Clinical Forum

Family Perceptions of Facilitators and Inhibitors of Effective School-Based Dysphagia Management

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L ong-term swallowing and feeding problems, identified as dysphagia, are a serious and often unrecognized consequence of neonatal conditions such as respira- tory distress syndrome (RDS), cardiac abnormalities, and neuro- logical disorders (Hawdon, Beauregard, Slattery, & Kennedy, 2001). Dysphagia has been defined as "impaired swallowing, secondary to dysfunction in oral, pharyngeal, and/or esophageal phase, i.e., anywhere from the mouth to the stomach" (Arvedson & Brodsky, 2002, p. 612). The definition of feeding problems includes difficulty with "placement of food in the mouth; manipulation of food in the oral cavity prior to the initiation of the swallow, including masti- cation if necessary; and the oral stage of the swallow when the bolus is propelled backward by the tongue" (Logemann, 1998, p. 3).

Pediatric dysphagia has been linked with health compromise. It has been specifically associated with nutritional compromise (Bartz & Deubler, 1990; Kovar, 1997), growth faltering (Boddy, Skuse, & Andrews, 2000), respiratory compromise (Arvedson & Brodsky, 2002), and failure to thrive (Hawdon et al., 2001). Learning difficulties may also present as concomitants of pediatric dysphagia. Researchers have reported an association between impaired swallowing in childhood and significant developmental delays and disabilities (Heffer & Kelley, 1994). Swallowing and feeding problems tend to intensify during periods of most active growth, which occurs from birth through 2 years of age (Gisel, Birnbaum, & Schwartz, 1998). Unfortunately, long-term swal- lowing and feeding problems have been reported to persist in

ABSTRACT: **Purpose:** This qualitative study focused on the perceptions of family members of children with dysphagia by asking what the family-identified factors are that facilitate or inhibit effective school-based management of pediatric dysphagia.
Method: Semistructured interviews of 7 family members of 6 children with dysphagia, ages 2 through 11 years, were conducted. Collective case study and cross-case analyses were conducted. The findings were confirmed through triangulation, respondent validation, and member checking.
Results: Interviewees identified 5 facilitating factors that enhance school-based dysphagia programs: (a) setting, (b) therapist and/or program, (c) capitalizing on positive child characteristics,

(d) home–school interactions, and (e) external supports. Four factors that inhibit effectiveness also emerged: (a) setting, (b) therapist and/or program, (c) limiting child characteristics, and (d) home–school interactions.
Conclusion: Practitioners may consider addressing the factors that were identified as facilitators of effective programs. More research is needed concerning (a) factors promoting effective parent–professional relationships, (b) methods for increasing professional preparation in pediatric dysphagia, and (c) the efficacy of school-based pediatric dysphagia management programs.

KEY WORDS: pediatric dysphagia, school-based dysphagia management, family perceptions, therapist disposition

children who have experienced dysphagia in infancy (Hawdon et al., 2001).

Adequate nutrition to foster appropriate growth and development has been a challenge for many children with dysphagia. Nutrition mirrors the sum processes involved in accepting and using foods (Kovar, 1997). Suppressed development and complications relating to malnutrition are a common finding in children with dysphagia (Arvedson, 2000). According to a survey of parents of children with dysphagia, 64% of parents reported that a health care provider had never specifically addressed their child's nutritional and feeding needs (Sullivan et al., 2000). Other researchers have found that parents of children with dysphagia tend to seriously overestimate the nutritional intake of their children (Gangil, Patwari, Aneja, Ahuja, & Anand, 2001).

Although swallowing is the principal way in which nourishment is commonly delivered, in some cases, it may be necessary to use non-oral feeding methods such as nasogastric (NG) and gastrostomy tube (GT) feeding. NG feedings are generally used on a temporary basis, whereas GT feedings provide nutritional support on a long-term basis (Arvedson, 2000; Kovar, 1997). Children with dysphagia need not suffer from malnutrition because many avenues are available to provide nutritional supports that will facilitate appropriate growth and development. George and Wellman (2001) advocated the inclusion of nutritional goals in children's individualized educational programs (IEPs). Unfortunately, the amount or extent of inclusion of swallowing and feeding and/or nutritional goals on children's IEPs has not been investigated.

Children with dysphagia may receive early intervention (EI) services that involve the management of dysphagia before entering the school system. These services are usually provided using a team approach, with speech-language pathologists (SLPs) often providing direct dysphagia treatment. Family perceptions of EI services for pediatric dysphagia have been found to be relatively positive, with family members reporting a high degree of satisfaction with the services (Stoner, Bailey, Angell, Robbins, & Polewski, 2006). According to Stoner, Bailey, et al., this high degree of satisfaction appears especially evident when therapies are provided in a relaxed atmosphere in the home and when they incorporate demonstration between the therapist and families.

School-Based Management of Pediatric Dysphagia

Management of dysphagia in school settings is becoming a common occurrence. In a 2004 American Speech-Language-Hearing Association (ASHA) survey of SLPs, 11% of school-based professionals providing services in elementary and secondary schools reported regularly treating children with dysphagia. The percentages increased substantially when services were provided in residential educational settings (26%) and preschool settings (31%) (ASHA, 2004).

Students with moderate-to-severe cognitive and/or multiple disabilities have been steadily moving from educational placements in clustered schools to home school placements. Students' home schools are where they would attend if they did not have any disabilities (Brown et al., 1989). Many of these students have disabilities that affect the processes of swallowing and feeding. It is now commonplace for children with feeding tubes, ventilators, and other health care needs associated with dysphagia to attend a wide variety of schools in their own communities.

Children with dysphagia present a particular challenge for school personnel who are involved in the supervision and feeding of children and youth with disabilities. This challenge appears to be complicated by the fact that, historically, dysphagia treatment has occurred predominately in medical settings (Silliman, 2000). Management of dysphagia and incorporation of achievable swallowing and feeding goals on students' IEPs have been identified as current challenges for school-based SLPs. In response to these challenges, ASHA has emphasized the need for SLPs to acquire the necessary medical knowledge and skills to manage swallowing and feeding disorders (ASHA, 2002).

