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**Dysphagia Management for School Children: Dealing With Ethical Dilemmas**

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**The Case of Hillary**

Hillary is a 6-year-old with severe cerebral palsy and cognitive disability. Hillary has been attending a private school for children with developmental disabilities and severe handicaps for the past 2 months. According to her record, the student has a history of oral-pharyngeal dysphagia with silent aspiration and several bouts of pneumonia in the past 2 years. She has a PEG tube by which she receives her nutrition, hydration and medications.

One morning Hillary’s home-room teacher approached the speech-language pathologist with a note written on a prescription paper ‘ordering’ oral feeding for Hillary while she is at school.

The speech-language pathologist, John, is very concerned. He feels that it would be against professional standard to allow Hillary to eat orally. John feels that Hillary’s mother and physician do not have the student’s best interest at heart.

**Dysphagia Intervention in Schools**

As more students with chronic conditions receive their care in a traditional school setting, the speech-language pathologist is required to have a medical knowledge base for pediatric communication and swallowing disorders. Dysphagia intervention is becoming a more prominent component of the caseloads of speech-language pathologists who practice in the school setting. While this can be a rewarding challenge, scenarios in which clinicians find themselves can also have a more acute feel when managing a feeding tube and/or risk for aspiration. The “team” of school professionals extends to include pediatricians and pediatric neurologists as well as child psychiatrists and psychologists.

Often, when clinicians perceive moral angst, they search for “the right” answer. A case-based approach in ethics illustrates that more often than not a single “right” answer does not exist. Clinical ethics is a discipline of bioethics that concentrates on the analysis and resolution of ethical issues involved in the care of an individual. Clinical ethics focuses on developing practical solutions that comprise a range of acceptable options. Speech-language pathologists should use ethical principles, sound clinical judgement, legal guidance, and optimal communication skills to navigate a course of action for each individual ethics case. The above case exemplifies some familiar tensions faced by school-based speech-language pathologists. This article will employ ethical principles, paradigms, and precedents in the discussion of the *Case of Hillary.*

**Approaches to Ethical Dilemmas**

Recent literature has addressed ethical issues in pediatric dysphagia. Lefton-Greif & Arvedson (1997) thoughtfully describe the principles that should direct our practice as clinicians. These principles are the philosophical basis of the morals that guide our behavior in the service of other persons (Beauchamp & Childress, 1994). These principles instruct rules by which we can abide. These rules are translated as licensure and certification regulations and professional codes of ethics (ASHA, 1994) that are effective in leading professional practice. Some clinical ethical challenges, however, require more in-depth understanding of principles and precedent cases (Jonsen, Siegler & Winslade, 1992) than can be addressed in a
Code of Ethics. For instance, when the principle of autonomy (respecting the wishes of the patient/proxy) conflicts with a professional’s sense of beneficence (the ‘principle’ that one must always promote what is good for a patient) an ethical conflict may arise. Since parents are typically considered the default proxy decision-maker for their children, inHillary’s case the principle of autonomy would guide us to respect the wishes of the student’s mother (i.e., to feed Hillary by mouth). John, however, feels that this decision is not made with appropriate beneficence for Hillary. He is afraid that, in fact, the decision may cause harm to Hillary.

Case-based analysis is often most useful in determining a range of acceptable outcomes in stressful scenarios such as this and is promoted by LeFort-Greif (2001) and Sharp & Genesen (1996). Sharp & Genesen (1996) apply an ethical decision-making paradigm described by Jonsen, Siegler and Winslade (1992) in the book Clinical Ethics. The model weighs Medical (or clinical) Indications (recommendations) against the Patient/Proxy Preferences. Ideally ethical dilemmas should be resolved through a communication process between the patient/surrogate and the clinician/care team. Sharp & Genesen indicate that occasionally other factors, such as the evaluation of the patient’s Quality of Life (if the patient is unable to communicate it directly) and other Contextual Features (e.g., if the parent wishes a student who cannot self-feed to maintain nutrition and hydration by mouth) may need attention in determining an acceptable and pragmatic approach.

Hillary’s mother seems to be making a request that is not in her daughter’s best interest based on Hillary’s medical history and disabilities. An added layer to this case is the “prescription” written by the physician to allow Hillary to eat orally during school. John, therefore, feels conflict not only with student’s mother, but also with another member of the student’s “team.”

Team Communication

Optimizing communication and managing conflict are simple first-line solutions that may be employed in an ethics case. It is important to make certain that all interested parties are operating with the same set of facts, or are “on the same page,” if you will. Dowdy and colleagues (Dowdy, Robertson, & Bander, 1998) described a study in which a prospective ethics consultation (with involvement of all care providers) was used for each case admitted to a hospital intensive care unit for a period of several months. This initial communication meeting allowed all team members to know and discuss any challenging issues that might arise in the care of the patient. They were able to hear discussions and decisions and ask questions of the appropriate personnel. The study participants felt that the overall process of decision-making and the continuity of care delivery were enhanced with this mode of communication.

