CASE STUDIES in Pediatric Dysphagia

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Inc.

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Typeset in 11/13 Garamond by Flanagan’s Publishing Services, Inc.
Printed in the United States of America by Integrated Books International

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Library of Congress Cataloging-in-Publication Data:

Names: Wilson, Jennifer J. (Speech-language pathologist), author.
Title: Case studies in pediatric dysphagia / Jennifer J. Wilson.
Description: San Diego, CA : Plural Publishing, Inc., [2023] | Includes bibliographical references and index.
Identifiers: LCCN 2022056083 (print) | LCCN 2022056084 (ebook) | ISBN 9781635503975 (paperback) | ISBN 1635503973 (paperback) | ISBN 9781635503982 (ebook)
Subjects: MESH: Deglutition Disorders--diagnosis | Deglutition Disorders--therapy | Deglutition--physiology | Diagnosis, Differential | Infant | Child | Case Reports | Interview
Classification: LCC RC815.2 (print) | LCC RC815.2 (ebook) | NLM WI 258 | DDC 616.3/23--dc23/eng/20230130
LC record available at https://lccn.loc.gov/2022056083
LC ebook record available at https://lccn.loc.gov/2022056084

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Introduction

It's March 2020. The week before there was speculation, but I received the email notifying me that the University of Tennessee was closed due to COVID-19. Suddenly, it was time to get "up to speed" on how to do clinical simulations and teletherapy.

I contacted Plural Publishing and asked for permission to use the case studies in *Pediatric Swallowing and Feeding* by Arvedson, Brodsky, and Lefton-Greif. I had read these case studies during my lunch break every day as I was preparing for the American Board of Swallowing and Swallowing Disorders exam. They were challenging, but the thing I loved about them was the stories that they told. The journey began.

As clinical faculty, we were learning the clinical simulation process quickly. Through Simucase, we were introduced to new terms, like *debrief*. I wrote up a protocol for the case studies as simulation tools and the meetings began.

First, the students were sent case studies to read independently. Next, either one-on-one or small group meetings began. It was a front-porch clinical simulation at its finest. Students read the case studies out loud, learning how to attack the new terms. After each paragraph, we stopped and rehashed what had been read. How old was the child? What would we expect developmentally at this age?

As the cases unfolded, the layers of the story emerged. Students were able to imagine parental perspectives, role-play relaying results of modified barium swallow studies, and discuss oral sensorimotor findings. As we began doing the cases, previous cases came to mind. I shared anecdotal stories. Connections were made through bringing these cases to life that were different from any supervision experience I had provided.

We spent time talking about what we had learned and what therapeutic approaches might have been good to try if you had seen that client for therapy. The takeaways from each case helped provide a sense that others' perspectives were taken, new terms were learned, and skills in professional discussion were developing in these students.

A few months later, the university clinic reopened. The in-person cases slowly started again. However, I knew that I had been changed as a supervisor. I was inspired to open a dialogue about differential diagnosis, assessments, and referrals, considering that every case in pediatric dysphagia was unique.

I was also ready to have conversations about intervention. There is so little empirical evidence to support pediatric dysphagia intervention. This population is so difficult to research because each case is so unique. I wanted to begin to "talk about the elephant in the room."

We are always talking about how there is so little research, but the bottom line is these children can't wait for the research. We must do the best that we can for them with deep learning regarding oral and pharyngeal anatomy and physiology and rely on our medical counterparts to support our intervention. We need to spend some time talking with each other and listening carefully. We need to encourage a culture of wisdom and experience through mentorship.

Each chapter culminates with an expert interview. Some were researchers, and some were experienced clinicians. The strides they have made for our profession through research and intervention are incredible. The perspectives shared were so varied and provided so much more depth than I would have ever imagined. I am so grateful to the professionals who helped us understand research, unique training, and future directions of our profession.

The book content won't be timeless. Studies will be completed so research findings can be applied. Technology will improve the way that we evaluate and treat. Yet, discussions sharpening our ability to provide the best care for our patients can move us forward as clinicians.

