The Right to Eat? Can Caregiver Training Improve Participation in Feeding for Children with Cerebral Palsy

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Eating together is an important human activity. It is how we celebrate, it is how we interact, and it is how we learn about our cultures and our heritage. Yet for many children with cerebral palsy (CP), especially at gross motor function classification scale (GMFCS) levels 4 and 5, eating is not a participatory event. It is something that is “done” to them and something they have little influence over.¹²³

We would like to explore developing collaborative feeding plans and the important elements of risk management that will allow the participatory activity of feeding to happen happily and safely for children of GMFCS levels 4 and 5.

Feeding activities can place those who are involved in the assessment and development of feeding plans at odds with other members of the medical team or with school or community programs because of safety concerns. However, there are techniques that will allay fears and give feeders more confidence in allowing children to participate in oral feeding/eating. With the appropriate information, we can be advocates of safe feeding plans and impart that information to others involved in the care and feeding of children with CP, whether that occurs by enteral or oral means, even if the intake orally is limited and participation in feeding is limited to social participation.

The reason for the anxiety surrounding oral feeding for children with CP is related to the fear of aspiration. But we all know that feeding is much more than aspiration. Aspiration is not something that is in the forefront of our minds when we sit down to eat. We are beginning to understand that “aspiration,” like feeding itself, is multidimensional and “the characterization of the consequences of aspiration is not always straight forward.”⁴ We all have been taught that there is a causal relationship between aspiration and lower respiratory tract infection⁵, but in reality, we can only demonstrate an association between aspiration and lower respiratory tract infections. Many of us will know children

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who aspirate without any apparent negative respiratory consequences of aspiration.\textsuperscript{6,7,8} We also are aware that even if children do aspirate and demonstrate respiratory infections, parents may choose to continue to practice oral feeding/eating with their children.

The authors of this instructional course do not want to be dismissive of aspiration or of lower respiratory tract infections in children with CP, as they are the leading cause of morbidity and mortality in this population.\textsuperscript{1,9} On the other hand, we want to stimulate thought regarding aspiration. **Aspiration should not be the only consideration when it comes to seeking causes of lower respiratory tract infections** in children with CP. We consider a significant, potentially life changing intervention like removing feeding from children who are at risk of the consequences of aspiration, however, we do not undertake the drastic intervention of removing children from their family homes if their parents smoke. Yet, smoke exposure, like aspiration during feeding, is a risk for pneumonia. (Smoke exposure likely increases your aspiration risk, due to desensitization of the airway from the constant presence of particulate matter. \textsuperscript{10})

In one study of adults with aspiration pneumonia, aspiration during swallowing was not an independent risk factor for aspiration pneumonia. The independent risk factors for aspiration pneumonia were: lack of self-feeding, smoking, bad teeth and multiple medical diagnoses.\textsuperscript{11} These may be risk factors for children with CP, of which we should be mindful, as they are amenable to intervention.

Dealing with the many factors than can worsen the risk of pneumonia and not just the aspiration risks, is important in our care for children with CP (smoke exposure, dental caries, for example.) In fact, aspiration itself may only become clinically significant if the perfect storm occurs: if there is chronic inflammation from aspiration and then the child gets a viral illness or if other respiratory irritants act in concert with aspiration and a systemic illness. Aspiration is not to be dismissed, but in and of itself, aspiration may not cause respiratory illness without confounding factors.\textsuperscript{12}

We do appreciate that aspiration does however, determine how we look at feeding: think of the Eating Drinking Ability Classification System (EDACS.) It is stratified by aspiration or the ability to make feeding “safe” including food processing and efficiency.\textsuperscript{13} But we

\textsuperscript{10} Dua et al. Effect of chronic and acute cigarette smoking on the pharyngoglottal closure reflex. Gut 2002; 51:771-775
\textsuperscript{13} Sellers D, Mandy A, Pennington L, et al. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. \textit{Dev Med Child Neurol} 2014; 56: 245-251
can also map feeding in terms of participation using the WHO International Classification of Functioning, Disability and Health (ICF) (www.who.int/classifications/icf/en) so that participation can be emphasized and not just aspiration and efficient feeding.\textsuperscript{21}

