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Viewpoint

Risk Feeding: An Australian Pediatric Palliative Care Perspective

Claire Radford,^a Jeanne Marshall,^{a,b} Anthony Herbert,^{a,c} Helen Irving,^{a,d} and Kelly Weir^{e,f}

Purpose: This article explores the challenges of risk feeding from an Australian Paediatric Palliative Care perspective. There is currently limited evidence to guide risk feeding in pediatric clinical practice. Therefore, this article uses evidence from the adult palliative and end-of-life care context (extrapolating to pediatric application), in addition to the authors' clinical experience in supporting children and their families with risk feeding. Recommendations for the clinical management of pediatric risk feeding are discussed, including the suggested focus for families and

the interprofessional team along the different phases of the palliative care continuum.

Conclusion: There is currently limited information to guide decision making regarding risk feeding in pediatrics. Overall, in the absence of evidence-based practice guidelines, it is the authors' recommendation that a risk feeding plan is developed in consultation and collaboration with the family, treating physician, and interprofessional team. Further research is required to support guidance for clinicians working in this area.

The topic of risk feeding has gained momentum over recent years, particularly in the field of adult palliative care and geriatrics, where discussions primarily focus on the end-of-life phase. For children with life-limiting conditions or who are palliative, pediatric risk feeding presents a different set of challenges for health professionals. Families often want their children to be able to eat and drink without tube feeding to support quality of life, and where children have known dysphagia or oropharyngeal aspiration, oral feeding in this context is considered as risk feeding. This article explores the ethical and practice challenges of pediatric risk feeding as well as the role of the speech-language pathologist (SLP) in the context of pediatric palliative care (PPC).

Understanding PPC

PPC for children and young people can be defined as "an active and total approach to care...embracing (sic) physical, emotional, social and spiritual elements, and focusses on the enhancement of quality of life" (Together for Short Lives, 2018, p. 9). PPC is not just limited to the provision of supportive care for symptom management but also includes the simultaneous provision of active treatment, targeting a cure or quality of life (CareSearch Palliative Care Knowledge Network, 2017). At its core, PPC is child focused, family centered, and goal directed (Himmelstein, 2006) and should involve the child and family members in all care planning and decision making.

As a result of advances in emergency medicine, critical care, and medical technology, many children and young people with life-limiting conditions are now living longer than in previous years with increasingly complex care needs, and it can be difficult to predict the duration and nature of their clinical journey (Waldman & Wolfe, 2013). Together for Short Lives (2018) outline four categories of life-limiting conditions, which is a helpful framework for considering clinical cases (see Table 1).

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Table 1. Categories of life-limiting conditions.

Category	Definition	Example conditions
1	Life-threatening conditions for which curative treatment may be feasible but can fail	Children with cancer when treatment fails (e.g., Stage 4 neuroblastoma), irreversible organ failure, and cardiac anomalies
2	Life-limiting conditions, where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities	Complex cardiac disease, cystic fibrosis, and Duchenne muscular dystrophy
3	Life-limiting, progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years	Neurodegenerative conditions (e.g., Batten disease), metabolic conditions (e.g., mucopolysaccharidoses), and neuromuscular conditions
4	Irreversible but nonprogressive (stable) life-limiting conditions causing severe disability, leading to susceptibility of health complications and likelihood of premature death	Severe cerebral palsy or multiple disabilities (e.g., following brain or spinal cord injury) Complications that may cause death include severe recurrent pneumonias or intractable seizures

Note. Adapted from *A Guide to the Development of Children's Palliative Care Services* (4th ed., p. 11), by Together for Short Lives, 2018, Bristol, England: Publisher. Copyright 2018 by Together for Short Lives. Adapted with permission.

The role of the SLP in PPC is an emerging area of practice. Krikheli et al. (2018) conducted a systematic scoping review, and while there was limited literature specific to PPC, the authors describe the scope of the SLP in the broader palliative care context. They include cognitive-communication management, augmentative and alternative communication, feeding/dysphagia management, dysphagia management in end-of-life care, oral health care and secretion management, and respiratory and upper airway management as within SLP scope, all of which are applicable to the PPC space.