Introductory Interview

Rebecca Smith, MS, CCC-SLP, CNT, is a clinical educator/adjunct instructor. She is a Certified Neonatal Therapist, Voice and Dysphagia at Appalachian State University. She is also pursuing her clinical doctorate.

Jennifer Wilson (J): Tell us about your current work in pediatric dysphagia.

Rebecca Smith (R): I work in a medical focus university-based clinic in a rural community. I see a lot of variety throughout my day. I'm working toward developing an infant and pediatric feeding and swallowing program in the clinic.

To do that, I have been focused on making sure that I am myself up to date in evidence-based practice patterns. I want to make sure that I am using the best patient-reported outcome measures, that I'm making connections with providers in the area, and that I'm also supplying resources to students. A lot of them receive little pediatric dysphagia-focused coursework in their graduate programs. Our university is different in that we do have an elective pediatric dysphagia course that they can take. I'm planning on teaching in the fall. I'm developing that coursework and planning. It's tying together nicely for my interest.

J: You are also working on developing your dissertation, right?

R: In this process of developing my research interests, I began realizing how teaching and research were coming together as I was developing this program in the clinic. I talked to mentors in the fields who have done similar things at their university-based clinic, people in the field of pediatric dysphagia I really respect. They all commonly were telling me about the infant child feeding questionnaire tool as developed by Feeding Matters. They expressed the importance of making sure that I'm capturing the four domains of pediatric feeding disorder in my intake paperwork for patients and then also in my evaluations and making sure that I'm educating students about them. Getting that consistency in talking to people, this sparked an interest in looking more at, "Do providers understand the four domains of pediatric feeding disorder as established by Goday et al. consensus paper, with support from Feeding Matters. What are providers currently doing now to show patients with disordered feeding? If they're given education on the four domains and introduced to the six-item screening tool that was developed by Feeding Matters and colleagues, where if there's two or more positives on the screening tool, then it is indicative of a need for a possible referral to feeding specialists, will that result in early identification of pediatric feeding disorder? Will it result in a change of practice? How will increased awareness be reflected in their clinical practice patterns?" I think just really marinating on those thoughts helped me focus my research interests and as I'm developing my dissertation. I know that I'm going to have to narrow that significantly just for the purposes of getting my PhD finished but I see myself continuing in this line of research.

J: Talk a little bit about your earlier work leading up to your transition now into the academic world.

R: Most of my clinical background was in acute care, specifically in the neonatal intensive care unit. I also did objective swallow studies for outpatient pediatrics. Patients would come to the hospital to get a study and then they would go back to their clinic. They were treated by whoever referred them for this study. I really enjoyed the hospital setting. I enjoyed the variety of my day and the pace, but I felt that in my next position, I wanted to make a different kind of difference.

J: Talk about how you made that transition from a community hospital to the university-based clinic.

R: I was at a point in my career where my interest was moving toward investigating best practice and how to best educate students in my area of clinical interest. That led me to start a PhD program. I was thinking, I'm in this program, I want to go somewhere that would support me and continuing this academic journey, a place that's going to have the resources for me to do the research that I want to do and be able to measure change in students' learning. The hospital certainly was supportive of me getting my PhD, but it wasn't really something that I would have used there in the clinic and then clinical setting at the hospital because it wasn't a university-based hospital or it was a community hospital and, in that setting, I was able to make connections in the community. It gave me the opportunity to educate more generic providers on specialty services like talking a lot about trauma-informed care in the NICU (neonatal intensive care unit) and how to provide counseling and communicating with patients and families that are in a vulnerable stage in their disease journey. They taught me a lot of important things but ultimately when I was interested in continuing with my career, I was ready to make a change.

J: Tell me about your academic training in pediatric dysphagia.