SLPs are not the only school personnel who are involved in feeding children with dysphagia at school. A team approach is critical for comprehensive management of pediatric dysphagia. Several teaming models for dysphagia management have been recommended (Bailey & Angell, 2003; Homer, Bickerton, Hill, Parham, & Taylor, 2000; Lefton-Greif & Arvedson, 1997). Although team membership and operation may vary across schools, it is important that all members of dysphagia management teams acquire extensive knowledge concerning the evaluation and management of pediatric dysphagia. Information about subject areas associated with pediatric dysphagia such as nutrition and health, behavior, communication, and physical disability is necessary (Bailey & Angell, 2003). SLPs often serve as leaders of school-based dysphagia management teams, although "no single discipline can adequately address the needs of these children" (Arvedson, 2000, p. 28). School-based teams may include professionals such as SLPs, occupational therapists, social workers, physical therapists, dieticians, nurses or other medical personnel, special educators, and behavior specialists (Bailey & Angell, 2003; Homer et al., 2000).

Several authors have suggested that increased educational preparation may be necessary for professionals who have limited knowledge and experience in the area of pediatric dysphagia (e.g., Power-deFur, 2000; Silliman, 2000). SLPs are bound by the ASHA Code of Ethics (2003), which provides principles related to professional and institutional commitments (Lefton-Greif & Arvedson, 1997). According to the code, ASHA-certified SLPs should "engage only in those aspects of the profession that are within the scope of their competence, considering their level of training, education, and experience" (ASHA, 2003, p. 14).

Along with an appropriate level of knowledge and skills in the area of pediatric dysphagia, team members must be familiar with a wide variety of instructional and positive behavior management strategies that are appropriate for learners with moderate-to-severe or multiple disabilities. Research in psychology and special education fields has suggested that team member disposition and attitude are important for both interacting with parents/guardians and motivating a wide variety of learners with disabilities (Fialka & Mikus, 1999; Friend & Cook, 2002; Parrott & Daros-Voseles, 2004; Turnbull, Turnbull, Erwin, & Soodak, 2006). Team members must also be familiar with the use of adaptive equipment, instructional strategies appropriate to meet the needs of diverse learners, positive behavior management methods, and models for facilitating mealtime communication in children with severe communication impairments (Bailey & Angell, 2003).

Family Involvement

Children with disabilities who are between the ages of 3 and 21 are offered special education and related services through IEPs. In 1997,

the Individuals With Disabilities Education Act (IDEA) granted parents/guardians the right to participate in all educational decisions, including the development of IEPs (Fiedler & Swanger, 2000). Within the framework of IDEA, parents are considered valued members of multidisciplinary teams (Ruddy & Sapienze, 2004; Turnbull et al., 2006). Family involvement appears to be an important aspect of the provision of effective therapeutic services for children with dysphagia. Because many children require specialized assistance or supports to maximize swallowing and feeding safety and efficiency in all feeding settings, it is important to include parents/guardians for generalization of effective strategies/methods.

Mueller, Piazza, Moore, and Kelley (2003) reported that parents can be trained to administer appropriate therapy for children with swallowing and feeding disorders. Specifically, Kumin, Von Hagel, and Bahr (2001) reported that infants with low muscle tone who regularly received oral motor treatment from their caregivers at home demonstrated improvement in their oral motor function for eating and drinking. It is essential that family members be included as contributing, valued members of professional teams to ensure the effective management of swallowing and feeding problems (Arvedson, 1998). Family members are critical partners in the teaming process. Winters (U.S. Congress, 1988) used the analogy of family members as a missing puzzle piece to describe the futility of working with children and not with their families.

Family members of children with disabilities have noted that swallowing and nutrition are areas that cause them considerable stress (Sullivan et al., 2000). Studies have shown that, in general, parents who participate in EI programs perceive less stress than do parents who do not participate in EI programs (Brown & Bhavnagri, 1996). Judge (1998) investigated the relationship between parental coping strategies and family strengths within families of young children with disabilities. Findings from this study indicated a strong value in engaging parents in problem-focused behavior such as seeking social support to alleviate stress. Involving family members in children's dysphagia management allows family members to take a problem-focused approach, which may aid in reducing their stress.

Family perceptions are critical to the improvement of school-based dysphagia management programs. It is clear that parents and guardians have unique information regarding their children's individual characteristics, medical complexities, and educational needs. As team members, their unique perceptions may provide critical insights that can assist the development of appropriate school-based management programs for children with dysphagia as well as generalization of effective management strategies. In an initial investigation of family perceptions of dysphagia management programs in EI and school-based settings, Stoner, Bailey, et al.'s

(2006) interviews with parents and guardians indicated less satisfaction with school-based dysphagia management programs than with EI dysphagia management programs. Stoner, Bailey, et al. recommended further solicitation of parental perceptions to inform effective dysphagia management programs at all levels.

PURPOSE OF THE CURRENT STUDY

Although school-based dysphagia team models have been described by several authors (e.g., Bailey & Angell, 2003; Homer et al., 2000; Lowman & Murphy, 1999), little is known about dysphagia management in school settings. The purpose of this investigation was to investigate family perceptions of school-based dysphagia management programs. Specifically, the study's research question was: What are family-identified factors that facilitate or inhibit effective school-based management of pediatric dysphagia? Family insights regarding recommendations for improvement of school-based pediatric dysphagia management programs were an additional focus of this investigation.

METHOD

Participants

Participants in this study included 7 parents or guardians of 3 boys and 3 girls, ages 3 through 11, who were identified with dysphagia. A total of 5 mothers, 1 grandmother, and 1 father participated in the study. All of the children were identified by their parents/guardians as having pediatric dysphagia. The children's primary disabilities included cerebral palsy, scoliosis, FG syndrome, CHARGE syndrome, microcephaly, and hypotonia. Table 1 lists the participants' demographic characteristics. Participants were recruited from a group of family members who had enrolled their children for pediatric dysphagia services in a summer swallowing and feeding improvement clinic within the department of speech pathology and audiology on the campus of a large Midwestern university.

Research Design

Qualitative research methodology was employed in this study due to the purpose of the study and the nature of the research questions. Several researchers have provided guidelines for selecting qualitative methodology (e.g., Bogdan & Biklen, 1998; Leedy & Ormrod, 2001; McMillan & Wergin, 2002). Specifically, Creswell

Table 1. Demographic characteristics of the participants.

