The Right to Eat: Balancing Risk, Harnessing Opportunities?

Gina Rempel, MD, FRCPC
Children’s Hospital Winnipeg
Rehabilitation Centre for Children, Winnipeg
grempel@hsc.mb.ca

Marianne Gellert-Jones, MA, CCC-SLP
HMS School for Children with Cerebral Palsy,
Philadelphia, Pennsylvania
Mjones@hmsschool.org

Cindy Dodds PT, PhD, PCS
Medical University of South Carolina
doddscb@musc.edu

Barb Borton, MSc, OTM
Rehabilitation Centre for Children, Winnipeg
bborton@rccinc.ca

Disclosures: Gina Rempel has received an honourarium from Nestle Health Sciences & will not include practice recommendations & will address only evidence-based science in the presentation. The other authors have no commercial relationships relevant to the topic being presented.

Outline:
Families of children with feeding & swallowing problems related to underlying neurodisabilities like CP are increasingly choosing to feed their children orally even when there is a high risk of aspiration. This decision can place feeding team members at odds with each other & with individuals who are feeding the children in various settings because of differing views on the safety of oral feeding. Join therapists from different disciplines for an interactive discussion on aspiration & its risks, balancing those risks with good health & nutrition. Drawing on the literature on the ethics & quality of life considerations of oral feeding presenters will lead case discussions on critical elements that allow the incorporation of oral feeding into nutrition care plans for individuals with a variety of oral feeding skills. Participants will come away with an understanding of the importance of oral feeding as a life-enriching activity & how to make elements of oral feeding a reality for more children requiring enteral nutrition support.

Objectives as related to children with CP with a variety of feeding competencies:
- Elucidate the risks of oral feeding in different care settings
- Identify ways to mitigate some of the risks of aspiration
- Articulate the importance of feeding training to foster participation in feeding

What is known about aspiration risk?
For children with neurodisabilities like cerebral palsy (CP) aspiration risk is increased
- Aspiration during feeding can result in chronic lung disease but the characterization of the effects of aspiration is not always straightforward: It may not make you sick!
- Aspiration is likely an important risk factor for lung disease, however, in & of itself, it may not be become clinically relevant unless accompanied by other risk factors

How do we balance the risk of aspiration with quality of life?
- Modify mealtime environments & food consistency, viscosity and texture to match skills
- Ensure optimal dental care
- Eliminate smoke exposure
- Include optimizing nutritional status in the care planning

What are important training elements for individuals feeding a child?
- Teach those involved in feeding in experiential ways: Explain, demonstrate, experience
- Enhance processing & swallowing safety by supporting, pacing & positioning
- Incorporate ethnocultural & selective eating patterns into care plans
- Address value the shared sensory, emotional & social experience of families eating together
- Look at feeding in the context of the whole child, family & child skill set, environment.
Questions

1. Which of the following are important risk factors for aspiration?
   a. Lack of self-feeding
   b. Dental caries
   c. Poor nutritional status
   d. a, b, c
   e. a & b

2. True or False
   Cessation of oral feeding & initiation of enteral nutrition has been demonstrated to decrease
   the risk of hospitalization and lower respiratory tract infections

3. Caregiver training should address
   a. Positioning of the individual
   b. Supportive maneuvers to facilitate mouth closure
   c. Matching food consistency & viscosity to the child’s skills
   d. Mouth care
   e. Pacing the meal to allow clearing of the mouth & safe swallowing
   f. All of the above

4. Important considerations for the development of feeding plans include all of the following:
   a. Making the child fit the plan
   b. Child & parental values around feeding
   c. Decreasing choices about feeding to decrease risk
   d. Optimizing nutrition is the most important consideration
   e. All of the above

ANSWERS: 1:E, 2: False 3: F 4: B

References

HANDOUT
2019 Nutrition Science and Clinical Practice
The Right to Eat: Balancing Risk, Harnessing Opportunities

Gina Rempel, MD, FRCPC
Children’s Hospital Winnipeg & Rehabilitation Centre for Children, Winnipeg
University of Manitoba, Canada
grempel@hsc.mb.ca