R: My graduate program I thought was a great program, but I left it with little knowledge of pediatric dysphagia and even less knowledge of infant feeding. I think that was partially because of the rurality of our program. Also, it was several years ago, and I feel like pediatric dysphagia was just covered as a part of the regular dysphagia coursework, which truthfully is how it is in a lot of places still now. I think that there is more of an emerging recognition of the need for more education, and we need to talk about it more. I think that now courses often include more sessions on pediatric dysphagia.

J: Post graduate school, what have been some strategies for you that you have used in getting skills in pediatric dysphagia?

R: For neonatal practice, I went to work at a large university-based hospital and that was a requirement of mine to work there, to be trained in the NICU. I didn't know anything about it. I was willing to learn, and they had a set of competencies that I was expected to achieve through continuing education and reading of research and then completion of skills check-offs. When you're fortunate enough to be in a situation like that where someone is handing you what you're supposed to know, it makes your learning journey a lot easier.

J: Have you talked to other speech pathologists about similar experiences?

R: I can tell you that most people are not in that situation. They take over a caseload in their CFY (clinical fellowship year) and a lot of times their CFY supervisor is not well versed in that subject. I know several former students who are experiencing that in their pediatric feeding disorder caseload.

J: Talk about how we can continue to grow and learn as feeding and swallowing specialists.

R: Even here at this university-based clinic, I'm really the first person that has had these research and clinical interests. I've had to really take responsibility for my own learning in a way that a lot of other people have many times before me. I am currently doing that through reading research, setting up mentors in the field (that was huge for me), and then taking sound continuing education courses. I think this is most challenging in pediatric dysphagia because there are so many types of courses that aren't necessarily grounded in evidence. You really must be a consumer of literature and surround yourself with people you trust to further your own education. I feel like I've done that where I'm now because I had a lot of diagnostic background but maybe not as much treatment background. I find myself taking coursework and really reading literature, speaking to occupational therapists, speaking to other people in the field who have a lot of knowledge about growth and fine motor development, neural development. In pediatric feeding disorder, you must look at everything, not just one piece of the puzzle.

J: Talk a little bit about challenges that feeding and swallowing specialists face in rural areas.

R: Well, I think there are a lot of challenges. I talk to my peers about that a lot. I think one of the biggest challenges that I face now is that there are a lot of pediatricians but not as many pediatrics specialties services such as GI (gastrointestinal), pediatric ENT (ear, nose, and throat). There are a lot of providers in town who are generalists. They must see a lot of different things because they just don't have the ability to specialize as much as they might like. There is a lack of provider presence. Oftentimes, when we need our patient to see pediatric GI, we must refer them to a place that's a couple of hours away. Transportation can often be an issue for these patients with weather-related issues and travel expenses. Getting an appointment is a problem sometimes. Some of these patients just can't afford to wait. That is a huge barrier.

Access to instrumentation can be a problem. It's not a problem for me. I'm fortunate about that but it is for some places that are rural, and I think that the lack of communication between specialty providers and the clinician that ends up seeing the patient in their rural hometowns can be a challenge. They don't always get all the report information. They don't really know what happened because they didn't go with the patient to the hospital and watch the instrumental study. Oftentimes, people in small private practices who are treating patients for pediatric feeding disorder have funding issues. There are ways to circumvent that if you educate yourself. They just must work a little bit harder in providing an evidence-based practice that is also possible and financially helpful.

We have a good amount of access to supplies. I feel fortunate. Not all home health practitioners have everything they need. Sometimes parents are the ones that must advocate for their children's medical supplies, but they don't even know where to begin. You can feel really disconnected I think in rural areas.

J: How do you feel that we can bridge the gap between clinical work and research in pediatric dysphagia?

R: A wonderful way to bridge the gap would be for there to be more individuals interested in pediatric dysphagia in academia. I think that would be a fantastic way to start bridging that gap. Also, for there to be more of a specific course and clinical rotation-based focus in pediatric dysphagia for those individuals who are interested in pursuing that after graduation. Involving the students in research because they're often excited to have opportunities to be involved in projects like that. That would be a wonderful way. Even those in academia who do not specialize in pediatric dysphagia could still create working relationships and research relationships with clinicians who also work in the field and who are not necessarily connected to an academic institution who have a research interest. I know of several. They don't have an academic background or they're not currently pursuing a terminal degree, but they're super interested in contributing to research. I think to get that going, they often need a connection to someone at an academic institution.