Dysphagia management is a challenging area for SLPs working in PPC. Dysphagia can be a symptom of many different life-limiting conditions (Vesey, 2013) and is often described as a natural step in the progression of disease (Kelly et al., 2018). Dysphagia may be immediately life threatening with an occlusive asphyxiation event (choking). Alternatively, dysphagia may present as nonimmediately life threatening or chronic, as with oropharyngeal aspiration, characterized by coughing, wet breathing, wet voice, some distress, face reddening, eye watering, increased work of breathing, and fremitus (DeMatteo et al., 2005; Frakking et al., 2016; Weir et al., 2011). Additionally, oropharyngeal aspiration may be silent (entry of material into the airway without a cough response), which is particularly associated with neurological conditions (Weir et al., 2011). Potential adverse health outcomes associated with dysphagia include malnutrition, dehydration, pneumonia, and respiratory sequelae (Vesey, 2013; Weir et al., 2005), all of which may contribute to more rapid disease progression or premature end of life. The goals of care for the child and family may change and adapt depending upon where the child is along the continuum of phases of palliative care (diagnosis, stable, unstable, deteriorating, terminal, and bereavement; see Figure 1), as will the role of the SLP.

What Is Risk Feeding?

“Risk feeding” is one of several terms used to describe a situation when a person continues to eat or drink orally,

despite the known risk of aspiration or choking (Royal College of Speech and Language Therapists, 2005; University of Auckland & Hutt Valley District Health Board, 2016). Other terms used in the literature include “comfort feeding” (Hansjee, 2013; Mater Misericordiae Health Service, 2012a), “feeding with risk” (Hansjee, 2013), “feeding at risk” (Gallagher, 2015), “careful feeding” (Trottier & Miller, 2013), or “careful hand feeding” (Gallagher, 2015).

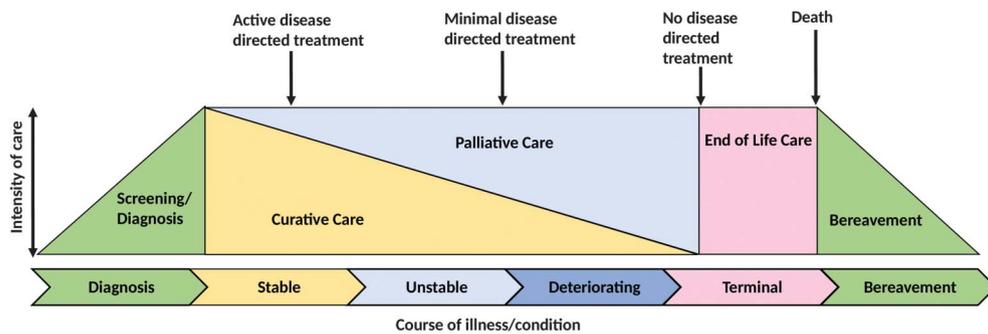
There is much debate about the use of the term “risk” in this context. In clinical practice, “risk” may imply a negative value judgment, place undue burden or guilt upon decision-makers, and encourage a risk-averse attitude in health professionals (Murray et al., 2019) in what is essentially an informed choice made by a person and/or their guardian. Given it is the most consistent term used in the literature to date, “risk feeding” will be the term used for the purpose of this article, with the acknowledgment that other terms may be preferred in specific clinical contexts.

Reasons for Risk Feeding

It is important to recognize that the act of eating and drinking provides more to a person than just nutrition. While serving a physical function, the pleasure of tasting food and drink and the social closeness achieved from sitting down to a meal with loved ones are described as important aspects of quality of life (Gallagher, 2015; Hanners et al., 2012; Mater Misericordiae Health Services, 2012a). Food may have specific religious, cultural, or spiritual significance to families, and in the case of children, it may symbolically represent the role of maternal nurturing (Maillet et al., 2002) and contribute to parent-child attachment. Taking all of this into account, it is evident that the decision to stop a child eating or drinking orally is not one taken lightly.