Cindy Dodds PT, PhD, PCS
Medical University of South Carolina
doddscb@musc.edu

Marianne Gellert-Jones, MA, CCC-SLP
HMS School for Children with Cerebral Palsy, Philadelphia, Pennsylvania
Mjones@hmsschool.org

Barb Borton, MSc, OTM
Rehabilitation Centre for Children, Winnipeg
bborton@rccinc.ca

Outline:
Families of children requiring enteral nutrition support due to feeding and swallowing problems are often choosing to feed their children orally even when there is a high risk of aspiration. This decision can place feeding team members at odds with each other and with individuals who are feeding the children in various settings because of differing views on the safety of oral feeding. Join therapists from different disciplines for an interactive discussion on aspiration and its risks, balancing those risks with good health and nutrition, and the evidence supporting caregiver training to enhance the safety of oral feeding. Drawing on the literature on the ethics and quality of life considerations of oral feeding for both adults and children with disabilities, presenters will lead case discussions on critical elements that allow the incorporation of oral feeding into nutrition care plans for individuals with a variety of oral feeding skills. Participants will come away with an understanding of the importance of oral feeding as a life-enriching activity and how to make elements of oral feeding a reality for more children requiring enteral nutrition support.

Objectives:
• Elucidate the risks of oral feeding in different care settings
• Identify ways to mitigate some of the risks of aspiration
• Articulate the importance of feeding training in foster participation in feeding for children with a variety of feeding competencies

Evidence and References
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 those most severely impacted (who are 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 who aspirate without any apparent negative respiratory consequences of aspiration.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.

We 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.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. 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.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.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.13 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.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. 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.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.17,18,19 Questions remain about strategies to manage aspiration risk. Improvement in nutritional status always underpins any feeding interventions. In addition, 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.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:

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.v2413.73
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.\textsuperscript{22}

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.

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
Sequelae 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:
    o Dependent feeding is the main risk factor
    o Smoking
    o Dependent for mouth care and cavities
    o 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

DOI 10.1002/ppul.21576
• 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


• 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)

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.** *Dev Med Child Neurol* 2014; 56: 245-251

**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

Ferluga ED, Sathe NA, Krishnaswami S, McPheeters M. **Surgical intervention for feeding and nutrition difficulties in cerebral palsy: a systematic review.** *Dev Med Child Neurol* 2014;56:31-43

- 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.

Craig, GM. *Psychosocial aspects of feeding children with neurodisability* *European Journal of Clinical Nutrition* 2013; 67, S17–S20; doi:10.1038/ejcn.2013.226
- 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


- Describing the development of a consistent system to describe food texture and liquid viscosity

• 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


• 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

Articles about the importance of nutrition in children with CP
The Right to Eat
Balancing Risk, Harnessing Opportunities

Presenters
Cindy Dodds, PT, PhD, PCS
doddscb@musc.edu
Gina Rempel, MD, FRCPC
grempel@hsc.mb.ca
Marianne Gellert-Jones, MA, CCC-SLP
mjones@hmsschool.org
Barb Borton, MSc, OTM
bborton@rccinc.ca

Disclosure of Relevant Financial Relationships
Gina Rempel has received an honorarium from Nestle Health Sciences.
Cindy Dodds, Barb Borton and Marianne Gellert-Jones have no financial relationships to disclose.

We will not discuss off label use and/or investigational use in our presentation.

Most of us view eating as a life enriching activity.
Objectives

To articulate the ethics and quality of life implications for participating in eating

To identify risks or oral feeding and ways to mitigate some aspiration challenges

To articulate the importance of feeding training in fostering participation in feeding for children with variety of feeding competencies

Session Flow

Cindy Dodds: It's more than meets the mouth 15 minutes

Quality of Life and the Right to Eat

Gina Rempel: Does feeding fit? 20 minutes

Delving Deeper: Putting your best mouth forward

Marianne Gellert Jones: Ready to Eat: Caregiver training improves swallowing safety 20 minutes

Techniques to improve participation in feeding 20 minutes

Discussion

Barb Borton: Looking at cases to develop enteral and oral nutrition care plans 15 minutes

Balancing risk of Aspiration/Health & Nutrition Participation, Quality of Life, and Ethics? (2011 Movie: The Intouchables)

Participation, Quality of Life, and Ethics?