Dealing with aspiration is about mitigating risk. So, one needs to think about risk management when it comes to dealing with the development of feeding plans. Parents, children and young adults are opting to eat in the face of aspiration.\textsuperscript{14} The same holds true for elderly people for whom oral feeding in the face of risk is becoming a major topic of discussion because non-oral feeding has more inherent risks than careful hand-feeding.\textsuperscript{15,16}

Feeding interventions for children with feeding and swallowing dysfunction and aspiration are understudied and evidence for the success of the various interventions is lacking.\textsuperscript{17,18,19} Questions remain about strategies to manage aspiration risk. However, there are some strategies to teach parents and caregivers on how to approach feeding that may bear fruit and may help in developing feeding plans that all team members can stomach. Especially poignant are some of the articles looking at feeding in countries with resource challenges. They can demonstrate improvements in acceptance and participation for children with disabilities when basic feeding training is introduced.\textsuperscript{20,21}

Aside from basic education about the children’s abilities and their underlying conditions, elements of feeding training include (but are not limited to) the following teaching points:

- Positioning
- Bolus size, consistency and viscosity
- Allowing increased time to swallow/eat
- Pacing the meal
- Watching for fatigue, especially if mealtimes are prolonged
- Decreasing high bacterial burden in the mouth
- Eliminating smoke exposure

\textsuperscript{14} Craig, GM. \textit{Psychosocial aspects of feeding children with neurodisability} European Journal of Clinical Nutrition 2013; 67, S17–S20; doi:10.1038/ejcn.2013.226
\textsuperscript{15} Amarantos E., Martinez A., Dwyer J. \textit{Nutrition and Quality of Life in Older Adults} Journals of Gerontology: The Gerontological Society of America 2001, Vol. 56A (Special Issue II):54–64
\textsuperscript{17} Morgan AT, Dodrill P, Ward EC. \textit{Interventions for oropharyngeal dysphagia in children with neurological impairment}. (Review). Cochrane Database of Systematic Reviews 2012, Issue 10. Art. No.: CD009456
\textsuperscript{18} Snider L, Majnemer A, Darsaklis V. \textit{Feeding Interventions for Children with Cerebral Palsy: A Review of the Evidence}. Physical & Occupational Therapy in Pediatrics; 31:58-77
\textsuperscript{21} Hettiarachchi S, Kitnasamy G. \textit{Effect of Experiential Dysphagia Workshop on Caregivers’ Knowledge, Confidence, Anxiety and Behaviour During Mealtimes}. Disability CBR Inclusive Development 2013; 24:75-97; doi:10.5463/DCID.v24I3.73
The goal for teaching feeding strategies and of mitigating the risks for oral feeding is fostering participation in the meaningful life activity of eating and this should be an essential intervention goal.  

An annotated reading list of articles regarding participation in feeding, mitigating risk and caregiver training follows:

**Articles on Swallowing Dysfunction and Aspiration**

- Review article describing feeding difficulties, assessment, intervention strategies including sensorimotor and surgical options to improve nutrition
- Evidence for intervention is limited.

- Swallowing problems increase the RISK of pulmonary consequences
- Risk of aspiration partly dependent on the condition of the child
- Risk of aspiration can decrease with time as developmental gains are made
- Aspiration risk may increase at times
  - Increased risk with uncontrolled seizures
  - Fatigue
- The more severe the motor deficits the more severe the swallowing dysfunction however, even children with mild motor deficits can have dysphagia
- Efficacy of interventions reviewed. Evidence overall for interventions is poor.
  - Positioning (limited evidence)
  - Bolus size
  - Bolus consistency/viscosity (limited evidence)
  - Increased time to swallow/eat
  - Importance of pacing the meal
  - Watching for fatigue if mealtimes are prolonged
  - Neuroelectrical stimulation (insufficient evidence in one trial, no improvement over oro-motor therapy in another)
- There is an expectation that at least pleasurable amounts of food are given to all children regardless of skill level. Some oral feeding that is physiological, that fits the social situation that maintains or improves the overall health, hydration and nutritional status, and the pulmonary status in particular. All children deserve opportunities for oral feeding.

- Sixteen signs of aspiration evaluated. Stratified by GMFCS.