In cases where clinically assisted nutrition and hydration (CANH) is not suitable nor appropriate, risk feeding may in fact be the only option for a family. There are clinical

Figure 1. Phases of palliative care over the trajectory of illness (Masso et al., 2015; Myatra et al., 2014). Adapted from “End-of-Life Care Policy: An Integrated Care Plan for the Dying,” by S. N. Myatra, N. Salins, S. Iyer, S. C. Macaden, J. V. Divatia, M. Muckaden, P. Kulkarni, S. Simha, & R. K. Mani, 2014. *Indian Journal of Critical Care Medicine*, 2014, 18, p. 619. Adapted with permission.



examples where a child does not tolerate any enteral feeding options (nasogastric, gastrostomy, or jejunostomy tube feeding) and others where a child is deemed too great an anesthetic risk for feeding tube placement (Hauer, 2017; Siden et al., 2009). In such cases, families and health professionals need to consider whether the risks of CANH outweigh the benefits (Hansjee, 2013), and thus, risk feeding may potentially be the safest option for the child's nutrition and hydration requirements. Looking specifically at adults receiving palliative care, there is no evidence in the literature to demonstrate that CANH prevents aspiration pneumonia or malnutrition nor provides comfort in the end-of-life phase (Finucane et al., 1999; Sherman, 2003). Therefore, once again, risk feeding may be the most appropriate option for the person's comfort and care, and it is reasonable to assume this would also apply to children at end of life. The issue of forgoing or withdrawing CANH in PPC will not be addressed in this article, although it is acknowledged by the authors as an ethically challenging and important area for further discussion and debate (Diekema & Botkin, 2009).

Informed Decision Making and Consent

There is overall agreement in the literature that any legally competent adult can choose to continue eating and drinking, accepting the risk of swallowing-related health complications that may follow (Mater Misericordiae Health Services, 2012b; Speech Pathology Australia, 2019; University of Auckland & Hutt Valley District Health Board, 2016). A requirement of informed consent is that the person (or substitute decision-maker) is provided with adequate medical information, has a clear understanding of the options available to them with the associated risks and benefits, and the opportunity to ask questions (Kaizer et al., 2012), all of which are consistent with the ethical principle of autonomy.

Informed consent for children (often defined as those less than 18 years old) can vary greatly depending upon the child's developmental age, cognition and individual/family circumstances, and the relevant legislation in effect.

Health professionals have a responsibility to apprise themselves of the law operating in their specific jurisdiction (Kelly et al., 2018). In Queensland, Australia, the parent/guardian is the primary decision-maker for the child, including making decisions about risk feeding. Variances exist, however, in cases where the parents themselves are aged under 18 years, the child is under the care of child protection services, or when the Queensland Supreme Court or the Family Court are involved (Queensland Health, 2017). Considerations should be made for adolescents, in partnership with their families and the health care team, about whether they are Gillick Competent (also known as a mature minor) and thus are assessed as having sufficient understanding, intelligence, and maturity to appreciate the nature, consequences, and risks of the treatment options available to them (Larcher & Hutchinson, 2010; Queensland Health, 2017).

Professional Dilemmas

The professional dilemma that can arise for many SLPs working in PPC is: How do we proceed when a parent/guardian wishes for their child to continue oral feeding (or consume a specific texture/consistency) when assessment has indicated that it is not safe for the child? It can be an uncomfortable space to occupy, rife with potential for intra- and interpersonal conflict (Kelly et al., 2018). The Speech Pathology Association of Australia (2010) Code of Ethics contains a set of biomedical ethics principles to help guide professional practice; however, in cases of pediatric risk feeding, these principles may appear to be contradictory to further complicate one's professional dilemma, as demonstrated in Table 2.

A number of different approaches to such ethical challenges have been discussed in the literature (Gray et al., 2016). The “best interests” approach is frequently used; however, critics argue that, in many cases, only the “medical best interests” are considered, ignoring the social, emotional, cultural, and spiritual factors (Gillam, 2016). Gray et al. (2016) also point out that the burden of care for a child with a life-limiting condition will impact on many facets of family life, and thus, all treatment decisions should consider

Table 2. Outlining the potential contradictory applications of bioethical principles to pediatric risk feeding scenarios.

Ethical principle	Application to pediatric risk feeding
Autonomy: We respect the rights of our clients to self-determination and autonomy.	The SLP should respect the rights of parents/guardians to make an informed choice for their child to continue oral feeding, accepting the risk of swallowing-related health complications that may follow.
Beneficence and nonmaleficence: Our actions will benefit others, prevent harm, and will not unknowingly cause harm.	The SLP should not support oral feeding if they perceive it will cause harm to the child. The SLP should not prevent oral feeding if it provides benefit, quality, or comfort to the child and their family. The SLP should not abandon (discharge) the family to pursue risk feeding without professional support to minimize the harm.

Note. SLP = speech-language pathologist.

the “best interests” of the family as a whole, including parents and siblings.

