

# Experiences Associated with Pediatric Dysphagia: A Mother's Perspective

Jamie Hartwell Azios<sup>1,\*</sup>, Jack S. Damico<sup>2</sup> and Nancye C. Roussel<sup>2</sup>

<sup>1</sup>Department of Speech and Hearing Sciences, Lamar University, P.O. Box 10076, Beaumont, TX 77710, USA

<sup>2</sup>Department of Communicative Disorders, The University of Louisiana at Lafayette, P.O. Box 43170, Lafayette, LA 70504-3170, USA

**Abstract:** *Background:* Pediatric dysphagia arises from various etiologies but often coincides with complex health issues. Tasks associated with the management of pediatric dysphagia are often unfamiliar and arduous, leaving a heavy burden on the primary caregiver. Little is known regarding how these experiences affect caregivers and family systems.

*Aims:* This study was conducted to examine dysphagia and its vast implications from a caregiver's perspective in order to reveal a perceived role in management.

*Methods & Procedures:* A qualitative case study design was chosen. Consistent with this tradition of inquiry, naturalistic data were collected through ethnographic interviewing procedures, collection of artifacts for analysis, and multiple lamination sessions obtained through electronic mail messages. These data were analyzed inductively, in which authors independently reviewed data several times and coded the data line by line with a category of idea or action that represented the raw data. As data collection and analysis continued in a cyclical fashion, several initial categories clumped into more abstract overarching themes related to the participant's experience with dysphagia.

*Outcomes & Results:* Data interpretation suggests that encounters associated with caring for multiple children with dysphagia are multifaceted and that consequences of dysphagia extend far beyond the individual with dysphagia and into the entire family system.

*Conclusion:* This paper argues for further consideration of social and affective factors in pediatric dysphagia management and the inspection of dysphagia from a dynamic lens that accounts for all layers of the disorder.

**Keywords:** Swallowing disorders, caregiver, restrictive diet, deglutition, maternal stressors.

## INTRODUCTION

Mothers often experience unique hardships when caring for a child with a disability. Sources of stress can come from factors which are individual to each family system and disorder. One aspect of disability in children that can potentially cause stress and anxiety in caregivers is dysphagia. Pediatric dysphagia arises from various etiologies but often coincides with complex health issues, which increase the challenge of assuring that a child receives adequate nutrition and hydration [1,2]. There is often a heavy burden associated with feeding that falls on the shoulders of the primary caregiver. In many instances, the caregiver of a child with dysphagia is responsible for duties that are arduous and unfamiliar. In cases of chronic dysphagia, these responsibilities may continue for long periods of time without respite or may become more of a burden as children age.

Treatment of chronic dysphagia, including pediatric dysphagia, is often approached from a biomedical

perspective [3] with a focus on nutrition and feeding-related medical complications, such as pneumonia. These aspects of the disorder are certainly critical for the health and well-being of the infant or child. However, such a focus may ignore the complexity of feeding/eating and place little or no emphasis on other factors that have an impact on the child and family system. Affective responses and/or social repercussions that coexist with pediatric dysphagia are often overlooked. This is disappointing considering the evidence that exists regarding the influence of parental well-being on overall health outcomes in children with other compromising medical conditions [4,5].

A few studies have examined the impact of alternative feeding methods on mothers' lives [6–14]. Taken together, these studies reveal that decisions regarding alternative feeding methods are complex and require an open discussion about long-term factors influencing the child and surrounding members of the family. Importantly, challenges continue to plague families even after feeding tubes are placed [8,9]. Dysphagia is not always severe enough to warrant gastrostomy tube (g-tube) placement. In these cases, children are placed on restricted diets that consist of different textures or require specific feeding strategies

\*Address correspondence to this author at the Department of Speech and Hearing Sciences, Lamar University, P.O. Box 10076, Beaumont, TX 77710, USA; Tel: 1-409-880-8174; E-mail: jhartwell@lamar.edu

for meals. These cases can present with different obstacles for caregivers.

There is little published literature that examines influences of dysphagia on families when children are allowed modified oral intake. Furthermore, there is no literature that examines perspectives of families with multiple children with dysphagia. This study was conducted to examine this unique scenario from the perspective of the primary caregiver. Specifically, the aim is to describe how a mother may construct her own conceptualization of dysphagia, her role in the management of her children's dysphagia, and the consequences of dysphagia for her family.

## METHODS

### Participant

The participant (referred to hereafter as Molly) was a mother of three children diagnosed with dysphagia through instrumental swallowing assessments. At the time of data collection, the children were two, three, and five years of age. The etiology of the dysphagia had not been identified and the family was seeing a team of medical specialists. All children were 100% oral for hydration and nutrition; however, recommendations had been made that diets be restricted to finely chopped foods and thickened liquids. The family resided in a mid-size city in the northwestern United States (U.S.) where Molly's husband was employed by the military and away from home for extended periods of time. As a result, Molly was often solely responsible for all care activities, upkeep of the home, and daily decision-making regarding health and finance.