Participant's name	Relationship to child	Child's name and age	Diagnosis of child	Years in public school
Diane	Mother	Carol, 11 years	Cerebral palsy and scoliosis	8
Kathy and George	Parents	Robert, 7 years	FG syndrome	1
Linda	Mother	Carter, 5 years	CHARGE syndrome	2
Sue	Mother	Collin, 6 years	Cerebral palsy	3
Helen	Mother	Jessica, 4 years	Microcephaly	1
Kim	Grandmother/legal guardian	Kylie, 3½ years	Hypotonia	.5

(2002) stipulated that qualitative research is used to study research problems that "require an exploration and understanding of a central phenomenon" (p. 30). Strauss and Corbin (1998) contended that "qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional methods" (p. 11). Thus, the study of perceptions of parents and guardians of children with swallowing and feeding problems lends itself to a qualitative methodology precisely because it is an important phenomenon about which little is known.

Interviews

Semistructured interviews lasting approximately 1 hr each were conducted with all participants. Interview questions were developed to address the study's research question. Kvale (1996) suggested that semistructured interview protocols consist of a sequence of themes and questions to be addressed while maintaining a feeling of openness to follow up on other themes of interest that may emerge during the interview process. In this study, the use of semistructured interviews allowed researchers to ask for clarification or additional information. Responses to two interview questions were the focus of this study: (a) What has worked to facilitate effective management of your child's dysphagia at school? Why? and (b) What has not worked as a facilitator of effective management of your child's dysphagia at school? Why?

A faculty member in the department of speech pathology and audiology and two graduate students involved in the interview process contacted the potential participants and scheduled the interviews. An additional faculty member in the department of special education and the two graduate students completed semistructured interviews with participating family members. The graduate students transcribed the interviews after they were digitally recorded. Before the interviews, an expert in culturally sensitive interviewing within the department of special education at the university trained the graduate students on how to conduct culturally sensitive and thorough qualitative interviewing. This training consisted of observing interviews conducted by the trainer, watching a video recording on semistructured interviews, conducting a mock interview during a practice session, and reading material on effective interview techniques.

Data Analysis

The approach used to analyze data in this qualitative study was the collective case study as described by Stake (2000). Collective case study involves the study of more than one case in order to "investigate a phenomenon, population, or general condition" (p. 437). Miles and Huberman (1994) contended that studying multiple cases gives the researcher reassurance that the events in only one case are not "wholly idiosyncratic" (p. 172). This approach assumes that investigating a number of cases will lead to better comprehension and better theorizing. In this study, cross-case analysis was used to analyze each individual case as a whole entity; comparative analysis of all cases followed. Studying multiple cases allowed the researchers to see processes and outcomes across several cases and to develop a deeper understanding through more powerful descriptions and explanations.

After completion of the interviews, the data were organized using a multiple coding approach (Barbour, 2001). Specifically, all researchers independently coded all interviews line by line. The researchers then met frequently to identify categories that emerged from their individual line-by-line coding. Disagreements about categories were discussed; categories were refined, expanded, and/or deleted; and concordance was reached. The constant comparative method, by which researchers continually return to the data for analysis, was used as an overall methodological framework (Charmaz, 2000). The research team, consisting of two faculty members in the department of special education and a faculty member and two graduate students in the department of speech pathology and audiology, analyzed the data. They used NVivo (Richards, 2002), a data management software program, to organize the large amounts of verbatim interview data.

Confirmability

Confirmability of the findings was achieved through three approaches: triangulation, respondent validation, and member checking. *Triangulation* is the process of corroborating evidence from different individuals, different types of data, and different methods of data collection (Creswell, 2002). In this study, corroboration was achieved when incidences occurred across cases. Evidence of corroboration was also gathered from different types of data such as home–school notebooks, personal communications, and school and medical records. All families but one provided the researchers with documentation of IEPs. The documentation was reviewed and was used to confirm information that was provided in the interviews.

Respondent validation is a process in which researchers ask participants to check the accuracy of the findings in the areas of descriptions, themes, and interpretations (Creswell, 2002). Once interview data in this study had been analyzed and described in narrative and graphic formats, all participants were asked to validate the accuracy of the conclusions. The researchers met with each participant, explained the findings of the study, and used a concept map as a visual representation of the findings. Participant feedback was requested, and all participants confirmed the accuracy of the findings. Confirmability of the findings was further assessed using *member checking,* the process of providing participants with the opportunity to review material (Janesick, 2000). All participants were provided with a transcript of their personal quotes that were included in the final report. Approval for use of each quote was obtained.

FINDINGS

Inhibitors to Effective School-Based Dysphagia Management

Parents/guardians reported four primary categories of inhibitors to effective intervention: (a) setting inhibitors, (b) therapist and/or program inhibitors, (c) limiting child characteristics, and (d) home–school interaction inhibitors. Examples of perceived inhibitors were given to provide additional insight. A graphic representation of the findings is depicted in Figure 1, and Table 2 contains lists of family-identified facilitative and inhibitory factors that influence school-based management of pediatric dysphagia.

Setting inhibitors. The setting in which the therapy was administered played an important role in the perceived effectiveness