As another option, the “harm principle” is an ethical tool that focuses on whether the child will be “harmed” by the course of treatment chosen by the parents (Diekema, 2004), not whether it is “optimal” for the child (Gillam, 2016). If there is proven evidence that the treatment course will place the child at risk of serious and immediate harm, then the parents’ choice of treatment should be overruled by health professionals (Gray et al., 2016).

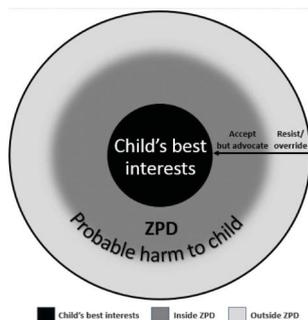
Gillam (2016) explores this idea further by describing the “zone of parental discretion,” which is an ethically and legally protected “space” where parents make decisions for their children (see Figure 2). In this space, parents have discretion to make decisions that are “good enough”, though potentially not optimal, but that there is no concrete evidence indicating the decision would directly lead to harm or serious setbacks for the child (Gillam, 2016).

Applying this framework to pediatric risk feeding, there is now a distinction between “real risk” and “assumed risk.” With real risk, there are clear and measurable clinical indicators that the child will be seriously harmed from risk feeding (Kaizer et al., 2012). Examples of this may include an identified risk of choking on a specific texture (immediately life threatening), reduced oxygen

saturation during feeds, where oral feeding consistently results in distress for the child, or where repeated aspiration events result in life-threatening respiratory sequelae. “Assumed risk” refers to the potential to cause a negative outcome (Kaizer et al., 2012) and potentially contribute to a shortened life, but definitive or causal evidence is not able to be provided. An example of this is the potential for aspiration to result in a diagnosis of aspiration pneumonia. As Langmore et al. (1998) demonstrate, there are a number of factors that place a person at greater risk of developing aspiration pneumonia beyond of aspiration alone. Therefore, in this example, unless there is definitive clinical evidence for a specific child that aspiration pneumonia will directly result from aspiration during oral feeding, aspiration pneumonia is only an assumed risk of oral feeding, and thus, parents retain the responsibility to balance the benefits and burdens associated with this option.

In many ways, for a child in the deteriorating and terminal phases of care (see Figure 1), the SLP’s ethical dilemma is lessened. Where the goals of care are firmly set in comfort and quality of life, it is more comfortable to support risk feeding, as although there may be risks of aspiration, this is not likely to significantly change the ultimate outcome or rate of deterioration/death. However, for children in the stable and unstable phases of care (see Figure 1), where goals focus on improving or maintaining health, an adverse event as a result of risk feeding may impact recovery/cure or potentially lead to deterioration.

Figure 2. The zone of parental discretion (McDougall et al., 2016). From *When Doctors and Parents Disagree* (p. 20), by R. McDougall, C. Delany, & L. Gillam (Eds.), 2016, Sydney, Australia: The Federation Press. Copyright 2016 by The Federation Press. Adapted with permission. ZPD = zone of parental discretion.



Management of Risk Feeding in Clinical Practice

Management should always involve a comprehensive interprofessional assessment, including medical, speech-language pathology, dietetics, and physiotherapy input (Mater Misericordiae Health Services, 2012b; Royal College of Physicians, 2010; Royal Hospital for Neuro-disability, n.d.; Speech Pathology Australia, 2019; University of Auckland & Hutt Valley District Health Board, 2016). As part of this assessment process, health professionals should explore the child and family’s preferences, values, and beliefs (University of Auckland & Hutt Valley District Health Board, 2016) as well as the risks and benefits to the child’s health if risk feeding is implemented (Mater Misericordiae Health Services, 2012b).

The Royal College of Physicians and British Society of Gastroenterology (2010) suggest four key questions that should be answered during the assessment phase to assist families and health professionals with complex and multifaceted decisions around risk feeding:

1. What is the underlying diagnosis?
2. What is the mechanism of the oral feeding problem?
3. Can the child (sic) eat and drink and, if so, at what risk?
4. What are we trying to achieve?