R: There are some who don't work directly for a specific university, but they work in teaching-based hospitals and are given research time but that is the exception not the rule. Most people, like myself, if I was going to be contributing to research in infant child feeding and swallowing when I was still at my last hospital, that would have been something I would have had to do on my own time. I wouldn't have had time in my day to really do that. It's simply hard for people to have a research interest, a full clinical load, and then keep any kind of work-life balance.

I struggle with it. I'm doing a little better here just because I have more flexibility in my schedule than I did when I was in the hospital. It's a problem that we talk about a lot, but there doesn't seem to be a lot of solutions for it, at least one that's easy.

I think that pediatric dysphagia specialists who are in academia need to step up in their contributions to research. So many clinicians are waiting for some of the methods they use to be validated. There's just such a lag in generating evidence-based creation of treatment practices and evaluation methods in this patient population and a lack of actual validation of those methods. Because of that, I think it creates a lot of polarization in choosing specific modalities and it's very confusing for new graduates where to go. I think a lot of it starts with people in academia asking questions and getting the data that is needed for clinicians to feel like they're choosing the best evaluation and treatment approaches. That can't really happen until people in academia step up and do more studies.

J: I love the way you were so transparent there about how it can feel uncomfortable as a recent graduate when you're wanting to follow evidence-based practice and you really must rely so heavily on clinical judgment. In that triad, that's really where we are in pediatric dysphagia and put that pressure on young clinicians that recently graduated who don't have a lot of clinical experiences is a precarious position, isn't it?

R: It is and they're more likely to get a job in pediatric and feeding and swallowing-based programs than they are in adult dysphagia, truthfully. Most home health, EI (early intervention), and private practice, places like that are what's going to hire these new clinicians, because there's such a shortage. They don't have a knowledge base and it's very scary for them. I also think that clinicians must challenge themselves. Researchers must rise to the occasion of doing more research in this area if they are able to do so. Clinicians must step up and read what little research on specific methods and find mentors and they must do things like that to achieve the best outcomes for their patients. They should never really be in a place where they're doing the same thing as 10 years ago that they're doing today.

1

Differential Diagnosis in Pediatric Dysphagia

INTRODUCTION

Pediatric feeding disorder (PFD) has been defined as impaired oral intake that is not age appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction (Goday et al., 2019) (Figure 1–1). Recent incidence data provide an estimate of the annual incidence of PFD in the United States to be between 1 in 23 and 1 and 37 for children under 5 years of age. The incidence for children under 5 years of age with chronic diseases was between 1 in 3 and 1 in 5 (Kovacic et al., 2021).

As PFD becomes more clearly defined and there is more clarity about an increased incidence, organizations like Feeding Matters and Dysphagia Research Society have helped provide networking and resources to professionals engaged in research, education, and intervention of pediatric

Medical	Nutrition
Feeding skill	Psychosocial

Figure 1–1. Four key domains associated with pediatric feeding disorder.

dysphagia (Dysphagia Research Society, 2022; Feeding Matters, 2022). Evaluation tools to better screen and evaluate skills have been introduced and assessed for test-retest reliability (Silverman et al., 2020; Thoyre et al., 2018).

However, the literature to support feeding and swallowing intervention has not emerged in alignment with these other advancements. In their 2016 article, "Pediatric Feeding/Swallowing: Yesterday, Today, and Tomorrow," Lefton-Greif and Arvedson (2016) postulate that the oral-motor and sensory-based intervention strategies used in treatment lack evidence-based support in the literature. As the literature is combed, this point has resonated repeatedly. Oral and pharyngeal treatment studies are characterized by limited sample sizes, diverse populations, and differing intervention techniques.