Figure 1. Graphic depiction of study findings and recommendations.
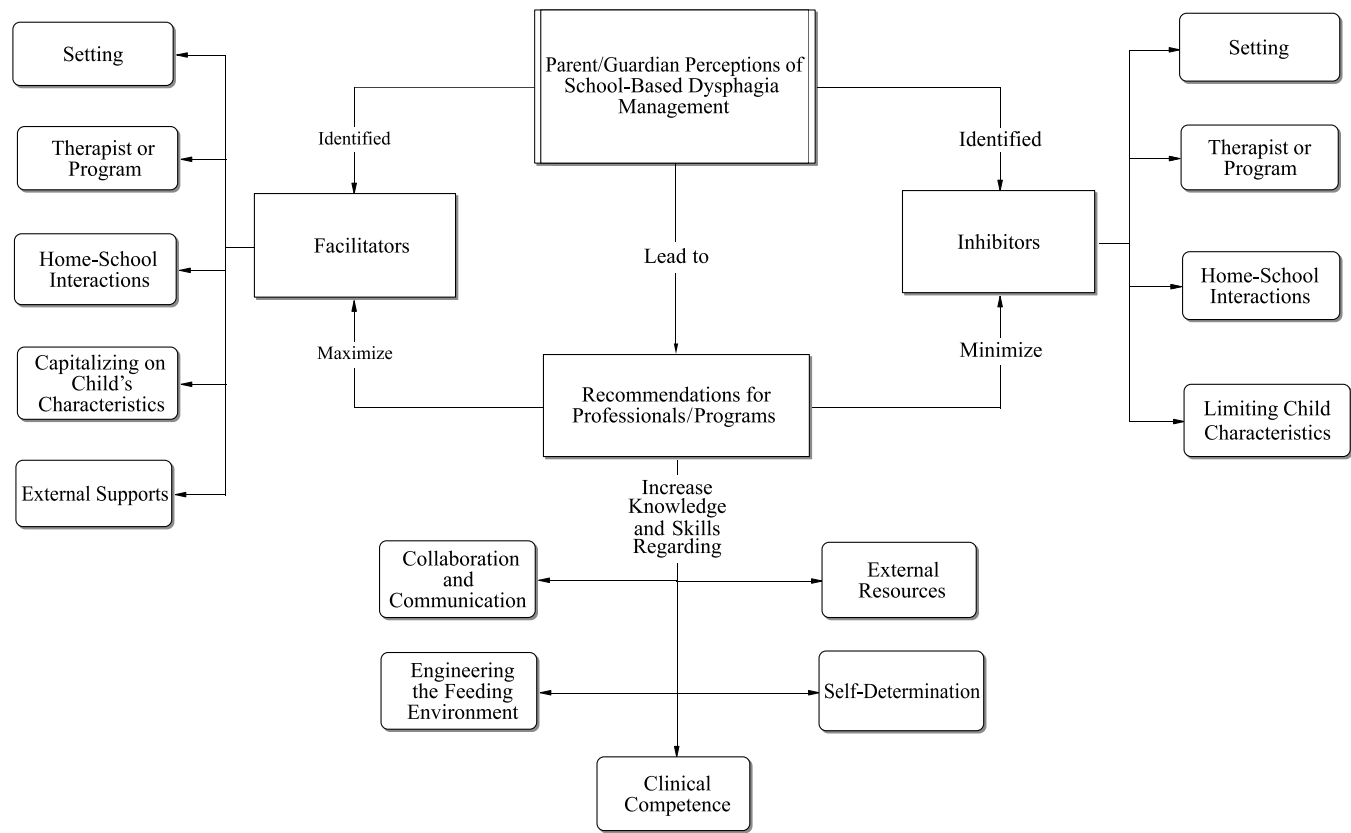
of the therapy program. All participants but one reported that an overstimulating environment impeded adequate therapy. Kathy stated,

> One thing with the school OT was that she was doing it late in the day, at the end of school, pulling him out into the hallway, it was at the time when the janitor was rolling the stuff down the end of the hall to get ready to clean because school was getting let out. The classroom across the hall was having music at the time. There were all kinds of things going on. It's not only what you're doing but how you're doing it. If you ran the feeding clinic over at a local restaurant, it wouldn't work because he gets really excited around people.

Sue reported that high stimulation in the environment and unfamiliar noises were distractions for her son. Making simple adjustments to the environment could make a significant difference. For example, Helen reported that her daughter Jessica is highly distracted by overhead lights. Helen found that taking Jessica into a quieter, darker room was most effective for providing treatment. Helen also reported using a verbal cue to gain Jessica's attention before presenting the spoon. She stated, "What hasn't worked is when there are too many people around." Sue discussed the problem of atypical noises in the school lunchroom, "I've noticed with Collin that if there's a new noise in the environment, he responds very dramatically to it."

Linda reported dissatisfaction with her son Carter's lack of inclusive educational opportunities, leading to a perceived non-stimulating educational environment. Linda indicated that Carter exhibits behavior problems that limit his ability to eat with the other children and that these behaviors are related to his special education placement.

> He's in a class where none of the kids talk and he's verbal. That's his hearing impaired class. And that's the big, that's the main problem I think. He can't interact with the other children because he's not going to take the time to sign to them. His signing is so poor. I mean he doesn't have to sign, he's verbal. His signing is poor and by the time he might get across what he wants to say, the other child is not going to wait because they don't know what the heck he is talking about because the signing is so poor. And he talks to them and they can't hear him…and I think a lot of times his response is behavior. And that can get in the way of his education.

Therapist and/or program inhibitors. In addition to settings in which therapies are administered, participants reported that inhibitors related to therapists and/or therapy programs negatively influenced the effectiveness of dysphagia management. For example, the positioning and type of chair used during feeding could have a positive or negative effect during mealtime. Sue reported that when her son is in his chair, "he can get himself twisted, and he starts to slump." Sue holds Collin in her lap during feedings, supports him, and monitors his swallowing. Sue also reported that her anxiety of choking is lessened when she is holding Collin on her lap; she can more easily help him instead of struggling to get him out of his chair if he were to choke. Collin is fed in his wheelchair at school.

Table 2. Family-identified facilitators and inhibitors of effective school-based management of dysphagia.

Facilitators	*Inhibitors*
Setting	*Setting*
Inclusive educational opportunities	Overstimulation
Environmental modifications to limit distraction	Noise, movement, and lighting distractions
Availability and support of multiple team members at mealtimes	Lack of inclusive educational opportunities
Opportunities for mealtime communication	
Opportunities for mealtime choice making	
Respect for child preferences	
Opportunities for advancement of swallowing and feeding skills, positive mealtime behaviors, diet levels, and communication skills	
Therapist or program	*Therapist or program*
Positive therapist disposition	Positioning supports different from those used in home environment
Caring attitude	Negative therapist characteristics
Willingness to learn	Negative disposition
Willingness to try new approaches	Decreased interest
Vigilant and ongoing assessment of child's characteristics and idiosyncrasies	Negative attitude
Encouragement of family involvement	Limited knowledge
Model-demonstration of effective strategies for family members	Inexperience
Provision of information and resources to families	Limited flexibility
Explanation of therapy programs	Lack of perceived administrative support
Implementation of team approach	Liability concerns
Adequate therapist knowledge/skills level	Fear of injury or accidents
Positive school-based behavioral supports	Personnel shortages
Use of adaptive equipment	High caseloads
Support and encouragement of self-feeding	Limited time with students
Capitalizing on positive child characteristics	*Limiting child characteristics*
Family's encouragement of child's willingness to learn	Medical complexities
Family's belief in child's abilities	Learning challenges
Child's determination	Previous alarming medical episodes
Opportunities to practice self-determined behavior	Day-to-day variability of intake and swallowing and feeding skills
	Child's negative behavioral characteristics
	Child's distractibility
	Child's sensory deficits
Home–school interaction	*Home–school interaction*
Use of communication notebooks	Limited home–school and school–home communication
High expectations	Limited family understanding of dysphagia management program
School personnel's knowledge of child's individual characteristics	Limited family understanding of IEP
Consistency of positive behavior management across settings	Incongruence between family and school personnel related to child's eating safety and feeding/eating goals
Team meetings	Incongruence among school-based team members' philosophies and approaches
Parents as advocates	
External supports	
Information, resources, and expert consultation	
Support of professionals outside school environment	
Staff and family educational programs and workshops	

