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Home and Parent Training Strategies for Pediatric Feeding Disorders: The Caregivers' Perspective

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Home and Parent Training Strategies for Pediatric Feeding Disorders: The Caregivers' Perspective

Abstract

Background: Twenty to 45% of the general pediatric population experience feeding problems. When children with disabilities exhibit feeding problems, they are more likely to develop maladaptive mealtime behaviors that may lead to poor nutrition. Home training to help treat a child's feeding delay or disorder is a vital component of feeding treatment and supports holistic, family-centered treatment models. It is important for occupational therapists working with this population to understand the impact of these behaviors on individual and family functioning.

Method: This quantitative study examined caregivers' perspectives of the training families receive to support their child's feeding delay or disorder, and how family mealtimes may be affected. One hundred and eight participants completed an online survey using primarily Likert scale questions.

Results: Caregivers report that (a) they are receiving current and evidenced-based interventions; (b) they feel supported, yet feel they need more support; (c) family relationships are adversely affected by a child's feeding challenges; (d) caregivers desire to connect with other caregivers of children with feeding delays or disorders; and (e) they need stress management and coping strategies.

Conclusion: Feeding treatment is strengthened with more family-focused topics like family relationships and interactions, caregiver burden and stress management, and increased caregiver support.

Comments

The authors report no potential conflicts of interest.

Keywords

feeding, home training, pediatrics

Credentials Display

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Many typically developing (TD) children display picky eating behaviors, such as refusal of food, tantrums, and a restricted diet, beginning around 2–3 years of age (Rogers et al., 2012). Twenty-five to 45% of the general pediatric population are reported to experience feeding problems (Lukens & Silverman, 2014) with avoidant restrictive food intake disorder being the most common concern (Sharp et al., 2016). Children with developmental disabilities, such as autism spectrum disorder (ASD), and neurodevelopmental disorders, like cerebral palsy, are more likely to develop mealtime behaviors and experience more negative side effects from a lack of proper nutrition (Rogers et al., 2012). It is estimated that 46%–75% of children with ASD have feeding and eating issues, including restriction of food intake to specific textures and colors, specific rituals around food presentation and utensils, restricted diets, not remaining seated at the table, and only eating the same type of food for every meal (Rogers et al., 2012). Other reports estimate that 89% of children with cerebral palsy experience poor nutrition and growth, and in the first year of life, 57% of children with neurodevelopmental disorders exhibit feeding issues (Clawson et al., 2007). Children with developmental disabilities, such as ASD and cerebral palsy, are more likely to develop mealtime behaviors and experience more negative side effects from a lack of proper nutrition (Rogers et al., 2012). Improper nutrition can lead to myriad secondary problems for all of these children, including vitamin deficiencies (Rogers et al., 2012; Sharp et al., 2017), cognitive delay (Sharp et al., 2016), decreased immune function, decreased emotional development (Sharp et al., 2017), decreased muscle strength, decreased cardiac work capacity, decreased bone density, motor delay, and further developmental delays (Clawson et al., 2007).

Occupational therapists value occupations, an individual's everyday activities that are central to their identity and that have particular meaning and provide a sense of competency (AOTA, 2014). Occupations fall into different categories with feeding, eating and swallowing, parenting, and health management and maintenance (AOTA, 2014) being consistently present in families with a child who has special needs and/or a feeding delay or disorder. Children with special needs often experience mealtime occupations as a challenge physically, developmentally, socially, and emotionally (Suarez et al., 2014). When children experience feeding difficulties, the occupation of parenting is negatively affected, as caregivers often feel frustrated with mealtimes and how they impact the family. Caregivers will seek answers and strategies to help their child eat more to attempt to restore a pleasant mealtime routine with their family (Suarez et al., 2014). When parents are not given appropriate strategies to assist their child in the occupation of eating well, they will often turn to maladaptive methods, including coercion, bribing, and punishment, which, in turn, make feeding issues and behaviors more intense (Adamson et al., 2013).