Is this the case for children with medical complexity?
Decisional Conflict and Resolution Concerning Gastrostomy Tube Intervention

• Context of child and family
• Struggle between value in eating and potential loss with g-tube
• Process of Care
  • Knowledge and Information
  • Support

(Mahant, Cohen, Nelson, Rosenbaum 2018; Mahant, Jovcevska, Cohen 2008; Adams, Elias 2014)

Videos

Quality of Life Conceptual Model

(Patrick, Chiang 2000; Dodds, Riempel 2016)

Related Evidence

Brady et al. 2006: Persons with disorders of consciousness: Are oral feedings safe/effective?

• 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.

Craig, GM. 2013: Psychosocial aspects of feeding children with neurodisability

• 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.
Cassens et al. 1996: Enhancing taste, texture, appearance, and presentation of pureed food improved by resident quality-of-life and weight status

Amarantos et al. 2001: Nutrition and Quality of Life in Older Adults Journals of Gerontology

- Dietary, anthropometric, biochemical information does not capture
- Sensory
- Psychological
- Social aspects of food and eating
- Measures of nutrition do not address quality of life

“A 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.”

Consider How Feeding is Addressed in Available QOL/HRQL Outcomes

Caregiver Priorities and Child Health Index of Life with Disabilities

Assessment of Caregiver Experience with Neuromuscular Disease

The main factor in our decisions about oral feeding and our anxiety in feeding children with varying skill sets

Let’s explore the barriers and fear of eating so they can be addressed

ASPIRATION
Yet when most of us think about feeding/eating, we are not considering aspiration, nutritional content of every bite or whether or not there will be negative consequences. Our focus is usually on the socialization at the table, the taste and texture and the feeling of satiety after the meal…

So how can we integrate these elements of feeding into the feeding plans of the children whose care we participate in?

EATING IS MORE THAN ASPIRATION

- Aspiration does not always have long-term negative consequences.
- Aspiration and respiratory illness: causal relationship or association?

Eating and Drinking Ability Classification System - Algorithm

ASPIRATION IS COMPLEX: determining its significance is challenging

- Despite risks, oral feeding associated with fewer hospitalizations compared to GT feeding.
- Respiratory illnesses were the same in both groups.
- Careful handfeeding as safe as tube feeding in some adult settings.

ASPIRATION IS COMPLEX: determining its significance is challenging

- The characterization of the consequences of aspiration is not always straightforward.
- Aspiration is an important risk factor for pneumonia but in and of itself may not be significant enough to result in negative consequences.

IS ASPIRATION AN INDEPENDENT RISK FACTOR FOR PNEUMONIA?

- Lack of self feeding.
- Smoking.
- Dental caries.
- Multiple illness.

References:
2. Yet C. Yet to consider aspiration, nutritional content of every bite or whether or not there will be negative consequences. Our focus is usually on the socialization at the table, the taste and texture and the feeling of satiety after the meal…
3. EATING IS MORE THAN ASPIRATION
- Aspiration does not always have long-term negative consequences.
- Aspiration and respiratory illness: causal relationship or association?
4. ASPIRATION IS COMPLEX: determining its significance is challenging
- Despite risks, oral feeding associated with fewer hospitalizations compared to GT feeding.
- Respiratory illnesses were the same in both groups.
- Careful handfeeding as safe as tube feeding in some adult settings.
5. IS ASPIRATION AN INDEPENDENT RISK FACTOR FOR PNEUMONIA?
- Lack of self feeding.
- Smoking.
- Dental caries.
- Multiple illness.

References:
IS ASPIRATION EVER SEEN IN TYPICAL INDIVIDUALS?