Several participants stressed their perception that negative therapist disposition, interest, attitude, or knowledge was an inhibitor to effective dysphagia management. Sue said,

> We had a therapist who made it really kind of difficult. This is how it's going to be—this is what we're going to do. You're going to do this and this…it came to a point where I was—like— "No." We now have one therapist who tends to be on the nervous side and sometimes as a parent you have to push them a little, you take them off the fence.

Helen stated,

> I didn't have a lot of confidence in the therapist at all, so that didn't help out. It didn't seem like she wanted to educate herself. It was a tough time with the school, even when the therapist did attend a [pediatric

dysphagia] workshop, she just wasn't interested in it. So that made it tough.

Lack of therapist knowledge about dysphagia management was suggested by 2 parents/guardians. Linda and Helen felt that therapists working with their children were inexperienced and unprepared to provide effective dysphagia management services. This led to perceived hesitancy to provide services. Linda reported that the SLP working with her son seemed to be "in over her head. I'm not saying that she didn't do things with him, but she didn't seem to know a lot about it." Likewise, Helen said,

> What I see is if a therapist comes in and they're not comfortable with a feeding issue or they just plain don't know what to do with Jessica, because

Jessica can be difficult…. If they don't know what to do with Jessica, I wish they'd just speak up and say, "You know what, I'm a therapist and I've been a therapist for however long and I've seen many people, but I don't understand this one. Is it OK if we bring in help from somewhere else or can I research this?" And even if they took Jessica's IEP time for a week or 2 weeks or whatever it takes to research it and then to help her along after they've researched it and familiarized themselves with it. Then they come in and help her instead of just letting me or the aide do all the work. If they're just not comfortable with the feeding issue to see if we could bring in someone else who is more comfortable. I think there are some speech pathologists that are great in different areas. One may be communication, another may be great at feeding therapy. I think that if they should fit their specialties to the needs of the child, I don't think it would be impossible, so that would be my comment on that.

Kathy is the mother of a child with significant disabilities and has worked closely with therapists as an administrator in a statewide EI system. Kathy's comments reflect the importance of positive and flexible attitudes in both therapists and parents/guardians.

I think we just have to kind of be able to respect each other; that we as parents have to realize that those therapists and teachers have been trained in ways that we haven't, but also the therapists need to realize that they can also gain a lot from the knowledge that a parent has about the child. However, I will say there have been some therapists that I have changed because we didn't have a good relationship. There was an occupational therapist at school that was a really nice person, but we would try and go and observe and be part of it and try to give some input, and you know she had her way of doing things and it wasn't working with Robert. He was getting really frustrated and that was just her, so we asked for a different therapist. I always hate to do that because I don't think they're bad people and I don't think that there are ulterior motives. It's not that they don't want your child to succeed, I think it's just an attitude thing.

George's comments corroborated with Kathy's: "With Robert, you just have to be kind of creative. Some things he just won't react well to, but I think that what is important is how you interact with him rather than a specific strategy."

An additional program inhibitor was lack of perceived support from administration. When participants mentioned lack of administrative support, it was paired with liability concerns and/or fears or personnel/funding issues. Helen alluded to a perceived inhibitor of SLP shortages and high SLP caseloads that limit therapists' time with students. She also painted the most vivid picture of her perception of administration and teacher fears and/or liability concerns.

They were scared of her, which worried me. And we did have problems with that. They didn't want to feed her at school. The principal didn't even want us to tube feed her at school. So we invited the principal to her doctor's appointment … but I don't think that helped a lot because I think that scared her more about what could happen. When she found out that we had to have Jessica in a certain chair and a certain position. And—you know—Jessica retched once and passed out. I don't know— the therapist thought she had a seizure. I say she just lowered her blood pressure enough to where she kind of went to sleep for about 20 seconds. They were able to arouse her, but that put a big scare on the principal and the teacher.

Limiting child characteristics. Some participants mentioned individual child characteristics that they perceived as limiting their children's ability to progress in the area of swallowing and feeding. All of the participants discussed difficulties due to their children's learning problems and medical complexities. Some discussed previous "scary episodes" related to feeding. Linda stated, "Even as a child, we would give him a bottle and his stats [oxygen saturation levels and other physiological parameters] would go

down." Kim said, "We had to take her to [hospital name] because we couldn't keep her temperature up and she kept having stomach reflux—every thing she ate—it just wouldn't stay in there," and Diane said, "She has days where she eats well and there's other days when she doesn't, she'll gag, and I think it's related to constipation, that's part of the problem." Diane also discussed a frightening incident that occurred in her home.

A year ago she had hip surgery and she had to be positioned correctly and there was an incident where we were feeding her at home and she kind of quit breathing on us and everything. And we believed that was because she wasn't positioned correctly that was part of the reason. I wasn't there. My husband was. She just rolled her eyes back and quit breathing and they called 911 and my husband got her breathing by the time the ambulance got there. Well, it was between my husband and my other daughter. My daughter had taken a little bit of CPR at school. You know, they show them how to do it with dolls. She basically knew what to do.

Kim, Kathy, Sue, George, Helen, and Linda each mentioned specific behavioral characteristics that their children exhibited that they perceived as negatively affecting their progress. Kim stated, "She has got a mind of her own. I tell you something else, she has her moods. She'll get mad and she'll throw something." Linda said, "For some reason, we haven't really figured out a way to manage his behavior at school. So he can learn what he needs to learn. And that's our big issue right now." Kathy talked about interference that she perceived to occur when her son becomes overexcited with activities in the classroom. This leads to increased self-stimulatory behavior and results in Robert's removal from classroom educational opportunities.