It is concerning that more attention is not given to the feeding issues children experience (Rogers et al., 2012). Feeding and eating are vital occupations and critical activities of daily living. Further, there are secondary effects on the co-occupation of parenting and caregiving (AOTA 2014; Olson, 2004) when there is a problem with those activities (Suarez et al., 2014). Occupational therapists play a significant role in treating feeding issues in children. Occupational therapists are trained to address the core skills needed for feeding and to emphasize a holistic and family-centered model of care (Suarez et al., 2014). For occupational therapists to provide quality treatment, it is important for them to understand and recognize mealtime behaviors displayed by children, as well as to understand the experiences of the family of the child with a disability (Rogers et al., 2012). When working with children with feeding difficulties, it is important for occupational therapists to understand the best intervention approaches and use the most appropriate methods to treat each child and family's individual feeding difficulties to improve not only the child's nutrition, but also the child and caregivers' quality of life. It is beneficial to understand and know when and how to provide family training to ensure continuation of care at home; generalization of skills learned; and to improve mealtime occupations, routines, and attitudes for the entire family (Suarez et al., 2014).

Parental Stress Raising Children with Feeding Difficulties

Parent-child interactions stem from attachment, bonding, and social-emotional development, which can take many forms for individuals and is ever present through the lifespan. A portion of the existing literature of parent-child relationships examines the increase in parental stress when raising children with feeding disorders. Provost and colleagues (2010) sought to compare the feeding behaviors of children diagnosed with ASD to their TD peers. Twenty-four parents of children with ASD and 24 parents of TD children participated in the study. All parents were asked to complete a mealtimes survey focusing on mealtime history, location, food preferences, eating problems, and related behaviors. The results showed that while some areas were similar across both populations of children, other areas were distinctly different for the children with ASD (Provost et al., 2010). The study reported that 54% of TD peers compared with 8% of children with ASD eat a variety of foods, and 67% of children with ASD had distinct food preferences compared to 0% of the TD peers. There were higher percentages of children with ASD (50%) who refused to try new foods compared to their TD peers (8%), and 46% of children with ASD mouthed non-food items compared to their TD peers (4%). The results of this study show the parents of children with ASD were reporting feeding concerns more frequently than the parents of TD peers between 1–3 years of age. It is suggested that these abnormal eating preferences grow stronger as the child with ASD gets older, leading the authors to stress the importance of early knowledge and identification of these problem behaviors coupled with family-centered care models to aid in treatment for those children with ASD (Provost et al., 2010).

Another study performed a systematic review to examine and compare relationship satisfaction in couples raising children with ASD with those raising TD children (Wilkes-Gillan & Bourke-Taylor, 2017). The authors found that couples raising a child with ASD were more likely to experience lower relationship satisfaction and that these couples would benefit from supports that help them maintain their relationships. Communication and shared ideas about both the relationship and leisure activities are listed as useful strategies to help with relationship satisfaction. The authors also suggest this evidence supports that parental stress may be reduced through parental mental health and well-being (Wilkes-Gillan & Bourke-Taylor, 2017).

Two additional qualitative studies examined the parent perspective of feeding their children diagnosed with ASD (Rogers et al., 2012; Suarez et al., 2014) and food selectivity (Suarez et al., 2014). Both studies examined the feeding challenges of children with ASD who were 4–11 years of age using semi-structured interviews, and many themes were discovered through this process. The mothers described mealtimes as a disaster and emphasized the negative effect this had on the entire family. These feelings resulted in the mothers attempting to make mealtimes less negative, which usually involved giving up their vision of a cohesive family meal (Suarez et al., 2014) or catering to their child's individual needs at meals (Rogers et al., 2011). These mothers reported searching for answers and strategies to help their child, which included assistance from many different health care professionals. Some reported not feeling supported by these professionals (Rogers et al., 2011), while those who did feel supported reported the relationships did not last and the mealtime dilemma was not corrected (Suarez et al., 2014). It is vital to include the family routines, habits, and mealtime patterns when creating outcomes and to use a holistic approach to treatment with this population of children (Rogers et al., 2011; Suarez et al., 2014).