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68% children had clinical signs of aspiration and this increased with declining gross motor function
Parents reported clinical signs in 46% of children
Most common signs on direct assessment were coughing, multiple swallows, gurgly voice, wet breathing and gagging
38% of children with typical development had signs of dysphagia mostly observed on fluids
Coughing may not prognosticate aspiration
Sequelea and prognosis in children with CP are poorly understood
Parental report agreed with clinical assessment in 60% of cases. Single cough with thin liquids is also common in typical children age 18-36 months

- Chronic pulmonary aspiration in children is an important cause of recurrent pneumonia, progressive lung injury, respiratory disability and death.
- There is no gold-standard test for aspiration. Although new techniques have been introduced since the 1990s and significant advances in the understanding of dysphagia and gastro-oesophageal reflux have been made, characterisation of the aspirating child remains elusive

- Two central questions: is feeding safe and is it adequate? We can usually figure out if aspiration is occurring but quantifying it and predicting the long term impacts on lung function is more difficult
- The authors present two cases with divergent outcomes
- The characterisation of aspiration and its significance is difficult

- Characteristics of dysphagia in children with CP related to motor function.
- VFSS signs were significantly more common in the severe groups (GMFCS 4&5)
- Dysphagia is closely related to GMFCS
- Silent aspiration observed in children with GMFCS levels 4-5

- Reviews independent variables associated with aspiration pneumonia which are:
  - Dependent feeding is the main risk factor
  - Smoking
  - Dependent for mouth care and cavities
  - Multiple medical diagnosis
- Aspiration during feeding in this study was not one of the main risk factors for aspiration, suggesting that while it is an important contributor, it is not the only factor that impacts whether or not aspiration will be significant.

- Discusses swallowing function in detail and the evaluation of aspiration and dysphagia.
- Management of different aspects of aspiration is discussed.

**Articles on Pneumonia – Consequences of Aspiration**

Kaneoka A, Pisegna JM, Saito H, et al. **A systematic review and meta-analysis of pneumonia associated with thin liquid vs thickened liquid intake in patient who aspirate.** *Clinical Rehabilitation* 2017;31:1116-1125
- Drinking thin liquids with safety strategies does not increase the risk of pneumonia compared to offering thickened liquids to patients who aspirate.
- This result is only generalizable to patients at low risk of pneumonia.
- People with poor cognitive status, acute and chronic respiratory illness, gastroesophageal reflux, tooth decay, nasogastric tube placement and tracheostomy were often excluded from the studies.

- Several risk factors required for aspiration to reach clinical significance.
- Biological and environmental factors may play significant roles in determining the clinical outcomes of aspiration.

- 9.7% of children diagnosed with aspiration pneumonia experienced more complications than children with non-aspiration pneumonia.
- Children with aspiration pneumonia had longer length of stay, transfers to ICU, greater hospital costs and more re-admissions.
- Diagnosis of aspiration pneumonia is somewhat subjective. This study is based on Pediatric Health Information System database.

- Oropharyngeal aspiration is known to be associated with aspiration and direct causality is often assumed.
- Children with multisystem involvement demonstrate a higher association of pneumonia.
- Impact of oropharyngeal aspiration on development of pneumonia is considerably reduced once other factors in children with multisystem involvement are taken into account.
• Aspiration of food or liquids may have less of a direct causality on children than previously thought
• Aspiration may be an important risk factor for pneumonia but in the absence of other risk factors is rarely sufficient to cause pneumonia

Articles on Classifications Systems for Children with CP

• Describes the use of ICF for the description of feeding problems in children.

• Describes four functional classifications systems for cerebral palsy: GMFCS, MACS, CFCS (communication), EDACS (eating and drinking)

**EDACS:** Valid measure to assess eating & drinking ability for children with CP ≥ 3 years. Stratifies by efficiency and aspiration and adds in “independent”, “needs assistance” and “totally dependent”
• **Level 1:** can eat & drink safely and efficiently no different from peers
• **Level 2:** eats & drinks safely, may have some limitations in terms of food loss & generally require more time to complete a meal than peer
• **Level 3:** Eats & drinks with limitations of safety & efficiency. Hard lumps may be difficult & aspiration may be a risk. Usually eats pureed or mashed foods. Cough may be seen with fast flowing liquid
• **Level 4:** Significant limitation with safety, however, the risk of aspiration can be managed & oral feeding is possible
• **Level 5:** Unable to eat or drink safely