In his classroom, if they see that he's getting excited or if he starts to do self-stimming [self-stimulating behavior], they have a tendency to pull him out of the classroom into the hall. So now we've kind of gotten to a place where we don't know. Is it kind of feeding into the problem?

Helen, Kathy, George, Kim, and Sue each mentioned that their children were easily distracted, which they perceived as having a negative effect on their ability to learn. Kim referred to Kylie's sensory deficits as having a limiting effect: "She wouldn't let people touch her—so for a long time when they first started therapy, she wouldn't let them work with her." Some participants discussed their own management strategies for improving their children's eating behaviors at home. These included techniques such as moving to isolated areas with dimmed lights; playing soft, rhythmic music or low volume television; limiting others' physical movements in the meal environment; and using verbal and tactile cues to gain their children's attention during feeding activities.

Home–school interaction inhibitors. The primary home–school interaction inhibitor appeared to be limited school-to-home and home-to-school communication exchanges. When asked to describe their children's feeding management at school, some participants were unsure of what their children's school management program included. Kathy stated, "That's a tough question. Again, I'm not quite sure all the time what they're doing, although they work a little bit with him on self-feeding." Kim expressed confusion about speech pathology services in general: "Because—like—when they said speech therapy—what they're doing right now is feeding her and I don't understand. I said, 'She's going to speech therapy and why are they feeding her?'" When asked if she had been to an IEP

meeting and if Kylie's therapy and educational goals had been discussed with her, Kim responded "No." A copy of Kylie's IEP was requested by the researchers, but Kim did not provide it, so this information could not be confirmed. Sue did not remember if Collin had swallowing and feeding goals on his IEP. She also discussed her lack of understanding about the school program, which led to decreased use of therapist-recommended strategies at home.

> I think that like it never really stuck with me, the massaging, the oral preparation programs that they do at school. I haven't done it much at home because I'm not sure what it is I'm stimulating, what is the benefit? Is it something that will help him? It's not something that has ever been explained to me well enough that I know exactly what to do … so we do a totally different eating routine at home.

Another home–school interaction inhibitor mentioned by Sue and Helen could be described as incongruence between parents/guardians and school personnel related to children's eating safety and/or their feeding/eating goals. Sue described a difficult interaction with a therapist:

> At the time, Collin had been on the Ketogenic diet for most of his life, which is a very strict diet and the goal is to decrease seizures. He had to eat everything. It wasn't an option. Well, you know, after 20 minutes, the therapist said not to feed him anymore. But you had to make sure he ate everything, so even if it took 2 hours, he's got to eat all of it. That was difficult for her to comprehend or understand. It was a medical treatment. It was a treatment for a more serious issue. She had a hard time with the diet and we went 'round and 'round and battled about that. She wanted a multitude of tests that weren't going to change his treatment; they were just basically going to be more invasive … so, I just kept putting them off. You know we were going to wean him from the diet in another 6 months anyway. After 6 months we can do these tests. I understand that feeding is important, but feeding is one component of his life. It is also important that we manage his seizures.

Helen described the disagreement that occurred between her and a school SLP and another school professional related to therapy goals:

> I would say that the SLP was trying but I think the school was holding her back. She was trying to come up with different ideas, different techniques, different spoons, and working with Jessica in a quiet setting. But there was an orthopedic facilitator who was also bringing a lot of confusion into the picture by saying that Jessica socially needed to be with her peers [at lunchtime], and so I told the SLP that the orthopedic facilitator was a consultant only. We had to call many IEP meetings to discuss the situation until it was resolved.

Facilitators of Effective School-Based Dysphagia Management

Parents/guardians reported five primary categories of facilitators of effective intervention: (a) setting facilitators, (b) therapist and/or program facilitators, (c) capitalizing on positive child characteristics, (d) home–school interaction facilitators, and (e) external supports. Examples of these perceived facilitators provide additional insight into parents' experiences and perspectives.

Setting facilitators. Linda discussed her perception that inclusion with peers facilitated learning for her son. She reported that Carter tends to imitate peers, and she felt that he would benefit from peer modeling at school lunchtimes. Helen supported the SLP's use of soft, rhythmic music at mealtime to help her daughter attend

to eating tasks. Diane appreciated the availability and support of multiple team members at lunchtime, stating, "There's usually a whole group there [in Carol's classroom]. They're like a team that works together." She also appreciated opportunities for mealtime communication and choice making that team members provide. "She gets choices of what to eat; she says 'yes' and 'no.' They've been using a lot of pictures and communication switches. That's helped a lot." Sue described Collin's setting as facilitating his progress:

> Well, right now the therapists do oral preparation with all the kids and then they have a lunch room where they all eat together. He does really well. They have been very good about finding out what his likes and dislikes are and other things like that. They find things that he likes and they try to give him foods that he really likes as well as trying out other foods and that sort of thing.

Therapist and/or program facilitators. Some participants described therapists who display positive disposition characteristics, caring attitudes, and a willingness to learn and try new ideas. Sue stated, "They're [current school personnel] pretty vigilant about watching Collin and knowing what his indicators are …. We have also had therapists who thought it was wonderful for us to be involved and showed us what to do and gave us information." Helen stated that Jessica's SLP "truly cares." Linda and Helen described perceived increased program effectiveness with previous therapists who had provided demonstrations and explained therapy programs. All participants indicated that they appreciated a team approach to school-based dysphagia management. Sue mentioned an SLP whom she described as "very knowledgeable." Helen described a helpful classroom assistant and the use of adaptive equipment to support Jessica's self-feeding attempts at school and to facilitate improvements in her swallowing and feeding skills. Linda, Kim, George, and Kathy also made positive statements about the use of positive school-based behavior supports.