Current Trends in Feeding Interventions

Several categories of feeding interventions exist in the current literature, and most feature some form of a parent training component. Feeding interventions appear in many different formats, including individually created and tested pilot programs; psychological interventions; specific protocols; multicomponent care, such as behavioral interventions, nutritional interventions, family training, and interdisciplinary teams; and intensive programs that may use multiple sessions, longer treatment times, and/or be multiple days and weeks in length.

Sharp and colleagues (2017) conducted a systematic review and meta-analysis on outcomes from intensive, multidisciplinary intervention programs for children with feeding disorders. Eleven studies were reviewed in which participants were young children with complex medical histories who experienced persistent feeding concerns requiring enteral or oral supplemental nutrition. Intensive behavioral intervention and tube weaning were the most common intervention approaches used in the studies, and various forms of parent training were used in all studies reviewed. Positive outcomes and treatment were associated with increased oral intake, reduced parenting stress, and reduced maladaptive mealtime behaviors, concluding that intensive multidisciplinary treatments benefit this population.

Lukens and Silverman (2014) conducted a systematic review to evaluate the effectiveness of psychological interventions for children with feeding difficulties. Thirteen studies were reviewed in which participants included children from birth to 18 years of age with pediatric feeding problems excluding eating disorders, such as anorexia or bulimia. Five main categories of successful psychological interventions emerged from their review: behavioral intervention; nutritional intervention; oral motor intervention; other psychological intervention, such as psychoeducation and family therapy; and caregiver teaching intervention. Two of these categories involved some type of parent training concluding that the use of multicomponent care is beneficial for treating children with feeding problems.

Even though both of these reviews encourage intensive, multicomponent, and interdisciplinary treatment of pediatric feeding delays or disorders, both suggest the need for further research. The length of the programs is of concern since each program has different guidelines and methods (Sharp et al., 2017). The majority of the current programs in the literature stress the use of intensive programs with many being on an inpatient basis, which raises cost concerns for families (Lukens & Silverman, 2014). The final limitation of these studies is the assessment of longevity of intervention protocols, including the parent training aspects (Lukens & Silverman, 2014; Sharp et al., 2017). While multicomponent care seems to be the standard of care, research does not provide much insight into the carryover and effectiveness of intervention taught to families on a long-term basis (Sharp et al., 2017).

With occupational therapy practice moving toward more holistic and family-centered care, an increase in parent training with traditional therapy interventions has been on the rise to treat pediatric feeding delays and disorders (Frolek Clark & Kingsley, 2020). A significant amount of research has shown that instruction-based interventions, including parent training with feeding, can result in improved parent-child interactions, decreased picky eating, and decreased maladaptive mealtime behaviors (Frolek Clark & Kingsley, 2020). Adamson et al. (2013) used an intervention from the Hassle Free Mealtimes Triple P protocol in which parents participated in group-based intervention for 8 weeks with at least one 1-hr session per week. Their protocol included one follow up assessment at 6 months post intervention. The parents in the intervention group showed significant positive changes in the child's and parent's behaviors at mealtimes, an increase in parenting self-efficacy in managing their child's feeding concerns, and significant changes to mealtime diaries of their children when compared to parents in the waitlist control group.

The effectiveness of the Autism MEAL Plan protocol was studied by Sharp et al. (2014). This protocol is a behavioral based training for parents of children with ASD and includes eight 1-hr sessions with no follow up assessment post intervention. The parent training sessions addressed various topics related to feeding interventions including behavior modification and promotion of self-eating behaviors. The study used a waitlist control design and had 10 families in the intervention group and nine families in the waitlist control group. The results showed a decrease in parental stress but no improvement in feeding skills with the children.