Molly became known to the first author through an online support network for families of children with disabilities. After meeting one another, the first author offered Molly the opportunity to participate in the study as a way to share her unique story with others. This type of data generation is common in qualitative research methods and has been described as an intrinsic case study [15] in which value is placed on determining what is important or interesting about a case itself within the world that it is occupying as opposed to comparing it to other cases to substantiate a grand theory or idea. Ethical oversight was provided by the Institutional Review Board at the University of Louisiana at Lafayette. Molly provided written and verbal informed consent prior to participating in this study.

### Procedures

Case studies are commonly used to investigate a specific "object", in this case a person. Case studies have been used effectively to explore a bounded system in which the object of inquiry is separate and easily discernible, the time frame for data collection is relatively short, and valuable information can be obtained from the investigation of a single case [15,16]. Consistent with this tradition, data were collected through multiple sources to ensure credibility of the findings.

Primary data sources included the collection of an ethnographic interview and various artifacts for analysis. Ethnographic interviewing required general, open-ended questions in which Molly was encouraged to construct her own narrative without the influence of researcher bias [17,18]. The interview was collected by telephone, audio-recorded, and orthographically transcribed. The telephone interview was necessary due to travel limitations and has been shown to generate data that is comparable to face-to-face qualitative interviews [19]. Artifacts included fifteen electronic journal entries written by Molly and medical documents that she had received from various healthcare professionals related to the management of pediatric dysphagia. Electronic journal entries were posted on a public blog and encompassed an ongoing narrative about the events in Molly's life and the presence of dysphagia in day-to-day interactions. Medical documents included those received from healthcare professions for educational or instructional purposes such as pamphlets with instructions for dietary restrictions or general suggestions on strategies to decrease aspiration risk.

Electronic mail messages between the first author and Molly were collected throughout the period of data collection and analysis. Messages were used to answer any questions the researcher had regarding previously collected data and to verify researcher suppositions and interpretations of meaning. This last data source served as a verification technique in order to triangulate the research findings and cross-reference results [20,21]. Lamination is an important verification strategy in qualitative research as it helps to establish a thickness of data interpretation after initial patterns begin to emerge from the data [22,23].

Analysis began with full immersion into the data to gain familiarity and to obtain a general picture of what was happening. After reviewing the data several times,

the authors began to code the data line by line and label the lines with a category of action or idea that represented each statement. Each category was listed and given a numeric value for the frequency of occurrence and a descriptive marker for the emotion exhibited during the statement. At this point, several of the initial categories began to cluster together and themes began to emerge from the data. Data saturation was reached when no new insights emerged from the data sources and the existing categories were well-established with various incidents, activities, or events supporting each individual theme. A rich description of each theme was formed detailing the behaviors, contextual elements, and actions of the individuals involved in the care of the children.

To increase the trustworthiness of data analysis procedures, commonly used validation strategies in qualitative research were employed. In addition to triangulation and lamination, a process of peer debriefing [24] was implemented in which the co-authors independently coded the data and then came together to discuss emergent themes and individual assumptions that had surfaced. This process allowed the authors to discuss and clarify researcher biases, ensure the credibility and authenticity of interpretations, and link reconstructed, cohesive patterns back to the raw data. Conflicting views were resolved through open and active discussions in which coders scanned back through the data to justify or negate claims and then negotiated until a consensus was formed.

## RESULTS

Several patterns or recurrent themes emerged from the data as a result of qualitative analysis: medical orientation, adult perspective, social concerns, affective issues, and movement from reactive to proactive. Comments were taken verbatim from the data to preserve the meaningfulness of the experiences described and to increase the reader's legitimacy of the themes constructed. Thus, the researchers are able explain connections between the Molly's statements and researcher interpretations. See Table 1 below for a list of themes with corresponding data excerpts.

Molly's account suggests that the construction of dysphagia is a complex phenomenon that has consequences that extend beyond those routinely associated with the medical model. Findings point to the perceived challenges present during interactions with others in society and also the active development of strategies that Molly devised to overcome specific obstacles. Data signify the dynamic nature of dysphagia and the set of cognitive, physical, social, and emotional strategies that were necessary for day-to-day management.