Capitalizing on positive child characteristics. Several participants suggested that their children's positive characteristics helped them be more successful in therapy programs. Sue said that her son, Collin, "loves to eat." When asked about her granddaughter, Kylie, Kim said, "You know, she's just amazing—all the things that she does every day. Every day she can do something new. She wants to keep going. I think she's determined that she wants to walk, too." Linda described her son, Carter, who has been diagnosed with CHARGE syndrome, as "very determined to swallow." He has been tube fed since early infancy when, according to Linda, a videofluoroscopic swallow study was performed that determined that he was "not swallowing." Linda described being told the following by medical personnel in the hospital just after Carter was born:

> Do nothing. They told us not to put anything in his mouth. I stuck a pacifier in there to keep him sucking. And when he was old enough, I gave him baby food even though he spit it out. I gave him chewing toys. They told us not to, but I did. They were afraid he would aspirate. He was never afraid of food or anything in his mouth. That's why I went ahead and gave him anything he wanted…because he's told us he wants to swallow … He'll go into [restaurant name] and order exactly what he wants and then he'll chew it and just put it in a cup, because he could not swallow it. But he always had a taste for things. He'd tell me, "Mom, I'm hungry" and tell me what he wanted and pick out things that he likes. He ate like a regular kid except that he never swallowed it. And then he started swallowing a couple of months ago. He was just like "Look, I can swallow!" He was real excited. If he swallows four

or five bites, he decides he doesn't want any more. I don't push him—he pushes himself.[1]

Home–school interaction facilitators. Parents/guardians discussed several factors that occurred at home and/or school that they perceived as facilitating their children's feeding/eating skills improvement. Sue, Helen, and Kim specifically mentioned a communication notebook that traveled between school and home on a daily or weekly basis. Kim stated, "Every day when Kylie goes to school, they'll send back what she did." Kim, Helen, and Linda described the importance of having high expectations for their children. Sue and Helen discussed their perception that it was important that school personnel are able to "read" their children. Kim mentioned that good behavior management at home would help school personnel be successful with Kylie at school. Helen discussed team meetings as part of the IEP process as benefiting her daughter. Helen and Sue both described their role in home–school interactions as that of "advocate."

External supports. Several participants related their perception of the value of seeking out information resources and experts to provide support for themselves and their children's therapists. Helen reported the largest number of outside supports for her daughter, Jessica, including SLPs outside of the school system, physicians with specialties related to the gastrointestinal system, and a geneticist. She stated that she started looking for external SLP support 2 years earlier.

> I believe it was at school when we were having problems with where to feed her and how to feed her. And we went to a workshop that [presenter name] was giving on dysphagia and swallowing disorders. When we saw her and listened to her speak, we knew she was good and were hoping that she would help and from there she told us about [resource name]. I contacted her after that and she was very interested in us…. She was a very big help to us after that and I felt much better knowing that I had somebody that knows about this.

DISCUSSION

Discussion of this study's findings addresses the two themes that emerged from the interview data: family perceptions of inhibitors and facilitators of effective school-based management of dysphagia. Additionally, recommendations related to these findings are offered.

Parent-Identified Inhibitors of Effective School-Based Pediatric Dysphagia Management

Parents described four categories of inhibitors, including (a) setting inhibitors, (b) therapist and/or program inhibitors, (c) limiting child characteristics, and (d) home–school interaction inhibitors. Setting constraints such as random noises and distracting activities in and around the classroom or lunchroom are inherent to the school setting (Berg, 1987) and may pose a problem for children

who have difficulty establishing or maintaining attention to eating tasks. Participants' comments indicated that some school personnel had attempted simple environmental adjustments such as dimming lights; using soft, rhythmic background music; and moving children to areas with fewer perceived distractions to minimize these inhibitors. These environmental modifications have been recommended by previous authors as ways to minimize distractions in the mealtime environment (Lowman & Murphy, 1999; Morris & Klein, 1987).

Another parent noted the use of a verbal cue as a strategy to gain her daughter's attention before presenting a morsel of food. Delivery of attentional cues is a well-established instructional enhancement strategy for learners with severe and/or multiple disabilities (e.g., Collins, Gast, Ault, & Wolery, 1991; Wolery, Ault, & Doyle, 1992). It is clear that individualized problem solving within school environments by team members may lead to similar simple environmental adjustments that may yield a significant impact for children with dysphagia.

Parents/guardians described therapist/program inhibitors in the areas of team member disposition with descriptions of inflexible, timid, or reticent team members. Parents/guardians appeared to tolerate therapists' knowledge and skill deficits as long as the therapists expressed a willingness to gain new information. The perceived need for continuing team education in the area of pediatric dysphagia corroborates with previous literature (e.g., Power-deFur, 2000). The perception that the "best" therapists really cared about their individual children also appeared to confirm that team member disposition is critical to fostering home–school relationships. It is clear that team members should make a special point of expressing care and acknowledging positive features of families and their children. Lowman and Murphy (1999) supported this contention, stating that the use of positive communication strategies is particularly important in working with families.

Reports of perceived team member and school administration fears and liability concerns reflect O'Toole's (2000) observation that in an era of increased litigation, it is natural for SLPs to have concerns about providing therapy to school-based clients with medically related disabilities. This finding also confirms the importance of continuing education for team members in the area of pediatric dysphagia. SLPs should thoroughly understand the specific nature of a child's oropharyngeal swallowing disorder and whether or not the child can swallow safely and efficiently under any circumstances (Arvedson & Lefton-Greif, 1998). Therapists must follow local school policy procedures regarding recordkeeping and confidentiality, applicable legal guidelines, and ASHA's Code of Ethics (O'Toole, 2000). The two most important factors influencing a therapist's ability to reduce exposure to liability are awareness and education (ASHA, 1994). Clear communication between team members such as external medical personnel and parents/guardians is vitally important.

In this study, limiting child characteristics included additional medical problems experienced by children and personality characteristics perceived by parents/guardians as inhibitors to the provision of effective pediatric dysphagia management. Parents/guardians described inhibitors of achieving success in effective management of pediatric dysphagia when children experienced other health problems such as seizures and constipation. It is clear that health and medical problems experienced by children with dysphagia can have a negative effect on their swallowing and

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[1]It is important to note that the authors are reporting parents'/guardians' perceptions—not advocating for these actions. In fact, advancing children to oral feeding against medical advice may have lifelong adverse health effects for children who are often already medically fragile. Additionally, Carter exhibited safe swallowing with select consistencies during a videofluoroscopic swallow study and was given a medical release to begin dysphagia therapy before attending the swallowing and feeding improvement clinic at the university.

feeding processes. These problems are a common occurrence in many children with severe and/or multiple disabilities (Lowman & Murphy, 1999). Sharing health information and/or symptoms from home to school and from school to home is necessary to optimize all caregivers' understanding and ability to provide appropriate supports for children with dysphagia.