Another protocol studied by Sharp and colleagues (2016) tested the effectiveness of a manual-based and technology supported feeding program called Integrated Eating Aversion Treatment (iEAT). Twenty children 12 months to 6 years of age with a diagnosis of avoidant restrictive food intake disorder and their families were randomly sorted into equal intervention and waitlist control groups. A multidisciplinary team guided other professionals to administer intensive feeding behavioral strategies, through the use of a manual, at therapy meals that were conducted four times a day for five consecutive days. Parents were trained on site during this week, followed the manual protocol, and were invited back for follow up assessment 1-month post discharge. Children in the treatment group showed significant increases in bite acceptance, volume of food consumed, and a decrease in negative mealtime behaviors compared to children in the waitlist control group.

Owen and colleagues (2012) tested the effectiveness of an interprofessionally led parent training program. The caregivers of 30 children, 1–3 years of age, referred for moderate feeding issues, participated in four 90-min sessions over an 8-week period with a 1-month follow up. The results showed that feeding difficulties and parental behaviors were significantly less at post intervention compared to pre intervention. The results also showed the majority of the parents understood how to make positive changes in their child’s eating patterns post intervention.

These studies using parent training as a core component taught parents various topics in didactic formats (Adamson et al., 2013; Owen et al., 2012; Sharp et al., 2014; Sharp et al., 2016) and used homework assignments (Adamson et al., 2013; Owen et al., 2012; Sharp et al., 2014) to foster generalization of skills in the home. The studies that conducted follow up testing (Owen et al., 2012; Sharp et al., 2014), with the longest gap post intervention being 6 months (Adamson et al., 2013), showed improvement in feeding skills and parent satisfaction with progress. However, researchers advise and strongly suggest more detailed follow up research be conducted to verify the longevity of feeding interventions using parent training.

Matson et al. (2009) discuss parent training as a critical element to therapy techniques, specifically for generalization of skills to the home and community, yet they recognize limited follow up research for duration and generalization of programs that leads to mixed results for the effectiveness of the programs. If the parent-child relationship is hindered by increased maladaptive behaviors at mealtimes, and if families are given strategies to alter meal-based routines, then occupational therapists need to explore and understand if these strategies are affecting family meals and the parent-child relationship.

Method

Population

The population for inclusion in this study was parents of children who had been diagnosed with a feeding delay(s) or disorder(s) and were currently receiving feeding therapy that included home or parent training strategies. The children could be no older than 13 years of age and could not have a diagnosis of anorexia or bulimia. English was reported to be the primary language of the parents, and there were no exclusions based on race, gender, age, religion, sexual orientation, or marital status.

Initial solicitation of the participants occurred through pediatric feeding-related social media groups and professional networking. Following this initial solicitation, snowball sampling was used to obtain the remainder of the participants. The participants recruited through social media had access to the internet posting explaining the study and a hyperlink to the survey. The local participants were invited to participate though a printed flyer explaining the study and providing a web address to access the survey. After the participants read the initial invitation, they were asked to click a link or visit a web address to take the survey. As this was an online survey, consent was presented prior to taking the survey at the web address and consent was implied when each participant clicked the link to take the survey. Participation in the survey was voluntary, and the participants were able to withdraw from the survey at any time without consequence.

Research Design

This research was reviewed and approved in accordance with Quinnipiac University's IRB procedures for research involving human subjects. This study used a quantitative, investigator developed, web-based survey that used closed-ended, multiple choice, and Likert-scale questions. The survey for this study was open for 3 months to collect data. The first section of the survey collected simple demographic information from the participants, including the age, gender, and diagnoses of the child. No identifying information was collected from any participant on the questionnaire. The next section of the survey included Likert scale and multiple-choice questions designed to capture parent perceptions, which yielded numerical and quantitative data. These questions measure the type and subjects of home training interventions used, how easily the parent was able to administer these strategies, and how these affected the family. The survey questions were developed based on information obtained from *The Occupational Therapy Practice Framework* (AOTA, 2014) and extensive review of the current literature findings from credible scholarship, such as peer-reviewed articles. To ensure that the questions captured the intended information, they were piloted prior to implementation with content experts. Refer to Table 1 for a sample list of questions. Modifications to the questions were made in response to expert feedback. While this was not a mixed methods study, the respondents were given the opportunity to leave commentary on select questions.