To fully explore the benefits and burdens of risk feeding, the family and interprofessional team need to consider both the category of life-limiting condition for the child (see Table 1) and their phase along the palliative care continuum (see Figure 1). Following assessment, health professionals should partner with families to discuss the results and goals of care. All appropriate feeding management plans should be explored, with specific discussion about the risks, benefits, and viability of each option so as to ensure parents/guardians can provide informed consent (University of Auckland & Hutt Valley District Health Board, 2016). It is recommended that written or visual information is shared with families as part of the education process to help guide and support informed decision making (CareSearch Palliative Care Knowledge Network, 2017; Royal Hospital for Neuro-disability, n.d.; Speech Pathology Australia, 2019). For example, this might include reviewing a videofluoroscopic swallow study with the family (and child if appropriate) and interpret the child's corresponding clinical signs. The importance of using clear, jargon-free, and nonambiguous language was also highlighted in the literature as an important component of the informed consent process (Hanners et al., 2012; University of Auckland & Hutt Valley District Health Board, 2016). Novice clinicians may benefit from scripting out discussion points prior to meeting with families to maintain clear and concise communication, particularly for potentially emotionally

charged conversations (Hanners et al., 2012). Table 3 outlines the authors' suggested focus of risk feeding management with respect to the child's phase along the palliative care continuum.

The concept of harm minimization replaces absolute safety in developing a plan to satisfy the family's oral feeding goals, maximize swallowing function, optimize oral nutrition and hydration, and minimize the risk to pulmonary health (Hanners et al., 2012; Langmore et al., 2009; University of Auckland & Hutt Valley District Health Board, 2016; Trottier & Miller, 2013; Weir et al., 2005). SLPs are very skilled in advocating for texture modification, positioning, and specific feeding strategies as means of reducing the risk of aspiration and associated respiratory sequelae.

The plan should also consider the significant risk factors for the development of aspiration pneumonia, many of which are frequently exhibited by children with palliative care needs. This includes dependency upon others for feeding, poor pulmonary clearance and weak cough, reduced mobility, increased time lying down after eating, poor oral health care (Langmore et al., 1998), suboptimal management of reflux (Hanners et al., 2012) or excessive secretions (Trottier & Miller, 2013), and consideration of physiotherapy for chest health.

Maintaining excellent oral health care is integral to maintaining pulmonary health in persons at risk of aspiration (Hanners et al., 2012; Langmore et al., 1998; University of Auckland & Hutt Valley District Health Board, 2016). Unfortunately, this is often deprioritized in the context of the child's overall condition (Trottier & Miller, 2013). While aspiration of food or fluid is not ideal, aspiration of plaque or bacteria contained in oral secretions or residue places the child at even greater risk of developing respiratory complications and systemic infection (Gibson & Nelson, 2000; New South Wales Health, 2016; Whiteing & Hunter, 2008). Early referral to an oral health care practitioner for an individualized plan is highly recommended.

Finally, risk feeding is about promoting quality of life, continuing to eat and drink despite the risks, so long

Table 3. Suggested focus for the family and interprofessional team in managing risk feeding along the phases of palliative care.

Phase of palliative care	Focus of risk feeding management
Deterioration and terminal phases	Prevention of choking risk (including food and fluids pooling in the mouth), an immediately life-threatening and distressing event (e.g., supportive positioning and head support, feeding in a side-lying position, or avoiding chokable textures) Ensuring that oral feeding remains a positive experience for the child (e.g., avoiding distress/discomfort or force feeding) Advocating for parenting/nurturing tasks to replace oral feeding where it is not a positive experience for the child (e.g., mouth cares, oral tastes, smelling preferred foods, oral stimulation/touch, tastes of citrus flavors, tastes of expressed breast milk)
Stable and unstable phases	Identifying and preventing the impact of "real risks" associated with oral feeding or for specific textures/consistencies Managing symptoms associated with known oropharyngeal aspiration (e.g., physiotherapy for chest health/airway clearance, antibiotic regimen) Hypothesizing the impact of assumed risks on current treatments to improve or maintain the child's health Implementing a range of harm minimization strategies to reduce the "assumed risks" Establishing a review schedule and/or specific triggers/thresholds to indicate that a review of the risk feeding plan is required

as the experience is pleasurable and provides comfort (Hanners et al., 2012; Trottier & Miller, 2013). Overt aspiration can actually be uncomfortable (Hanners et al., 2012), and it is important that the child and family are aware of this. Forcing a child to eat or applying guilt should be actively avoided (Langmore et al., 2009; Mater Misericordiae Health Services, 2012a). This can be difficult to manage in the context of family beliefs and values and can be especially complex when parents perceive their nurturing role to be inextricably linked with feeding their child. In such cases, beliefs and values should be sensitively discussed with families along with clinical assessment of the child's experience. Health professionals can help parents to reframe perceptions and identify alternate means of nurturing their child when oral feeding no longer represents a positive experience for them.

