

Ethical and Legal Challenges in Feeding and Swallowing Intervention for Infants and Children

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ABSTRACT

Over the past decade, speech-language pathologists (SLPs) have increased their involvement in the assessment and management of infants and children with complex feeding and swallowing problems. Given the complex problems demonstrated by these infants and children that vary across a range of conditions and degrees of severity, SLPs need to increase their knowledge in all the topics covered in this issue. This article will discuss the current state of evidence-based decision making, levels of evidence for studies of treatment efficacy, ethical principles in evidence-based decision making, and ethical decision-making considerations with feeding and swallowing issues using examples of three types of populations of infants and children with complex feeding and swallowing problems.

KEYWORDS: Dysphagia, deglutition, evidence-based, bioethics, pediatric

Learning Outcomes: As a result of this activity, the reader will be able to (1) describe ethical principles and their relationship to feeding and swallowing issues in infants and young children, (2) state three rules of ethics related to clinical intervention with infants and children with complex dysphagia, and (3) describe the three components of an evidence-based clinical approach to the care of infants and young children with feeding and swallowing problems.

Over the past decade, speech-language pathologists (SLPs) have increasingly found themselves involved in assessment and management of infants and children with feeding and

swallowing problems. These infants and children demonstrate complex problems that vary over a wide range of conditions and degrees of severity. Feeding issues frequently are at the forefront of

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ethical and legal decision making related to criteria for nutrition and hydration¹ with registered dietitians primary professionals to make recommendations regarding nutrition and hydration. SLPs play important roles in defining the oral skills, timing of pharyngeal swallows, and overall safety of oral feeding for whatever volume of liquids and food each child can consume. This means there is a need for increased knowledge regarding all the topics discussed in this issue (etiologies, health issues, oral sensory and motor factors, clinical and instrumental assessment procedures, and intervention strategies and techniques). Additionally, regardless of practice setting, SLPs must make clinical decisions in ways that are evidence based and with an appreciation for moral and ethical principles.

In the United States, SLPs practice under the aegis of the American Speech-Language-Hearing Association (ASHA) Code of Ethics,² respective State Codes of Ethics, and scope of practice. In other parts of the world, guidelines may differ, but all SLPs function within the context of ethical practice guidelines. Other professionals involved in the care of children with complex feeding and swallowing disorders function within the framework of a code of ethics for respective professions as well as scopes of practice. In this article, we will discuss the current state of evidence-based decision making, levels of evidence for studies of treatment

efficacy, ethical principles in evidence-based decision making, and ethical decision-making considerations with feeding and swallowing issues using examples of three types of populations of infants and children with complex feeding and swallowing problems.

EVIDENCE-BASED DECISION MAKING

Clinicians are often heard to say, “Every infant (or child) is different, and I have to see what works for that infant. No matter what the evidence might say, it never is directly applicable to my patient.” Individual differences do matter. However, clinical judgment regarding those individual differences is just one part of evidence-based clinical practice, and never forms the total decision making process. Two additional sources of external information are essential components of evidence-based practice: (1) best available external evidence, and (2) patient or family values and expectations (Table 1).^{3,4} Best predictors of success or failure are the family’s and patient’s values and expectations.⁵

Levels of Evidence for Studies of Treatment Efficacy

Reports in the literature reveal varied levels of evidence (Table 2).⁶ Randomized control trials

Table 1 Components and Sources of Information for Evidence-Based Decision Making

Components	Sources of Information
Clinical judgment	<ul style="list-style-type: none"> • Patient data collected from medical/educational records and in direct consultation • Knowledge base of each clinician—increasing over time with experience and new knowledge
External evidence	<ul style="list-style-type: none"> • Objective measures for outcomes of intervention • Peer-reviewed scientific information • Validity measured by control in design to avoid bias & error • Application and testing in clinically relevant populations • Clinicians may alter practice by conducting “mini-trials” based on original research
Family/patient values and expectations	<ul style="list-style-type: none"> • Determination of understanding of family and child about the feeding and swallowing issues relative to the “whole” child and family • Determination of willingness of family and child to make a commitment to any intervention regimen