Table 1

Sample Survey Questions

Exclusion Questions
Is your child younger than 13 years old? ____ Yes _____ No
Has your child(ren) been diagnosed with anorexia or bulimia? _____ Yes _____ No
Has your child(ren) been diagnosed with a feeding delay/disorder? _____ Yes _____ No
Do you currently receive and implement home training for your child(ren) with a feeding delay/disorder? _____ Yes _____ No
Sample Demographic Questions
What is the age of your child(ren)? _____ newborn to 11 months _____ 1–3 years _____ 4–7 years ____ 8–13 years
Please select your relation to your child(ren) with a feeding delay/disorder. _____ Mother _____ Father _____Grandparent _____Other relative _____ Foster parent

_____ Legal guardian ______ Other
Are the therapists/professionals working with your child certified as feeding specialists? _____ Yes _____ No _____ Not Sure
Is your child(ren) receiving their feeding therapy from a program/organization that offers a specialized feeding program? _____ Yes _____ No _____ Not sure
Sample Family Training Questions
How often are you given home training to help with your child's feeding delay/disorder? _____ Frequently (every other session) _____ Often (every 3–5 sessions) _____ Seldom (every 6–10 sessions) _____ Never
How easily are you able to understand the home training provided to you? _____ Very easily understood _____ Somewhat easily understood _____ Neither easily understood nor difficult to understand _____ Somewhat difficult to understand _____ Very difficult to understand
How comfortable do you feel using home training provided to you? _____ Very comfortable _____ Somewhat comfortable _____ Neither comfortable nor uncomfortable _____ Somewhat uncomfortable _____ Very uncomfortable
If somewhat or very uncomfortable using the home training, why?
How often do you feel you need additional support, if any, to be able to implement home training received? _____ Frequently _____ Often _____ Seldom _____ Never
What topics of home training for feeding do you think have positively impacted mealtimes with your child(ren)? _____ Diet recommendations _____ Mealtime routines _____ Sensory strategies _____ Mouth/facial exercises (oral motor skills) _____ Other _____ None _____ Behavior modifications (strategies to alter your child's behavior) _____ Specific feeding techniques (Sequential Oral Sensory [SOS], Beckman Oral Motor, etc.)
How positively or negatively do you think home training has influenced your relationships with your child(ren)? _____ Very positive _____ Somewhat positive _____ Neither positive nor negative _____ Somewhat negative _____ Very negative
How often do you feel it necessary to alter the home training given to you in order to meet the needs of your family? _____ Frequently _____ Often _____ Seldom _____ Never
How often does your feeding therapist/professional check with you regarding your understanding and use of home training when home training is given? _____ Frequently (every or every other session) _____ Often (every 3–5 sessions) _____ Seldom (every 6–10 sessions) _____ Never
Do you feel supported by your child's feeding therapist/professional? _____ Yes- If so, please explain why. _____ No- If not, please explain why not.
Is there anything else you would like to report related to home training and your child's feeding delay/disorder?

Data Collection and Analysis

This research study was conducted using the online survey platform SurveyMonkey. Once all the data were collected, the results of the survey were analyzed through basic descriptive means, as well as through analysis completed through the SurveyMonkey website. The closed-ended section of the questionnaire was analyzed to determine frequency of responses and overall trends in the data. Data from SurveyMonkey analysis were used to make charts and graphs.

Results

One hundred and eighty-seven individuals began the survey, and 108 of those individuals completed it to the final question. The first four questions of the survey were exclusionary questions that sought to filter out the participants that did not meet the inclusion criteria. If the respondents' answers to these questions did not meet the inclusion criteria for the study, their survey was ended, and they were exited from the survey.

The following sections will describe the results from the survey. As not all of the participants completed the entire survey, the number of respondents may be variable.