Articles on Intervention for Swallowing Dysfunction

• Reviewed studies providing effectiveness data for feeding interventions in people of all ages with CP. Conflicting results on sensorimotor interventions. Some studies suggest that interventions such as oral appliances may enhance oral skills but there is a clear need for rigorous, comparative studies. Evidence for surgical interventions is insufficient to low. Weight gain is demonstrated

• Systematic review of outcomes of GT. In the introduction they review that chronic pulmonary disease “related to aspiration” is the leading cause of death in children with CP
• Children gain weight but other results mixed
• Complications were site infection, granulation tissue in 30-40% of children
• Death rates 7-29% though this was likely not related to surgery
• Evidence for effectiveness of surgical interventions is insufficient to low
• The risk of intervention with GT in relation to the risk of not treating is poorly understood

Thickening liquids is an established bolus modification intervention, however
• Patients disliked the thickened liquid impacting acceptance, hydration and quality of life
• There continues to be a lack of robust empirical evidence to support the therapeutic benefits of thickening
• Suggest adding techniques such as carbonation, positioning, flavor enhancement, unlimited water protocols between meals
• Develop a broader approach to managing aspiration

• Children with aspiration who are fed orally with techniques such as thickening fluids to decrease the risk of aspiration, have a decreased risk of being hospitalized than children who have gastrostomy tubes placed to manage the aspiration

• There is currently not enough high-quality evidence from randomized controlled trials or quasi-randomised controlled trial for any particular type of oropharyngeal dysphagia intervention in this population of children.

Feeding intervention demonstrates potential benefits for children with cerebral palsy but current level of evidence is poor and empirical data are lacking.
• Sensorimotor activities show not definite improvement in feeding
• Positioning: limited evidence that positioning has positive impact on feeding safety, efficiency, decreasing aspiration risk
• Changing consistency/viscosity: limited evidence demonstrating softer food consistencies enhance feeding safety and efficiency
• Oral implanted devices: Moderate level of efficacy

Articles on Participation


• Participation in meaningful life activities should be an essential intervention goal. Develop creative solutions that will ultimately benefit children with a wide variety of impairments and challenges and their families, everywhere.

• Participation means involvement in a life situation. ICF-CY provides a very strong foundation for understanding body structure and function of individuals and the relationship between having a health condition and body structure and function outcomes. Within in the activity and participation domains of the ICF-CY less is understood about the processes that define the constructs. More importantly very little is known about the transactions among ICF-CY domains and this knowledge gap greatly limits our capacity to design more effective interventions.

• Participation is a complex multidimensional construct that is not a “downstream effect” of rehabilitation at the body function and structure or activity level. This change in thinking involves challenging the view that participation restriction can be solved only by addressing environmental barriers. Intervention at the level of the body: or the level of society may be necessary to promote participation in individuals but neither alone is likely to be sufficient.

Articles on the Ethics of Oral Feeding


To link

• Individuals with severe brain injury with disorders of consciousness

• Oral feeding during coma recovery did not negatively affect safety or cost and may enhance quality of life for individuals and families.


• Nutritional status (dietary, anthropometric, biochemical)

• Nutritional status information does not capture sensory, psychological, and social aspects of food and eating that may also be important to the individual

• Measures of nutrition do not address quality of life

• “Food and nutrition are essential components of ‘the good life’.”

• Mealtimes provide a “sense of security, meaning, order, and structure to an individual’s day; imbue that person with feelings of independence, control, and
sense of mastery over his or her environment; and provide opportunities for making food choices."

- Increase social interactions
- Conceptual model of the nutritional dimensions of feeding/mealtime is needed.


- Per parental report, tube feeding interferes with family mealtime where conversation and participation in family life occur
- Parents may need advice on how to manage tube feeding in the context of the family meal.