Table 2 Levels of Evidence for Studies of Treatment Efficacy⁶

Level of Evidence	Types of Studies
Ia	Well-designed meta-analysis of > 1 randomized controlled trial
Ib	Well-designed randomized controlled trial
IIa	Well-designed controlled study without randomization
IIb	Well-designed quasi-experimental study
III	Well-designed nonexperimental studies, e.g., correlational and case studies
IV	Expert committee report, consensus conference, clinical experience of respected authorities

(RCTs) represent the highest and most robust level of evidence, but there are limited research studies in the areas of feeding and swallowing given that they require large numbers of subjects who are randomized to an intervention arm or a nontreatment arm of protocols. Although RCTs are desirable to address some questions in the areas of feeding and swallowing, the lack of sufficient RCTs does not mean that clinicians ignore reports that evaluate efficacy or effectiveness of treatment (ability of an intervention to produce the desired beneficial effect in expert hands) through other types of research studies. In some areas, the only available evidence may be obtained from a single group of patients receiving the same treatment (case-series), two groups of patients with one group treated with

an experimental procedure and the other group with no treatment (cohort study), or single subject data. It is critical that all studies are evaluated carefully to make inferences regarding treatment value in answering certain clinical questions.³ The importance of critical reviews of all literature cannot be overstated. Every research report must be evaluated on the basis of scientific merit and must be practically logical and defensible for the particular patient and the presenting feeding and swallowing disorder.⁷ In turn, to provide an ethical clinical practice, SLPs must add evidence-based components to strict clinical approaches (Table 3).

ETHICAL PRINCIPLES OF EVIDENCE-BASED DECISION MAKING

Ethical theories are broad-based and reflect a philosophical commitment to moral reasoning and decision making that may apply to many situations throughout all types of human interactions, not just medical-based issues. Bioethics reflects the adaptation of ethical considerations with the emphasis on how best to support quality of life with changing advances in medicine and biologic sciences. Ethical principles include:

1. Autonomy (Respect the ability of individuals to make informed decisions affecting health; parents are decision makers for infants and children who cannot make their own decisions.)
2. Nonmaleficence (Avoid doing harm.)
3. Beneficence (Do good.)

Table 3 Steps for Combining Clinical and Evidence-Based Approaches for Patient Care

Clinical Approach	Added Evidence-Based Components
1. Gather data from records and reports.	+ Published studies
2. Assess the patient.	+ Quality of studies
3. Request further information as needed.	± Depends up new information
4. Consider clinical evidence.	+ Published evidence
5. Formulate hypothesis of what is wrong; how to diagnose or treat the problem.	+ What is a robust intervention; + use the robust intervention
6. Match intervention with patient preferences.	No addition
7. Try out hypothesis that led to intervention.	No addition
8. Assess outcome.	No addition
9. Modify intervention with data from patient's new state and from new assessments.	+ New published evidence

4. Justice (Distribute goods and resources fairly.)

Related ethical principles include:

1. Veracity (Tell the truth.)
2. Fidelity (Be faithful and loyal to profession and in professional relationships.)
3. Confidentiality (Do not disclose information inappropriately.)^{8,9}

The ASHA Code of Ethics provides the basis for SLPs to practice with all patient populations (Table 4).² SLPs, who use their best clinical judgment on the basis of the best evidence available while taking into account individual patient (and family) values and expectations, are adhering to ethical guidelines. SLPs who omit any one of those components from the process risk ethical misconduct that may affect an individual's safety or health, or both.⁷

ETHICAL DECISION MAKING WITH FEEDING AND SWALLOWING ISSUES

Oral feeding should never jeopardize nutrition and hydration status or be detrimental to pulmonary health. When conflicts arise, decisions to administer or withhold nutrition and hydration require ethical deliberation. When decision-making capacity is lacking, as is the case with infants and young children, parents assume autonomy for the child, which is a fundamental ethical principle underlying medical care choices, along with beneficence, non-maleficence, and justice. The most important idea in clinical ethics is to center on the patient. Parents and professionals must show that they are acting in the child's best interest as the most reliable guide to good ethical deliberation. The ethical deliberative process identifies and clarifies the moral conflicts or dilemmas in preparation for consideration of possible options for action. Special care must be taken in ethical deliberations because the decisions result in actions, which, in turn, result in consequences. SLPs should always participate in this process with other members of the health care team and the child's caregivers (parents or guardians).