The need for further research was also a common point of discussion throughout the expert interviews of this text. While the framework is laid to better guide intervention, a scoping review revealed gaps in research of pediatric feeding disorder. Another gap mentioned was limited to first authorship in the domains of feeding skill and nutrition. Authors also cited that though research is occurring, it is not well represented in non-Western countries (Estrem et al., 2022).

Before grappling with the lack of evidence to support intervention, feeding and swallowing specialists should be trained in clinical reasoning. Researchers cite that the use of treatment strategies should be supported through applying scientific therapy practice (Gosa & Dodrill, 2017). Another good place to start is by having a firm foundation of knowledge in normal feeding and swallowing (Figure 1–2).

As more studies emerge regarding normal feeding and swallowing skills at specific ranges of development (Delaney et al., 2021), further support will be in place to guide intervention practices with this heterogeneous population. More information about cultural differences must be considered (Hall & Johnson, 2020). Gaining more data about parent and caregiver roles in development and intervention must also be researched.

Evie's case study provides a window into the complexities of diagnosing feeding skill issues, managing a multifactorial case (e.g., potential gastrointestinal issues, lack of caregiver consensus), and understanding

DEVELOPMENTAL STAGES IN INFANT AND TODDLER FEEDING
https://infantandtoddlerforum.org/media/upload/pdf-downloads/3.5_Developmental_Stages_in_Infant_and_Toddler_Feeding_NEW.pdf

FEED YOUR BABY & TODDLER RIGHT: EARLY EATING AND DRINKING SKILLS ENCOURAGE THE BEST DEVELOPMENT
Author: Diane Bahr, MS, CCC-SLP, CIMI

Figure 1–2. Supplemental resources to learn more about normal feeding and swallowing skills.

the importance of caregiver education and communication in managing acute issues (e.g., spitting out food, refusing food).

Evie lived in two different housing environments during treatment. She lived with both her foster parents and had increased visitation with her biological mom. The potential for lack of health equity for Evie was considerable given the differences between the two environments. Throughout the intervention, there was increased time spent with her biological mom. These transitions and the lack of reporting from her biological mom make it difficult to determine her response to intervention.

Following the case study, Dr. Katlyn McGrattan discussed the importance of considering swallowing physiology in determining our course of intervention. She drove home the point that we must use the best evidence available through a thorough understanding of anatomy and physiology. She also stressed the importance of relying on a team of professionals.

CASE STUDY: EVIE

Case Study Medical History

Episode 1: Evie was referred for outpatient services at 9 months of age adjusted due to difficulty transitioning to solid foods. (See Figures 1–3 and 1–4 for images of a 9-month-old and 3-month-old.) Both her foster mother and biological mother were present and provided relevant information.

Figure 1–3. Nine-month-old.

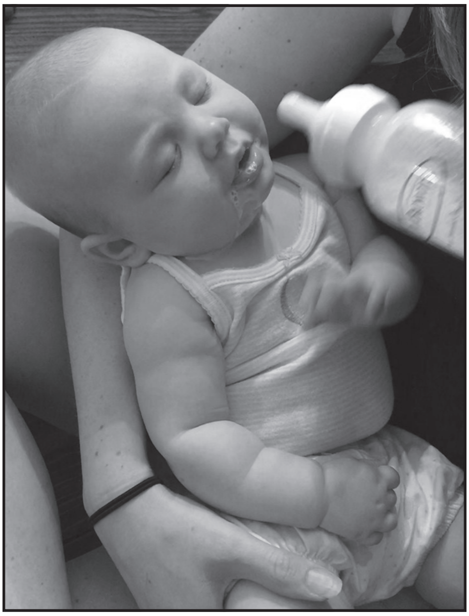

Figure 1–4. Three-month-old.