Documentation

Hanners et al. (2012) describe the use of primary and secondary recommendations as a clear method for health professionals to document the risk feeding plan. Using this strategy, the primary recommendation is always the safest option for the patient based on the results of the interprofessional assessment (nil by mouth, nil fluids orally, modified textures/consistencies, etc.). The secondary recommendation is the family's informed choice of diet option and agreed-upon harm minimization strategies, with a clear shared understanding that aspiration will likely occur. The risk feeding plan should be disseminated widely to all professionals involved in the child's care with the consent of the family, including the acute resuscitation plan in the event of asphyxiation. Recommendations for dissemination include all relevant hospital and health services, primary care physicians, discharge destinations, community services, respite services, and day cares/schools (Speech Pathology Australia, 2019; University of Auckland & Hutt Valley District Health Board, 2016).

Conclusion

There is currently limited evidence in the literature to guide risk feeding in pediatric clinical practice (Miles et al., 2016), with the vast majority of the information pertaining to adult palliative care and geriatrics. Further research and the development of guidelines/resources to support clinical practice specific to PPC and pediatric risk feeding are needed. However, developing a risk feeding plan for children in consultation and collaboration with the family, treating physician, and interprofessional team with clear documentation would be considered best practice in PPC in the absence of clear evidence-based guidelines. SLPs have a duty of care to provide a reasonable standard of care and one that would be similarly provided by another clinician with similar experience. Therefore, it is recommended that SLPs discuss clinically and ethically complex cases in professional supervision and actively seek a second opinion when in doubt. Open and clear communication

with the family (and child where appropriate) is required, including consideration of goals of care and a balance of benefits and burdens of oral feeding in each specific case. For many families and children, it will be appropriate to support risk feeding when the goals of care are comfort and nurturing, providing there are objective/subjective indicators of comfort and limited harm. The interprofessional team may also wish to seek formal advice from a clinical ethics consultation service, if accessible, for clinical cases where there is a significant difference between parent/guardian preferences and the health professional recommendations.

References

- CareSearch Palliative Care Knowledge Network.** (2017). *Paediatrics*. <https://www.caresearch.com.au/caresearch/ClinicalPractice/SpecificPopulations/Paediatrics/tabid/737/Default.aspx>
- DeMatteo, C., Matovich, D., & Hjartarson, A.** (2005). Comparison of clinical and videofluoroscopic evaluation of children with feeding and swallowing difficulties. *Developmental Medicine and Child Neurology*, 47(3), 149–157. <https://doi.org/10.1111/j.1469-8749.2005.tb01108.x>
- Diekema, D. S.** (2004). Parent refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics*, 25(4), 243–264. <https://doi.org/10.1007/s11017-004-3146-6>
- Diekema, D. S., & Botkin, J. R.** (2009). Forgoing medically provided nutrition and hydration in children. *Pediatrics*, 124(2), 813–822. <https://doi.org/10.1542/peds.2009-1299>
- Finucane, E., Christmas, C., & Travis, K.** (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *Journal of the American Medical Association*, 282(14), 1365–1370. <https://doi.org/10.1001/jama.282.14.1365>
- Frakking, T., Chang, A., O'Grady, K., David, M., & Weir, K.** (2016). Aspirating and nonaspirating swallows sounds in children: A pilot study. *Annals of Otolaryngology, Rhinology & Laryngology*, 125(12), 1001–1009. <https://doi.org/10.1177/0003489416669953>
- Gallagher, R.** (2015). *Swallowing problems in degenerative brain diseases*. http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Symptoms+_+Health+Concerns/Swallowing+problems+in+degenerative+brain+diseases.aspx
- Gibson, F., & Nelson, W.** (2000). Mouth care for children with cancer. *Paediatric Nursing*, 12(1), 18–22. <https://doi.org/10.7748/ paed.12.1.18.s19>
- Gillam, L.** (2016). The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*, 11(1), 1–8. <https://doi.org/10.1177/1477750915622033>
- Gray, K., Isaacs, D., Kilham, H., Tobin, B., & Waters, K.** (2016). Use of guidelines when planning home care of a girl with severe congenital myopathy. *Journal of Paediatrics and Child Health*, 52(1), 7–10. <https://doi.org/10.1111/jpc.13065>
- Hanners, J., Longnecker, D., Taska, L., Martin, S., & Dahlbeck, S.** (2012). *Primary and secondary recommendations: Recommending oral feedings with aspiration risk*. <http://www.asha.org/Events/convention/handouts/2012/1513-Primary-and-Secondary-Recommendations-Recommending-Oral-Feedings-With-Aspiration-Risk/>
- Hansjee, D.** (2013). *A safer approach to risk feeding*. <https://www.rcslt.org/-/media/Project/RCSLT/a-safer-approach-to-risk-feeding.pdf>