Family-centered clinical pathways that require biopsychosocial frameworks are described by Raina and colleagues.¹⁰ These pathways go beyond technical and short-term rehabilitation interventions that are focused primarily on the child and include the family. Raina and colleagues urged that their model be used to examine caregivers of children with other disabilities.

Ethical issues in medical decision-making have been examined with pediatric patients in various contexts. These contexts include, but are not limited to, very low-birth-weight premature infants in Neonatal Intensive Care Units (NICUs), severely neurologically impaired children living at home, and tube-fed children with need for end-of-life decisions in hospitals.

VERY LOW-BIRTH-WEIGHT PREMATURE INFANTS IN NEONATAL INTENSIVE CARE UNITS

SLPs in NICUs should be aware of the Born-Alive Infants Protection Act (BAIPA) that was passed by the United States Congress in 2002 (Public Law 107-207). Although SLPs do not have a direct role in the decisions related to life-sustaining efforts and typically do not get involved in the infant's care until later, they should be aware of BAIPA as they evaluate and make recommendations related to oral feeding potential in infants who may have guarded prognoses for a normal life. The purposes of BAIPA were, in part "to repudiate the flawed notion that a child's entitlement to the protections of the law is dependent on whether that child's mother or others want him or her." Legislators recognized that physicians disagree about the efficacy of resuscitating at the limits of viability, and therefore, the current standard of care permits doctors to deem resuscitation a futile endeavor. This law does not specifically protect a parent's decision-making authority.¹¹ The vitality of preterm infants appears to be one of the main factors reported in a grounded theory study aimed to generate knowledge concerning the ethical decision-making processes faced in a neonatal unit.¹² Findings indicated that life-and-death decisions are somewhat ambivalent. Experience does not always make decision-making easier. Situations with ambiguity result in decisions based upon the vitality of the infants concerned.

Table 4 Principles and Pertinent Rules in ASHA Code of Ethics² in Relation to Evidence-Based Practice

Ethical Principle	Selected Pertinent Rules of Ethics
<p>“Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally. . .”</p>	<ol style="list-style-type: none"> 1. Provide all services competently. 2. Use every resource, including referral when appropriate to ensure highest quality service. 3. No misrepresentation of credentials of assistants, technicians, or support personnel. 4. No delegation of tasks that require unique skills, knowledge, & judgment within scope of professional practice. 5. Inform persons served of nature & possible effects of services rendered and products dispensed. 6. Evaluate effectiveness of services rendered and provide services only when benefit can reasonably be expected. 7. Do not guarantee results of any treatment or procedure, directly or by implication; a reasonable statement of prognosis is appropriate.
<p>“Individuals shall honor their responsibility to achieve and maintain the highest level of professional competence.”</p>	<ol style="list-style-type: none"> 1. Hold certificate of clinical competence or be in training with appropriate supervision. 2. Engage in only those aspects of profession within scope of competence, considering level of education, training, & experience. 3. Continue professional development.
<p>“Individuals shall honor their responsibility to the public by promoting public understanding of the professions, by supporting development of services designed to fulfill unmet needs of the public, and by providing accurate information in all communications involving any aspect of the professions, including dissemination of research findings & scholarly activities.”</p>	<ol style="list-style-type: none"> 1. Do not misrepresent credentials, competence, education, training, experience, or scholarly or research contributions. 2. Do not participate in activities that are a conflict of interest. 3. Refer solely on the basis of interest of those being referred, not for personal financial interest. 4. Do not misrepresent diagnostic information, research, services rendered, or products dispensed.
<p>“Individuals shall honor their responsibilities to the professions & their relationships with colleagues, students, and members of allied professions.”</p>	<ol style="list-style-type: none"> 1. Prohibit anyone under one’s supervision from engaging in any practice that violates the Code of Ethics. 2. Do not engage in dishonesty, fraud, deceit, misrepresentation. 3. Reference source when using others’ ideas, research, presentations, or products in written, oral, or any other media presentation or summary. 4. Do not provide professional services without exercising independent professional judgment, regardless of referral source or prescription.