- Quality of life conceptual model

**Articles on Training Programs for Feeding**


- In resource poor countries, advanced interventions and technological solutions for feeding difficulties are not available. In situations of poverty, problems are exacerbated by factors such as lack of resources to buy food, limited time and facilities for cooking nutritious food, limited time and facilities for cooking special recipes and lack of access to rehabilitation and health services
- Care-provider training for children with feeding difficulties showed significant improvements in the children with CP in respiratory health (p<0.005), cooperation at meals (p<0.003), overall mood (p=0.001) and caregiver stress (p<0.001). No consistent improvement in growth compared to unaffected peers
- In situations of poverty, compliance is restricted by lack of education, finances and time. Care-providers with minimal formal education, living in conditions of extreme poverty are able to change feeding practices after a short low-cost training intervention, with positive consequences
- Interventions not related to increasing caloric intake: Adapt food consistency, adapt feeding method with appropriate position, foster jaw stability, Foster self-feeding (6 sessions)
- Significant improvements in the child's health and caregiver stress with feeding training


- Holistic approach to improve chewing function by providing postural alignment, sensory and motor training and food and environmental adjustments
  - Positioning for safe feeding
  - Placing food on molars
  - Sensory stimulation of gums and teeth
- Chewing exercises with chewing tubes
- Grading of food consistency (increasing as tolerated)

- 80 children, 3.5 years in randomized controlled trial with children receiving traditional oro-motor exercises for 12 weeks
- Children with the chewing training improved on a chewing scale developed by one of the authors compared to controls and on the Behavioural Pediatric Feeding Assessment


- Qualitative research design surveying SLPs in school and focus groups
- SLPs felt ill prepared to deal with dysphagia management in school settings
- Concern about working in isolation without appropriate supports and equipment
- Primary concern is aspiration and despite SLPs background, they felt ill prepared to manage individualized school feeding programs
- Requested written protocols and support from school administration to be able to learn skills before offering services


- Mealtime participation
- Opportunities for mealtime participation
- Mealtime development
- Barriers and facilitators to mealtime
- Clinical reasoning decision making flow charts for feeding/mealtime


- Anecdotal information, quotes & survey from parents regarding their relationship & inclusion as a member of their child’s Multi-Disciplinary Team (MDT)
- There is evidence that suggests a significant mismatch between the families and the team and thus barriers to training the families to improve success of the child with feeding needs
- Barriers identified include access to services, professional knowledge & skillsets
- Emotional reactions, decision-making & treatment planning were barriers to effective treatment
- All parents involved expressed interest in having a place at the table as part of the MDT when it involved their child’s feeding/dysphagia
- Failure to not include parents in this way was seen by the families as impacting care and in turn the health of their children

• Study examining the training of Carers, described as a group of highly experienced educational practitioners
• Goals for Carers regarding feeding needed to be more clear in terms of expectations
• Results indicated that Carers did best implementing feeding protocols when they observe feeding, followed models of the therapeutic team, engage in experience and practice with materials that improve feeding for the child, and had frequent follow-up
• A determination was made that in addition the area of communication within the context of the mealtime setting needs to be examined further, both in terms of clear and logical feeding plans and communication within the meal with the child

Hettiarachchi S, Kitnasamy G. Effect of Experiential Dysphagia Workshop on Caregivers’ Knowledge, Confidence, Anxiety and Behaviour During Mealtimes. *Disability CBR Inclusive Development* 2013;24:75-97; doi.10.5463/DCID.v2413.73
• Study of the knowledge of Sri Lankan mothers feeding children with cerebral palsy
• Limited knowledge of feeding children with disability affects mothers of children with cerebral palsy. Workshops to increase carers’ knowledge and confidence also decreases their anxiety and adherence to recommendations
• Experiential training for caregiver is important to ensure the children are fed safely

http://dx.doi.org/10.1016/j.apmr.2015.11.019
• Small adult study, outpatient
• 2 sessions per week plus home program with education of carers
• Oropharyngeal exercises, swallowing routine and caregiver participation
• Improvements seen in objective measures of swallowing safety and of lingual strength
• All but one patient (who had a progressive illness) improved in their oral intake, several weaning off their enteral support

• Children with disabilities more likely to be out of school than any other group of children
• Inadequate infrastructure to allow full participation in school is a challenge for educational services and eating at school
• Nutritional needs of children with disabilities are rarely considered when developing school feeding programs
• Inclusiveness assessments suggested to allow all children to participate in school feeding/eating programs

This study explores the differences between providing only written support to families during the training for feeding protocols versus the implementation of role-playing, observation and scripting within an ABA feeding therapy framework.

Children whose families received enhanced multi-dimensional training demonstrated improved acquisition of feeding skills over time than those who only received written materials.

It should be of note that many children engaged in dysphagia/feeding therapy have protocols included within their program to help decrease the learned behaviors that surround negative feeding experiences.