She was the product of a 27-week gestational pregnancy with a birthweight of 2 pounds and 12 ounces. Prenatally, she was exposed to methamphetamine, heroin, oxycodone, marijuana, and tobacco use. Her birth mother was also positive for hepatitis C. At birth, Evie was diagnosed with jaundice. She was later diagnosed with bronchopulmonary dysplasia. One minute after birth, Evie's APGAR score was 6, and 5 minutes after birth, her score was 8.

She passed her hearing screening bilaterally. A follow-up was needed at 9 months, which she also passed. She remained in the neonatal intensive care unit (NICU) for 4 months.

In terms of developmental milestones, Evie was reported to sit unsupported at 8 months adjusted and crawled at 9 months adjusted. During the evaluation, she stood and walked while holding onto supports (e.g., table, caregiver's hand). Speech and language milestones did not occur as expected. Babbling and the emergence of jargoning had not been observed. Evie made few sounds during the evaluation other than open vowel productions.

Feeding and Swallowing History: Evie was not breastfed and required formula changes. Her first bottle was given at approximately 3 to 4 months old unadjusted in the NICU. She was given cereal at 6 months adjusted, but she frequently spit it back up. Foster mom stated that "Evie has issues swallowing and controlling her tongue." (See Figure 1–5 for information

Age Range	Oral Motor Action
4 to 6 months	Introduction of cup
6 to 8 months	Suckling pattern for liquid intake from cup; wide jaw excursions; liquid loss
8 to 12 months	Sucking pattern for liquid intake; up-and-down jaw excursions; tongue may protrude underneath cup to provide stability for sucking; liquid loss during intake
12 to 18 months	Sucking pattern for liquid intake; may bite down on cup to gain jaw stabilization; upper lip closes on edge of cup for seal while drinking; less jaw excursion while drinking
18 to 24 months	Use of a more mature up-and-down sucking pattern; cup is held between the lips; internal jaw stabilization is emerging
24 months	Use of a sucking pattern for liquid intake; may hold edge of cup with teeth; eventual development of internal jaw stabilization without biting on edge of cup

Figure 1–5. Development of cup drinking skills. *Source: Pediatric Dysphagia: Etiologies, Diagnosis, and Management* (p. 75) by Willging, J. P., Miller, C. K., and Cohen, A. P. Copyright © 2020 Plural Publishing, Inc. All rights reserved. Used with permission.

about the development of cup drinking skills.) Evie did not use a cup for drinking and "has tended to lose liquid when she tries. She does not chew while eating." (See Figure 1–6 for a timeline of Evie's medical history.)

Evie was taking famotidine 40 mg/5 mL (8 mg/mL) oral suspension. This medication was prescribed to manage gastroesophageal reflux.

Evaluation

Lips: Appeared symmetrical. Pursing was evident. However, anterior liquid loss was noted throughout the evaluation. No drooling was observed.

Tongue: Appearance unremarkable. Tongue lateralization was not observed when presented with soft solid textures. Bolus organization, containment, and propulsion appeared to be inconsistent, and there was decreased evidence of each throughout the evaluation.

Jaw: Appeared symmetrical. Bite-through consistencies were not presented to adequately evaluate emergence of rotary chew.

Hard palate/soft palate: Both hard and soft palate were observed. Hard palate appeared high and arched, and soft palate appeared normal.

Speech/language and communication: There was one vocalization observed during the evaluation. Evie vocalized "uh," which appeared to be in response to her mom stating, "Uh-oh."

Evie's Case Study Timeline

- **Born at 27 weeks' gestation, maternal history positive for drug use and hepatitis C**
- **4-months in the NICU (Neonatal Intensive Care Unit)**
- **Discharged to foster care at 3 months old, adjusted age**
- **At the time of the 11-month evaluation, Evie lived with the foster family. Weekly visitation with biological Mom**
- **Current diagnoses: gastroesophageal reflux, bronchopulmonary dysplasia, neonatal abstinence syndrome**

Figure 1–6. Evie's case study timeline.