In Hillary’s case it is important for John to discuss the recommendation with Hillary’s physician to understand the basis of the decision. The speech-language pathologist may need to share relevant knowledge related to the evaluation and treatment of dysphagia that may influence the physician’s perspective. Conversely, John may find that he did not have all the correct medical information himself. John should also discuss the recommendation with Hillary’s mother who may not appreciate the clinical/behavioral consequences of the prescription. Often, issues that appear insurmountable at first glance can be solved by defining actual known risk involved and with the assurance that all parties have adequate understanding of each professional’s perspective.

Most institutions have a designated individual who manages/advises staff on “risk” in their practice within the facility. John should make sure the ‘risk manager’ at his school is fully apprised of the situation. This person should counsel the speech-language pathologist on the institution’s policies in similar (or precedent) cases and offer support and/or further education.

As independent professionals, speech-language pathologists have the right to refuse to participate in care that they do not agree with professionally. At the same time, we have an obligation not to abandon our client/patient/student. We can use the analogy of a physician who treats someone with severe diabetes and poor glucose control who refuses to take insulin as prescribed. While the MD may be frustrated and even emotionally distressed that the patient may be harming herself by not participating in care as recommended, the MD cannot abandon the patient if she still desires medical care. The physician can, however, transfer the patient’s care to another physician competent to manage the patient’s needs.

Professional Competence

Speech-language pathologists must be competent to manage any disorder that they propose to evaluate and treat. We hold a fiduciary duty to the persons we serve to have at least the minimal level of professional skill. As the population in the schools changes to include students with higher medical acuity, this becomes a more relevant issue. One aspect of professional competence is ‘knowing what we don’t know.’ The clinician is obliged to obtain relevant consultations. When treating a voice disorder, for
instance, a medical consultation to diagnose or rule out a structural abnormality is typically essential before intervention begins.

John must know all Hillary’s detailed medical information that will help him determine the possible options of treatment (or no treatment) and potential consequences. It is demonstrated in the literature for adult patients that the presence of a feeding tube may actually increase a patient’s risk for aspiration and not eliminate it (Lazarus, Murphy, & Culpepper, 1990). Collaboration with the MD to understand the child’s medical risk for respiratory complications with oral feeding will help John formulate and discuss recommendations with Hillary’s mother.

**Surrogate Decision-Makers**

As mentioned above, parents or legal guardians are usually the default decision-makers for a child. The threshold for questioning decisions made for a child is typically lower than for an adult. It is assumed that when an adult has named a proxy or surrogate decision-maker, he/she has had some sort of discussion with that person to express wishes for future health care. A child has likely not had this sort of conversation does not possess the emotional or intellectual maturity to make self-determining decisions.

The fact that the physician in this case views his patient’s mother as the appropriate decision-maker for Hillary is endorsed by the fact that he wrote a “prescription” for p.o. trials. The team should explore the reasons for the surrogates’ request to identify concerns that might be addressed (Brady Wagner, 2001). It is important to remember that children with disabilities such as Hillary’s may have limited interaction with family and others. Mealtimes may be one of the most social activities parents can share with them. The fact that Hillary’s feeding tube is still being used is a sign that her mother is not disregarding her daughter’s needs, but that she may be trying to offer what she feels to be some increase in Hillary’s quality of life.

**Time-Limited Trial**

When there is disagreement over recommendations, the use of a “time-limited trial” can be very helpful in fostering accord and in moving care in a positive direction. Perhaps the team (MD, mother, speech-language pathologist, etc.) can devise a trial of treatment for a specified period of time to address the physiology of Hillary’s dysphagia and to move toward a goal of safe swallowing. The proposed trial should be based on a joint review of all relevant clinical information (e.g. swallowing assessment results, aspiration risk, medical stability, etc.). Such a plan may give the student’s mother the understanding that the speech-language pathologist is invested and is continuing to make recommendations based on sound clinical judgement.

**Conclusion**

The case presented is one of the most challenging ethical dilemmas speech-language pathologists face—when the expressed preference of a parent for their child is in direct opposition to what is (at least initially) seen to be the most “beneficent” plan of care. That the decision involves medical acuity and potential harm to the student’s health compounds a sense of urgency to reach a “safe” solution.

It is likely not in Hillary’s best interest to abandon her clinical care because there is disagreement among her team members. Rather the speech-language pathologist may do much good to maintain involvement to add his expertise in the management of oral-pharyngeal dysphagia to ongoing decisions. Reaching consensus through enhanced communication and use of strategies such as the ‘time-limited trial’ can produce an optimal outcome for all.

**References**