- Hauer, J.** (2017). Feeding intolerance in children with severe impairment of the central nervous system: Strategies for treatment and prevention. *Children*, 5(1), 1. <https://doi.org/10.3390/children5010001>
- Himmelstein, B. P.** (2006). Palliative care for infants, children, adolescents, and their families. *Journal of Palliative Medicine*, 9(1), 163–181. <https://doi.org/10.1089/jpm.2006.9.163>
- Kaizer, F., Spiridigliozzi, A. M., & Hunt, M. R.** (2012). Promoting shared decision-making in rehabilitation: Development of a framework for situations when patients with dysphagia refuse diet modification recommended by the treating team. *Dysphagia*, 27(1), 81–87. <https://doi.org/10.1007/s00455-011-9341-5>
- Kelly, K., Cumming, S., Kenny, B., Smith-Merry, J., & Bogaardt, H.** (2018). Getting comfortable with “comfort feeding”: An exploration of the ethical aspects of the Australian speech-language pathologists’ role in palliative care. *International Journal of Speech-Language Pathology*, 20(3), 371–379. <https://doi.org/10.1080/17549507.2018.1448895>
- Krikheli, L., Mathisen, B. A., & Carey, L. B.** (2018). Speech-language pathology in paediatric palliative care: A scoping review of role and practice. *International Journal of Speech-Language Pathology*, 20(5), 541–553. <https://doi.org/10.1080/17549507.2017.1337225>
- Langmore, S. E., Grillone, G., Elackattu, A., & Walsh, M.** (2009). Disorders of swallowing: Palliative care. *Otolaryngologic Clinics of North America*, 42(1), 87–105. <https://doi.org/10.1016/j.otc.2008.09.005>
- Langmore, S. E., Terpenning, M. S., Schork, A., Chen, Y., Murray, J. T., Lopatin, D., & Loesche, W. J.** (1998). Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia*, 13(2), 69–81. <https://doi.org/10.1007/PL00009559>
- Larcher, V., & Hutchinson, A.** (2010). How should paediatricians assess Gillick competence? *Archives of Disease in Childhood*, 95(4), 307–311. <https://doi.org/10.1136/adc.2008.148676>
- Maillet, J. O. S., Potter, R. L., & Heller, L.** (2002). Position of the American Dietetic Association: Ethical and legal issues in nutrition, hydration, and feeding. *Journal of the American Dietetic Association*, 102(5), 716–726. [https://doi.org/10.1016/S0002-8223\(02\)90163-X](https://doi.org/10.1016/S0002-8223(02)90163-X)
- Masso, M., Allingham, S. F., Banfield, M., Johnson, C. E., Pidgeon, T., Yates, P., & Eagar, K.** (2015). Palliative care phase: Inter-rater reliability and acceptability in a national study. *Palliative Medicine*, 29(1), 22–30. <https://doi.org/10.1177/0269216314551814>
- Mater Misericordiae Health Services.** (2012a). *Comfort feeding*. <http://brochures.mater.org.au/brochures/mater-hospital-brisbane/comfort-feeding>
- Mater Misericordiae Health Services.** (2012b). *Risk feeding*. <http://brochures.mater.org.au/brochures/mater-hospital-brisbane/risk-feeding>
- McDougall, R., Gillam, L., & Gold, H.** (2016). The zone of parental discretion. In R. McDougall, C. Delany, & L. Gillam (Eds.), *When doctors and parents disagree: Ethics, paediatrics and the zone of parental discretion* (pp. 14–24). <https://doi.org/10.11157/anzswj-vol29isslid368>
- Miles, A., Watt, T., Wong, W. Y., McHutchison, L., & Friary, P.** (2016). Complex feeding decisions: Perceptions of staff, patients, and their families in the inpatient hospital setting. *Gerontology and Geriatric Medicine*, 2, 2333721416665523. <https://doi.org/10.1177/2333721416665523>
- Murray, A., Mulkerrin, S., & O’Keeffe, S. T.** (2019). The perils of ‘risk feeding.’ *Age and Ageing*, 48(4), 478–481. <https://doi.org/10.1093/ageing/afz027>