Parents’ attitudes toward their involvement in life-and-death decisions concerning their very premature or critically ill infants in hospital neonatal units were examined via qualitative

interviews followed by comparative method (grounded theory) to analyze the data.¹³ Interviews with 35 parents of 26 children (16 were still alive at the time, 10 had died) revealed that

parents agreed that they should not have the final word in decisions concerning their infants' future life or death. The burden would be too heavy for parents lacking sufficient medical knowledge and professional experience needed to make such decisions. Strong feelings of guilt would likely result. Parents stressed the importance of being well informed and listened to during the entire decision-making process. Their primary concerns were how all professionals communicate with parents experiencing a crisis and how serious information is presented. Parents may share feelings and concerns more freely with SLPS than most other professionals. SLPs must keep in mind their scope of practice because it is likely that the greatest concerns involve aspects of the infant's status and care that are not directly within the SLP scope of practice, except for the questions related to oral feeding potential¹⁴ and the concomitant risks for pulmonary stability. SLPs should always function within the context of a team of professionals with parents for these very complex decision-making processes.

Parents who have been part of an ethical decision-making process concerning a son or daughter in a neonatal unit were asked later how they experience life with a severely disabled child.¹⁵ Findings indicated that these parents have an extremely tough time and that their relationships with their children are somewhat ambivalent. The most serious problems are too little rest and sleep, and feeding the children. They described their home as a prison, from which it is impossible to escape. Sayeed¹¹ stressed the need for respite facilities for these families.

SEVERELY NEUROLOGICALLY IMPAIRED CHILDREN LIVING AT HOME

Recently, moral and ethical issues focused on home-care decisions for technology-dependent children cared for at home.¹⁶ The moral dilemmas that these children and their parents confront had previously been virtually unknown. Carnevale and colleagues¹⁶ examined moral dimensions of family experience where children were ventilator-dependent or on a positive-pressure device at home. Semistructured interviews and fieldwork observations were conducted in homes (12 families, 38 family

members). Principal themes related to parental responsibility. Parents acknowledged stressful and sometimes overwhelming situations as they lived with the threat of death on a daily basis. They reported that they had no "free choice" as they could not have chosen to let their child die. They worked hard to establish whatever normality they could for their own lives, other children in the family, and the child with the severe handicap. Conflicting social values were problematic to parents as they had to listen to comments that appeared to devalue the child. A deep sense of isolation was reported as neither extended families or medical systems could support the respite needs. An overarching phenomenon was daily living with distress and enrichment, which families described as difficult to balance, while at the same time, nearly all families would continue to care for the child at home. The findings of Carnevale and colleagues¹⁶ provide insights related to the need for all professionals to increase sensitization to multiple issues as they focus on narrow aspects of a child's needs. In the context of SLP intervention focusing on facilitating safe feeding and swallowing to whatever degree is possible, the SLP needs to set goals that are realistic and take into account the "whole picture," not just oral-motor therapy goals.

TUBE-FED CHILDREN WITH NEED FOR END-OF-LIFE DECISIONS IN HOSPITALS

Most reports of ethical practices that relate to tube feeding¹⁷ and end-of-life decisions¹⁸⁻²³ focus on adult issues. However, similar concerns hold for infants and children. SLPs are at the forefront in dealing with the consequences of life-saving measures and the technological advances that promote survival.²¹ Many ethical dilemmas arise in areas of management of persons with dysphagia across the entire life span. These dilemmas become particularly problematic when they involve infants and children. The U.S. Supreme Court and all states sanction refusal of any and all treatments by competent persons,¹⁸ but infants and most children with complex feeding and swallowing problems do not have their own autonomy. They must rely on parents and guardians for their decision making. These caregivers base their decisions in part on the

information provided by medical and health care professionals.

SUMMARY

It is possible that SLPs and other professionals can harm patients with inappropriate decisions regarding oral feeding. Not only does every SLP need to make the best possible clinical decisions for each patient in every session, the SLP also must be assured that decisions are made appropriately in light of evidence-based practice and the ethical and legal principles that take into account all aspects of well being for each child and family. SLPs are encouraged to function in the context of an interdisciplinary team wherever possible. Dysphagia is not a diagnosis in the medical sense of an etiology or diagnosis, but it is a sign with a galaxy of findings that must be identified to make optimal recommendations that, in some instances, may include a discussion with a medical-ethical panel.

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