### Medical Orientation

One of the most prominent and recurring themes was a consistent focus on approaching dysphagia from a medical model. The major concerns for healthcare professionals were health, development, and dietary

**Table 1: Recurrent Themes and Excerpts from Data**

Theme	Molly's comments
Medical Orientation	Um so at 3 1/2 she's 41 inches tall and the other day she was 31 pounds. Um so she is very very underweight um we have been fighting with our GI doc for a while to keep her off of a G-tube um but I don't know how much longer we are going to be able to do that.
Adult Perspective	Yeah that was one thing they got angry with me and they were like why doesn't she have a G-tube cause they saw in her chart that it was discussed. [...] Basically this was just some nurse we are not familiar with, had never seen before, and they were quite frustrated that I as a parent had not gotten my child this G-tube. I'm like it's not like I didn't go out and buy her new sneakers. You know it's a bigger decision than shoes or anything like that.
Social Concerns	I mean I have lost quite a few friends because they want to have us over for dinner and it's like nope, sorry. Or they want to take their kids take our kids to Chucky Cheese and I'll have to say no sorry. And they say well can't you just bring food for them. And I'm like no I'm not going to bring food for them and have them sit there and watch everyone else. Digging on pizza and everything else and have them feel left out.
Affective Issues	And I find myself resentful of silly things um things that most people probably wouldn't be like watching other people just go through the store and casually you know open a bag of something to give to their kids. It's like well shit my kid is screaming because he's hungry and I can't just open something for him here, I have to go home and prepare it for him so it's safe.
Movement from Reactive to Proactive	But I learned how to make Simply Thick myself. The main ingredient in Simply Thick is xanthan gum which is common in like what is it? It's used in like vegan cooking. And you can buy a package of it at the grocery store for eight dollars. And that package will last about a month in my house. So we went from paying \$26 a day to \$8 a month.

status. There was little or no focus on other real-life consequences such as social or emotional well-being.

When examining the excerpt in Table 1, there appears to be a great amount of inner struggle, indicated by word choice, such as “fighting”. While Molly recognizes that her child has certain needs, she remains adamant about keeping all nutrition and hydration via oral means. Molly obviously wants her children to be healthy, but she envisions health to be much different than that of the medical professionals working with her child. It seems for Molly, healthy also means free from artificial feedings methods. Evidence of a medical orientation was also apparent in educational artifacts. Artifacts detailed the outward behavioral indicators of dysphagia, such as choking, or the medical consequences of dysphagia with no mention of other possible ramifications.

### **Adult Perspective**

Professionals working with the children consistently adopted an inappropriate adult model of care. The focus was on a static perspective of dysphagia in which long-term needs or complex issues that the children would face in the future were not addressed. The family had great concerns for what the future would hold, but those fears were undervalued by many healthcare professionals involved in the children’s care.

In the example in Table 1, Molly narrates an experience from a recent hospitalization of her middle child where she disagrees with a healthcare professional about the decision to insert a g-tube. Molly describes a g-tube as a “bigger decision than shoes” and alludes to the fact that healthcare professionals working with her children do not always understand the dynamic, long-term effects of decisions such as g-tubes. Other instances of an adult perspective were also noted in the interview and in electronic journal entries. For example, therapy techniques typically employed with adults were suggested by healthcare professions (e.g., chin tuck posture, deep pharyngeal stimulation), which Molly felt were unappealing and inappropriate due to the children’s age and developmental changes.

### **Social Concerns**

There were significant social concerns that impacted the dynamics of the family. The children were often set apart due to their dietary needs. Consequently, they were isolated by fear and treated

as outliers in various social contexts. Because of these differences, Molly placed heavy emphasis on normality, using ‘normal’ as a metric for handling social issues. Stressors were placed on the family due to social isolation, labor intensive requirements, and a lack of understanding by others in the public.

In the excerpt in Table 1, we see Molly speaking of the loss of interaction because of her children’s dysphagia. There seems to be a general lack of understanding in the community about how dysphagia affects Molly’s family. Molly fears that her children will be isolated and treated differently than their peers because of dietary restrictions. Therefore, to protect her children, she avoids situations that impact her children’s ability to participate as other children typically would. In journal entries, Molly also detailed social concerns with activities that her children enjoyed such as purchasing ice cream from the neighborhood ice cream truck.

### **Affective Issues**

It was apparent throughout Molly’s narrative that caretaking resulted in emotional strains. She began to have many conflicting feelings regarding the care of her children. She experienced continued uncertainty about the future. As time progressed, Molly’s behavior changed to become more forceful and outspoken as she was required to make decisions in light of poor professional assistance.

The data in Table 1 suggest that Molly feels some anger that her duties as a mother are more demanding with the children’s diagnosis of dysphagia. She uses the word “resentful” here to describe her interactions with society, which also may be indicative of the public’s lack of awareness of disabilities such as dysphagia. It is possible that because dysphagia is not readily recognized or branded by physical abnormalities, Molly feels like society is unable to understand her reactions to events that occur in public.

