Time to Eat? Risk Management to 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.1,2,3

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 occur 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 can allay fears and give feeders more confidence to allow children to participate in oral feeding/eating. With the appropriate information, we all 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 who aspirate without any apparent negative respiratory consequences of aspiration. We also are aware that even if children aspirate and demonstrate respiratory infections, parents or the children, themselves may choose to continue to practice oral feeding/eating with their children.

The authors of this breakfast session do not want to be dismissive of aspiration or of lower respiratory tract infections in children with CP, which are the leading cause of morbidity and mortality in these children. On the other hand, we want to stimulate thought regarding aspiration and its consequences. **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.)

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. 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.**

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

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or the ability to make feeding “safe” including food processing and efficiency. But we 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.

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. 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.

Feeding interventions for children with feeding and swallowing dysfunction and aspiration are understudied and evidence for the success of the various interventions is lacking. 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.

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

21 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.v24i13.73
- Decreasing high bacterial burden in the mouth
- Eliminating smoke exposure.

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 can be found appended to an Instructional Course titled “The Right to Eat: Can caregiver training improve participation in feeding for children with cerebral palsy presented by the authors at the AACPDM 2018 in Cincinnati.

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