- 220 adults with no organic pharyngeal or esophageal disease:
  - 38% some abnormalities in swallowing stages
  - 28% penetrated the airway
  - 8% aspirated!

Barbiera et al. Radiol Med 2002;104:125-133

Use investigations with caution
Interrogate the study results to get solutions

DIAGNOSIS OF SWALLOWING DYSFUNCTION

- On clinical evaluation detection of aspiration better with liquids than solids:
  - 3 ounce water test- 100% specific, 51% sensitive
  - Clinical evaluations for aspiration likely more specific than sensitive
  - Better at deciding a child DOES NOT aspirate on clinical evaluation

Suiter and Leder: Clinical utility of the 3 ounce water swallow test in dysphagia. Dysphagia 2008;23:244-250

The evaluations of swallowing should not be the only determining factor about whether or not a child can eat

Think about:
- What do we need to know beyond the swallow study?
- A swallow study is not a medical fact

We acknowledge
- Respiratory illness has a 44% higher occurrence in children with neurological impairment
- The major cause of recurrent pneumonia is oro-pharyngeal incoordination

Diagnosis of swallowing dysfunction
- Video fluoroscopic swallowing studies
- Fiberoptic endoscopic evaluation of swallowing
- Bronchoscopy


While aspiration complex and determining its significance is challenging

While aspiration complex and determining its significance is challenging, there are other factors that contribute to pneumonia.

In children who aspirate, do we mitigate all other risks...
- Do we stop feeding if the child cannot self-feed?
- Do we stop feeding if the parents smoke?
- Do we stop feeding when there is dental decay?

Exploring the balance of risk and participation.

Feeding strategies are generally understudied and lack evidence.

Improved nutrition:
- Assess
- Monitor
- Optimize
**Improve Nutrition:**
- Assess
- Monitor
- Optimize

**Balancing Risks:**
- Poor bolus control
- Poor swallow trigger
- Constant choking & coughing
- Community too afraid to participate

**Challenging the Fear of Participation:**
- Socialize at the table
- Tube feed at the table
- Pleasurable sensory activities
- Training

**Feeding strategies: training**

**Training decreases fear**
- Training and education provide a framework for participation
  - Because you can systematically address concerns
  - If you educate people on
    - Balancing risks
    - Dealing with confounding factors
    - Having feeding plans that acknowledge concerns, participation in feeding may prevail

**So how do we communicate with organizations to allow children to eat even in the face of risk?**
**Shared Decision Making: Engage**
- Engage the child, family, care-providers and community agencies
- Get input and share information
- Set the stage to mitigate risk to promote participation

**Shared Decision Making: Deliberate**
- Elicit perspectives of all stakeholders
- Comprehensively assess the health, feeding skills and risks and the environment
- Consider the possible outcomes
  - Health
  - Quality of life
  - Value of participation

**Shared Decision Making: Decide Together**
- Integrate the information
- Review the evidence
  - Risks, benefits, certainty of outcome
- Acknowledge different perspectives
- Empower choice making

**Even in the face of risk**
- Children, youth and their parents are opting for oral feeding
- Sometimes this places them at odds with different groups
- Let’s gather evidence so we can deliberate and decide together

**Omar**
- 6 year old boy with cerebral palsy
- GMFCS V
- MACS V
- EDACS IV
- Family newly immigrated to Canada
- No regular medical care or therapy intervention

**Omar**
- Food soaked in liquid, few choices
- No adaptive equipment, poor positioning
- Nutrition borderline
Omar's Family's Goals

Continue oral feeding

Looking for positioning aids

Parents acknowledge musculoskeletal challenges from holding

The ICF

Body Structure Function Impairments

• Aspiration
• Positioning/postural control
• Coordination
• Oromotor skills
• Dental care
• Respiration
• Constipation
• Reflux
• Secretion control

Activity and Participation

Eating/Feeding

School

Community

Environmental Factors

Feeding environment
Positioning

Child and Family

Personal Factors

Environmental Factors

Feeding expertise/skill
Provider/Caregiver

System policies that support participation in school, home community

Individual attitudes regarding feeding, i.e. readiness

Physical Environment

School

Home

Community
Personal Factors

- Educational level
- Age
- Comfort
- Trust
- Motivation
- Spirituality and Beliefs