- Myatra, S. N., Salins, N., Iyer, S., Macaden, S. C., Divatia, J. V., Muckaden, M., Kulkarni, P., Simha, S., & Mani, R. K.** (2014). End-of-life care policy: An integrated care plan for the dying: A Joint Position Statement of the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC). *Indian Journal of Critical Care Medicine*, 18(9), 615–635. <https://doi.org/10.4103/0972-5229.140155>
- New South Wales Health.** (2016). *Feeding difficulties in children: A guide for allied health professionals* (Document No. GL2016_007). http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2016_007.pdf
- Queensland Health.** (2017). *Guide to informed decision-making in health care* (2nd ed.). https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf
- Royal College of Physicians & British Society of Gastroenterology.** (2010). *Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life*. Royal College of Physicians.
- Royal College of Speech and Language Therapists.** (2005). *Dysphagia clinical guidelines* (2nd ed.). Speechmark.
- Royal Hospital for Neuro-disability.** (n.d.). *Future feeding planning pathway*. Retrieved June 7, 2019, from <https://www.rhn.org.uk/future-feeding/>
- Sherman, F. T.** (2003). Nutrition in advanced dementia. Tube feeding or hand feeding until death? *Geriatrics*, 58(11), 10–12.
- Siden, H., Tucker, T., Derman, S., Cox, K., Soon, G. S., Hartnett, C., & Straatman, L.** (2009). Pediatric enteral feeding intolerance: A new prognosticator for children with life-limiting illness? *Journal of Palliative Care*, 25(3), 213–217. <https://doi.org/10.1177/082585970902500309>
- Speech Pathology Australia.** (2010). *The Speech Pathology of Australia Code of Ethics*. https://www.speechpathologyaustralia.org.au/SPAweb/Members/Ethics/HTML/Code_of_Ethics.aspx
- Speech Pathology Australia.** (2019). *The role of the speech pathologist in supporting informed choice and shared decision making in dysphagia*. https://www.speechpathologyaustralia.org.au/SPAweb/What_s_On/Events/CPD_Event_Display.aspx?EventKey=20QLDRISKF&WebsiteKey=2389b226-24db-469a-872a-0ebbb470851d
- Together for Short Lives.** (2018). *A guide to the development of children’s palliative care services* (4th ed.). <https://www.togetherforshortlives.org.uk/resource/a-guide-to-childrens-palliative-care/>
- Trottier, J., & Miller, N.** (2013). *Dysphagia and oral care issues at the end of life*. <https://pdfs.semanticscholar.org/4ef6/1272e814a984df45f385f808cf4b3fbc1844.pdf>
- University of Auckland & Hutt Valley District Health Board.** (2016). *Risk feeding guideline*. <https://flexiblelearning.auckland.ac.nz/speech-science-dysphagia-education-hub/6.html>
- Vesey, S.** (2013). Dysphagia and quality of life. *British Journal of Community Nursing*, 18(Suppl. 5), S14–S19. <https://doi.org/10.12968/bjcn.2013.18.Sup5.S14>
- Waldman, E., & Wolfe, J.** (2013). Palliative care for children with cancer. *Nature Reviews Clinical Oncology*, 10(2), 100–107. <https://doi.org/10.1038/nrclinonc.2012.238>
- Weir, K. A., McMahan, S., & Chang, A. B.** (2005). Restriction of oral intake of water for aspiration lung disease in children. *Cochrane Database of Systematic Reviews*, 9(4), CD005303. <https://doi.org/10.1002/14651858.CD005303.pub2>
- Weir, K. A., McMahan, S., Taylor, S., & Chang, A. B.** (2011). Oropharyngeal aspiration and silent aspiration in children. *Chest*, 140(3), 589–597. <https://doi.org/10.1378/chest.10-1618>
- Whiteing, N., & Hunter, J.** (2008). Nursing management of patients who are nil by mouth. *Nursing Standard*, 22(26), 40–45. <https://doi.org/10.7748/ns2008.03.22.26.40.c6426>