### **Movement from Reactive to Proactive**

Molly began to take an evolving role forced upon her by poor professional assistance. She began to anticipate and solve problems independently and use experiential knowledge to address real everyday issues with children. In order to provide optimal care for her children, she was required to independently develop effective strategies that would assist her in daily interactions that surrounded mealtimes.

Molly is able to use her own practical skills in order to problem solve (see Table 1). She does not rely on professionals to assist her in facing day to day complications. Instead, she becomes more proactive and enabled to find her own solutions. She devises a set of strategies that allow her and her children to overcome issues that coexist with the diagnosis of dysphagia. Over time, she becomes less reactive to professionals, insurance companies, and the general medical system and more willing to initiate approaches that she hopes will benefit the health and happiness of her children. This becomes an important source of empowerment and enables some control over a situation in which she initially feels helpless.

Similar narratives were also noted throughout electronic journal entries. Molly often used electronic journal entries to share triumphs that her family experienced as a result of a strategy that she had implemented during the day. For example, one entry described the problems associated with insurance companies agreeing to pay for procedures related to dysphagia and how she was successful in gaining documentation required to secure payment.

## DISCUSSION

In exploring the construction and consequences of dysphagia, a wide range of themes were identified. Themes that conveyed a mother's perspective on caring for children with dysphagia included a medical orientation; adult perspective; social concerns; affective issues; and a movement from reactive to proactive. Taken together, these themes highlight encounters associated with caring for children with dysphagia and the inseparable relationship between challenges associated with dysphagia and everyday life. Additionally, the scope of themes that emerged from the data suggests that the consequences of dysphagia extend beyond the individual with dysphagia into the entire family system that operates within a social sphere.

While some may argue that there is little value in investigating a single case, we believe that it is stories such as Molly's that contribute a great deal to learning. This research was intended to be a case study of one mother's perceptions of her role as caregiver to multiple children with dysphagia. Therefore, results should be interpreted with caution. The themes generated should not be generalized to other caregivers with children with dysphagia as the data represent the experience of one individual. Despite the

fact that the perspective here is representative of one mother, a number of clinical implications can be drawn from this investigation.

## CLINICAL IMPLICATIONS

Focus of care is perhaps the most important implication. In Molly's case, recommendations were made from a strictly static, unchanging picture that did not account for the multifaceted nature of dysphagia. As a result, there was little consideration for the children's dynamic needs and future concerns for health and social well-being were disregarded. Molly's concerns and personal observations were often deemphasized in favor of objective, instrumental assessments. If Molly disagreed with the immediate and static recommendations of a healthcare professional, such as g-tube insertion, she was forced to navigate future nutritional decisions alone. Only recently have tools been introduced that promote shared decision-making for individuals with dysphagia who refuse diet modifications [25,26]. These programs have been developed for adults with dysphagia who are dealing with end of life issues. Thus, they are inappropriate for parents making dietary decisions for children.

Our results support the assertion that dysphagia management must be guided by principles that reach beyond the current medical model and into authentic and contextualized perspectives. Comprehensive assessment has been advocated to include parental concerns and parent-child interactions [27]. However, there remains a paucity of protocols that examine children and parents in real-world situations. Molly discussed the development of several strategies that she deemed helpful in overcoming the social challenges associated with dysphagia (e.g, preparation of special snacks for her children for social outings). While a description of these strategies and their effectiveness was not a part of this study, it is conceivable that some of these strategies were helpful. The ways in which families develop approaches to manage dysphagia in routine situations are likely valuable indicators of success and will help healthcare professionals better understand ways to promote empowerment in individuals who address these issues on a long-term basis. Social and affective implications of pediatric dysphagia are apparent and will continue to be present throughout families' lives. In order to endorse a change that will improve both the health of the child and the quality of life for families, dysphagia should be examined through a dynamic lens in which every layer of the disorder is inspected.

And finally, these data revealed a rich description of the meaning of dysphagia from a mother's perspective, made possible by the employment of a qualitative research methodology. In the discipline of speech-language pathology, qualitative research has become more widely accepted as a viable, and superior, method of inquiry for investigating social phenomena in authentic contexts [28]. Qualitative research is foremost interested in adequately interpreting how social action is achieved and how contextual variables influence social phenomena [29,30]. Adopting qualitative procedures allow researchers to focus on the perspective of participants in order to appreciate how an individual reacts to and makes sense of what is happening in real-world situations. While experimental paradigms are sufficient for answering many questions that can be operationalized, they are unsatisfactory for determining the complex interaction of behaviors that make up social action or the true viewpoints of a particular group of people. Because eating is a sociocultural process through which various physical, emotional, and social roles are defined and negotiated, there is a need for qualitative research in the field of pediatric dysphagia to allow us to understand the various manifestations and consequences of dysphagia on the children involved as well as their families.

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