome measures also varied and no techniques appeared to influence weight gain, although it was noted that alternative feeding approaches (such as a gastrostomy tube) became necessary when a child was not able to maintain an acceptable weight (Snider et al, 2011). However, it should be noted that alternative feeding approaches are often not available in developing countries and for children residing in institutionalised settings.

CONCLUSION

Children with moderate to severe neuromotor disorders and feeding difficulties that reside in institutionalised settings need safe feeding practices that will minimise their risk of aspiration, increase their nutritional intake, and decrease caregiver stress while feeding. Due to low resources and lack of healthcare professionals within this setting, a low cost assessment of safe feeding is needed to support best practice in feeding with these children.

Despite the limited studies with a relatively low to moderate quality of research, this review suggests that techniques of positioning, jaw/oral support, and altering the texture and consistency of food presented can be used to increase the safety of feeding and potentially reduce the risk of aspiration. When children are in correct alignment and positioning, they are possibly able to consume more food, thereby contributing to better nutrition. Evidence for correct alignment and positioning has the most support within reviewed studies and should be considered as a foundation in the development of an assessment tool for this population. The research seemed to outline best practices in the area of safe feeding for children with moderate to severe neurological disabilities that could be included in an assessment tool for caregivers in institutionalised settings. While rigorously designed RCTs are limited in the feeding literature, the existing evidence should be taken into account when considering the design of a feeding assessment to be used with children with disabilities who reside in institutionalised setting around the world. There is a need for continued studies in this area with increased methodological rigour. **IJTR**

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