Evie was placed in a Rifton chair. Foster mom fed her Stage 2 baby food: mango and juice. Evie was prompted to accept bites from mom. She did not readily open her mouth for each bite. She demonstrated limited oral containment and propulsion but did not seem distressed in initiating a swallow. Dissolvable puffs were presented one at a time. Evie was able to contain the puffs but demonstrated limited tongue movement in propelling them to the base of her tongue. When Evie was offered more than one puff, she retained puffs in her cheeks. Foster mom reported similar behavior at home and a need to pace Evie to avoid her mouth-stuffing behavior. Evie was also observed to express approximately 1/2 to 1 oz of juice via a soft spout sip cup. There were no overt signs of physiological distress as she expressed the juice independently. (See Figure 1–7 for information on the development of jaw skills for feeding and swallowing.)

The primary issues were poor oral containment and propulsion with Stage 2 textures and lack of progression with more complex solids (e.g., Stage 3 baby foods, soft solids).

Diagnosis and Treatment Planning

Within the PDF definition, feeding and swallowing specialists should focus on determining whether there are problems with oral skills, pharyngeal skills, and/or esophageal skills. Often, this can be difficult to determine during an initial evaluation. In Evie's case, it was important to begin referrals and work toward a differential diagnosis. At first, it was questionable whether there were feeding skill issues for her. Interdisciplinary team members were necessary. Her foster mother was also very diligent in completing a feeding log so that her skills could be more thoroughly assessed outside of the outpatient therapy session.

What was an appropriate initial diagnosis for Evie? Consider the International Classification of Disorders, 11th Revision (ICD-11) diagnostic codes. The potential codes were oral dysphagia, oral pharyngeal dysphagia, pediatric feeding disorder–acute, and pediatric feeding disorder–chronic. (See Figure 1–8 for more information on differential diagnosis in the feeding skill domain of pediatric feeding and swallowing disorders.)

Who were the professionals currently involved in Evie's care? (Evie had a history of gastroesophageal reflux and was placed on a histamine-2 blocker by her pediatrician [Nguyen et al., 2022]). Did referrals need to be made to further determine concerns regarding skill? What were potential obstacles to progression of skills in feeding and swallowing? (See Figure 1–9 to see a list of team members for Evie.)

Feeding and swallowing therapy was recommended and a speech and language evaluation within the next 3 to 6 months. The Pediatric

Age Range	Lip, Tongue, and Jaw Motion in Response to Solids
5 to 6 months	Phasic biting predominates
6 to 9 months	Upper or lower lip may draw inward with presentation of food Cheek and lip tense with side placement of food to hold in place for chewing. Vertical jaw movements emerge during attempts at mastication Intermittent phasic biting occurs Diagonal jaw movement occurs in response to food placed on the surface of the gum Lateral tongue movements begin to emerge
9 to 12 months	Upper and lower lips pull in with presentation of food to the lip Begin to see active lip motion in conjunction with jaw motion Lips make contact in the center or the side as the jaw moves up and down during chewing Upper lip may move forward and downward during chewing Vertical jaw movement occurs with intermittent diagonal jaw motion Tongue moves food from the center to the side of the mouth during chewing
12 to 15 months	Lips become active during chewing Upper incisors or gums are used to clear food from the lower lip There is occasional loss of food or saliva while chewing Diagonal rotary jaw movements increase
15 to 24 months	Upper and lower lips are active during chewing Ability to chew with the lips closed develops Ability to control food intraorally without anterior loss when lips are open emerges Corner of lip and cheek draw inward to assist with control of food placement Jaw movements range between vertical, diagonal, and rotary Circular rotary chewing occurs when transferring food across the midline of the tongue from one side of the mouth to the other
24 months and beyond	Basic set of skills is in place for chewing; movements are refined as the child continues to develop strength and efficiency of chewing

Figure 1–7. Development of jaw skills. *Source: Pediatric Dysphagia: Etiologies, Diagnosis, and Management* (p. 72) by Willging, J. P., Miller, C. K., and Cohen, A. P. Copyright © 2020 Plural Publishing, Inc. All rights reserved. Used with permission.