Child and Family

- Culture who feeds

Omar Outcomes

Mitigating Risk is a **BALANCING** act

**SKILLED SUPPORT**
- Oral motor skill assessment and development
- Positioning and seating
- Appropriate utensils
- Texture and viscosity
- Treating constipation
- Training caregivers

**TRAINING CAREGIVER**
- Respecting culture/religion
- Understanding socioeconomics
- Recognizing feeding may be emotional
- Position of caregiver
- Use of appropriate utensils
- Blending food
- Boosting calories

Let’s look in detail at feeding training and its impact

Why Train?

People with significant feeding impairment are dependent on their primary caregivers who hold most of the information about their care:
- Caregivers report issues regarding access to support & training
- Translation across environments
- Lack of knowledgeable service providers
- Staff turnover & reassignments impact continuity of care
- Mismatch between the child’s needs & the skill set and level of the feeder

Who Are We Training?

- **Parents:** Acknowledge they are the experts when their child is concerned
  - Supplemental training, “a tweak” of their current regime
  - Skill training comes improved compliance
- **Paraprofessional:** may come with a diverse knowledge base
  - Supports in place ongoing
  - Refreshers and individualized training
  - Plan for follow-up

Meet them at their level
“Tell me and I forget, teach me and I may remember, involve me and I learn.”
Benjamin Franklin

Relevant
Achievable
Functional

What Have Others Determined About Training?
“A substantial amount of dysphagia intervention will be around training others to support those who have complex eating and drinking needs.” Harding & Halai (2009)

“Results suggest both modeling and rehearsal were sufficient to obtain high levels of treatment integrity when combined with verbal instructions, a finding that is consistent with previous research on modeling and rehearsal.”
Mueller, MM., Piazza, CC., Moore, JW. et al. (2003)

“By contrast, didactic instruction (written and verbal instructions) delivered once did not produce acceptable levels of treatment integrity, a finding that also is consistent with training literature.”

What Have Others Determined About Training?
“Experiential workshops helped participants to understand first-hand the reason for the advice given by healthcare professionals.”

“A combination of teaching methods could support the different learning styles of the participants and encourage better understanding and recall of information.” Hetiarachchi, S. & Kitnasamy, G. (2013)

Value of Multiple Training Techniques
Experiential training is a powerful tool
- Putting yourself in the child’s position
- Improves retention of information
- Multisensory experience improves processing


“Of particular importance are support and prompting guidelines relating to pacing, positioning, and awareness of swallowing, which can help prevent aspiration and asphyxiation. Moreover, speech and language pathologists should ensure that the reasons for following consistency modification and equipment use guidelines are fully understood by family caregivers, who appear to be more resistant to using the dysphagia guidelines and, on occasion, gave the authors the impression that they did not like being “told” how to feed their own family members.”

Figure 1: Histogram showing the comparison of adherence across observational setting for the different types of guideline.
Training Paraprofessionals

Pre and Post Test
- Initial training containing multiple experiential activities
- Individualized peer training
- Follow-up/ Conformance Measure
- Consider assigning primary and back-up feeders via a self-report on a feeding comfort scale

Training Food Prep Staff

Meeting the needs of the clients
- Variety of food options including those that meet dietary needs
- Food Preparation- Hands on demonstration of each texture
- Detailed Feeding Support Plans that are driven by the Diet Order
- Opportunity to trial new products
- Daily Check of Foods & Tasting all foods is a MUST
- Texture Changes in the moment both in the kitchen and at the table
- Training supports compliance and helps staff identify as having a role in client care

Old Terminology

Regular
Dysphagia Advanced/Chopped
Mechanical Soft/Ground
Thick Puree
Thin Puree
Pudding Consistency
Honey Consistency
Nectar Consistency
Naturally Thick
Thin

Why Follow IDDSI Standards?