Interestingly, some very similar personality characteristics were described by parent interviewees as both an inhibitor and a facilitator of effective management of pediatric dysphagia (i.e., child stubbornness vs. determination). Although stubbornness per se may be viewed as a negative characteristic, some individuals' stubbornness may manifest as tenacious, persistent, goal-oriented behavior defined as self-determination. Researchers have shown self-determination to be a desirable skill, a valuable competency, and a positive personality characteristic that leads to successful transitions to adult life (e.g., Malian & Nevin, 2002; Stoner, Angell, Goins, & House, 2006; Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998).

Other family members described specific maladaptive mealtime behaviors that were exhibited by their children as perceived inhibitors of effective dysphagia management. Problematic mealtime behaviors commonly co-occur with pediatric dysphagia (Arvedson, 1997; Kerwin, 1999). Many problems that children experience in the areas of feeding, growth, and food acceptance have been attributed to a combination of the medical or physical condition of children, inappropriate food selection, and/or inappropriate dynamics during feeding (Satter, 1990). Recently, use of a structured positive behavior management program has been found successful in decreasing the occurrence of problematic mealtime behaviors in a school-based pediatric dysphagia management program (Bailey & Angell, 2005).

Home–school interaction inhibitors were categorized as the perception of limited communication between home and school. This finding concurs with literature regarding the importance of clear communication in teaming and home–school relationships (Beukelman & Mirenda, 1998; Lowman & Murphy, 1999; Parette & Brotherson, 1996; Parette, Brotherson, & Huer, 2000). Some participants described team meetings and the use of notebooks with daily information as improving school-to-home and home-to-school information sharing. Family members' comments were generally positive when they described the use of these notebooks or a similar daily communication medium.

Interviewees also described incongruence between goals that were set at home and those that were set at school. Not only is it extremely important to include clear, observable, measurable, and achievable dysphagia improvement and nutrition-related goals on children's IEPs, but acknowledging and addressing parents' or guardians' goals for their children have long been identified as important factors in successful teaming (Parette et al., 2000). It is important that all team members have the ability to openly voice their opinions so that all perspectives of a problem can be identified and a consensus can be reached.

Family-Identified Facilitators of Effective School-Based Pediatric Dysphagia Management

Family members described five categories of facilitators of effective school-based pediatric dysphagia programs: (a) setting facilitators, (b) therapist and/or program facilitators, (c) capitalizing on positive child characteristics, (d) home–school interaction facilitators, and (e) external supports.

Settings were described as facilitators when children were included with peers whenever possible per individual student abilities in supportive mealtime environments. This finding reflects previous researchers' recommendations that caregivers engineer mealtime environments to support children's individual needs and abilities (Arvedson, 1997; Arvedson & Brodsky, 2002; Lowman & Murphy, 1999). Caregivers may need to limit distractions in mealtime environments in order to maximize the children's ability to attend to their eating tasks.

Family members indicated overwhelmingly that positive therapist disposition and caring attitudes facilitated improvements in their children. Fiedler (2000) defined dispositions as "reflecting the values and attitudes of professionals in terms of their commitment, sense of responsibility, and ethical behavior on behalf of children with disabilities and their families" (p. 12). Other researchers have investigated and emphasized the importance of effective professional dispositions and have listed specific characteristics of effective teachers/therapists such as creative, confident, positive, approachable, and responsive (e.g., Kauchak & Eggen, 1994). Interviewees in the current study reflected the field's contention that professional dispositions are valued and are necessary for effective teaching and therapeutic gains.

Perceptions of clinician competence also appeared to be tied to family perceptions of therapist disposition; several participants indicated that the "best" therapists were those who truly cared about their children. Therapist knowledge and skills were also important, although a perceived willingness to learn about complex issues was also stressed by parents/guardians as a facilitator of effective school-based dysphagia programs. Certainly, few would deny the necessity of administrative support and funding for staff development in the area of pediatric dysphagia to improve therapists' knowledge and skills when learning needs are indicated.

Parents/guardians in this study tended to describe characteristics of perceived self-determination when they discussed capitalizing on positive child characteristics. Mealtimes offer many naturalistic opportunities to give children experiences with making choices (Bailey & Angell, 2003). According to Stoner, Angell, et al. (2006), development of self-determination skills in people with significant disabilities is facilitated by opportunities to practice making choices and other self-determination skills at early ages. Practicing early self-determination skills within naturalistic settings such as meals may foster or reinforce the development of self-determination skills in other settings.

For this study's interviewees, facilitating home–school interaction patterns included instances of what they perceived as good communication exchanges between school personnel and family members. Communication and sharing across settings can help to minimize misunderstandings and facilitate improved family involvement (Parette et al., 2000). In this investigation, parents/guardians described effective strategies for home–school interaction that included daily notebooks, team meetings, notes from home to school or school to home, and phone calls. Use of these and similar strategies for improving family involvement has been previously described in the literature (e.g., Beukelman & Mirenda, 1998; Moore, 1992).

Finally, results of this investigation confirmed family perceptions of the effectiveness of seeking outside supports from "experts,"

support groups, or other parents/guardians of children with disabilities. Researchers have noted that families need more than mere information about their children's disabilities and the management of related challenges (e.g., Seligman & Darling, 1997; Turnbull et al., 2006). As they strive to access emotional and social support, families in the current study expressed a need for supportive professionals whom they could trust on a variety of levels. We recommend more research on issues of trust in relationships between families and education/clinical professionals.

CONCLUSION

Families in this study raised several interesting issues related to school-based pediatric dysphagia management. To adequately address these issues, we recommend that more research be conducted on factors that facilitate effective parent–professional relationships, especially when dysphagia or health-related concerns are involved. Families are looking for competent, trustworthy professional partners on whom they can rely for safe and effective services. Therefore, we highly recommend that professional preparation programs and continuing education providers incorporate information and evidence-based practices related to effective dysphagia management in educational settings. Additional focus on promoting positive therapist dispositions and home–school interactions is also recommended. Educational team members should be trained in ways to foster self-determination, identify resources for family support, and manipulate environmental factors to ensure the acquisition of eating skills, facilitate communication, and encourage appropriate mealtime behaviors. We also recommend that existing dysphagia programs and professional preparation programs emphasize collaborative efforts that foster open lines of communication, increase trust-building interactions, and encourage competent exchanges of information. Finally, we recommend further investigation of SLPs' and other team members' perspectives on effective school-based management of pediatric dysphagia as well as much needed research related to the efficacy of school-based interventions and programs.

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