- Standardized methods to measure each level
- Consistent terminology across disciplines and environments (it’s international)
- Food Labeling is being enacted to new standards
- Allows for more options but also allows facilities to identify fewer levels that best meet their client’s needs

Key Components to Include in Basic Feeding Training

- Review of Typical Diet
- Motor Feeding
- Positioning for Feeding
- Providing Support
- Equipment Selection and Use
- Food Preparation
- Texture Modification
- Presentation of Food & Liquids
- Special Dietary Needs
- Socialization
- Common Problems
- Safety
- Ending the Meal

Ready to Eat? Experiential Activities Enhance Training

Lip Closure
- Experience Lip Closure in Flexion and Extension
- Swallowing without Lip Closure

Positioning and the Impact on Swallowing
- Neutral Pelvic Alignment
- Kyphosis
- Lordosis
**What Happens Next Once Training is Completed with Staff?**

**Green Light** = May be fed by all Program Staff/Para-Professionals (EDACS Levels II-III)

**Yellow Light** = May be fed by experienced feeders only with specialized training (EDACS Levels III-IV)

**Red Light** = Fed by Feeding Professional Only with emphasis on therapeutic feeding/oral motor skills/secretion management (EDACS Levels IV-V)

**Sellers D, Mandy A, Pennington L, et al.** Development & reliability of a system to classify the eating and drinking ability of people with cerebral palsy. **Dev Med Child Neurol** 2014; 56

---

**Once basic feeding instruction is completed** 

- **Green Light**
  - Review of Individualized Feeding Support Plan
  - Observation of the feeding trainer
  - Opportunity for the new feeder to offer a small portion of the meal under direct supervision

- **Yellow Light**
  - New feeder performs all aspects of the meal
  - Mealtime set-up to Last Bite
  - Feeding under the direct observation of the trainer
  - Discussion and input is provided throughout

- **Red Light**
  - New feeder is independent and the trainer is positioned nearby to assist should they be needed

---

**What elements would you include in an individualized Feeding Support Plan?**

- Mirrors Diet Order
- Provides detailed instructions regarding:
  - Texture
  - Positioning Needs
  - Food Preparation
  - Feeding Techniques
  - Drinking Techniques
  - Individual & Parental Preferences
  - What to Expect: Typical Volume
  - Who Can Feed
  - Who can Respond to questions about this plan
Results of Training

• Pre and Post Training for Drinking with a Student who is EDACS Level IV
• Pre and Post Training Administering Medication to a Student who is EDACS Level IV

Teaching Videos

Final Thoughts

“When the Doctor asks me if I have any concerns, I always say no because he always has had this difficulty.”

“I was working this weekend and I noticed one of the kids scooping all their food onto the floor. All I did was turn the plate the way I was taught in training and that fixed it. I was so glad I could help.”

“I didn’t really train anyone to feed me, because I was so used to the way my older brother fed me. He just stuffed the food in.”

“I didn’t realize she was losing so much fluid, until I was shown another way. This looks better.”

Developing Feeding Plans

Engage stakeholder and gather information

Deliberate: Assess risks, engage the ICF principles, train

Decide together: Feeding is a team sport

Time for discussion

What are the barriers to feeding participation you face in your work setting?
What strategies do we need to foster participation in eating?

- Activate shared decision-making?
- Take responsibility for the plan?
- Negotiate critical elements with the children, families and professionals?

What tools do we need to help decide on feeding plans?

What are the key elements you would include in caregiver training?

- Any other considerations in your setting?
- Any other ideas for imparting knowledge?

Objectives

To articulate the ethics and quality of life implications for participating in eating

To elucidate the risks of oral feeding and how to mitigate them

To integrate important elements of feeding training in different community settings

Presenters

Cindy Dodds, PT, PhD, PCS
doddscb@musc.edu

Gina Rempel, MD, FRCPC
grempel@hsc.mb.ca

Marianne Gellert-Jones, MA, CCC-SLP
mjones@hmsschool.org

Barb Borton, MSc, OTM
bborton@rccinc.ca