Demographic Results

Questions 5 through 11 gathered basic demographic information about the respondents and their families. Frequency distributions for the demographic variables are presented in Table 2. The majority of the respondents reported to be mothers (89.58%) and reported having a child with a feeding delay or disorder who was between 1–3 years of age (55.97%). The majority also reported their child had been receiving therapy for their feeding delay or disorder for two distinct time periods: less than 6 months (34.53%) or 1–3 years (33.09%). It was reported that many of these children were being seen by feeding specialists (70.50%), and close to half were receiving therapy from programs or organizations that offered specialized feeding programs (49.64%).

Table 2

Frequency Distribution for Demographic Variables

Variable	n	%
Age of child(ren) (n = 134) *		
Newborn to 11 months	25	18.66
1–3 years	75	55.97
4–7 years	32	23.88
8–13 years	10	7.46
Relation to Child(ren) (n = 144) *		
Mother	129	89.58
Father	3	2.08
Grandparent	1	0.69
Other relative	1	0.69
Foster parent	5	3.47
Legal guardian	2	1.39
Other	3	2.08
Diagnoses (n = 141)		
Cerebral Palsy	14	9.93
Down syndrome	7	4.96
Autism	12	8.51
Premature birth	46	32.62
Developmental delay	68	48.23
Failure to thrive	66	46.81
Cleft lip	2	1.42
Cleft palate	7	4.96
Aspiration	40	28.37
Sensory processing disorder	30	21.28
Feeding tube dependence (g-tube, j-tube, gj-tube, NG tube)	82	58.16
Delayed oral motor skills	64	45.39
Other	70	49.65
Professionals working with child (n = 139)		
Occupational therapist	95	68.35
Speech therapist	103	74.10
Dietician	47	33.81
Nutritionist	62	44.60
Psychologist	10	7.19
Pediatrician	96	69.06
Gastroenterologist	87	62.59
Pulmonologist	26	18.71

Other	32	23.02
Feeding Specialists (n = 139)		
Yes	98	70.50
No	12	8.63
Not sure	29	20.86
Specialized Feeding Program (n = 139)		
Yes	69	49.64
No	38	27.34
Not sure	32	23.02
Length of therapy services (n = 139)		
Less than 6 months	48	34.53
7–11 months	28	20.14
1–3 years	46	33.09
More than 3 years	17	12.23

Note. *Ten participants did not answer a specific question, resulting in a difference in participant number demographic data. Please see the *Limitations* section for more detail.

The majority of the children who were being seen by a feeding specialist were treated by speech and language pathologists (74.10%), occupational therapists (68.35%), pediatricians (69.06%), and gastroenterologists (62.59%). The respondents added 32 additional professionals under *other* for this question, five of which were mentioned four or more times and included (a) physical therapist (n = 8), (b) ear nose throat specialist (ENT) (n = 7), (c) cardiologist (n = 5), (d) neurologist (n = 5), and (e) endocrinologist (n = 5). The majority of diagnoses given to the children of the respondents were (a) feeding tube dependence (58.16%), (b) developmental delay (48.23%), (c) failure to thrive (46.81%), (d) delayed oral motor skills (45.65%), and (e) premature birth (32.62%). The respondents added 70 additional diagnoses under *other* for this question, seven of which were mentioned three or more times and included (a) dysphagia (n = 10), (b) hypotonia (n = 6), (c) gastroparesis (n = 3), (d) oral aversion (n = 9), (e) laryngeal cleft (n = 3), (f) avoidant restrictive food intake disorder (n = 3), and (g) congenital heart defects (n = 7).

Trends in Home Training

Several questions examined current practice and trends with home training in feeding therapy, including topics, methods, ease of understanding, and ease of implementation. One hundred and thirty-five respondents reported that the top three topics of importance to be addressed in feeding therapy were the inability to eat well, which includes the use of lips, tongue, and chewing skills; the inability to handle different textures in the mouth; and the use of a feeding tube. See Figure 1 for all frequency distributions on important topics to be addressed in feeding therapy as identified by the caregivers. The top three methods of home training given were verbal instruction of skills, demonstration and modeling of skills, and handouts and worksheets describing skills, as reported by 130 respondents. The frequency distribution for all methods of home training given is reported in Figure 2. The top three topics addressed in feeding therapy were mouth and facial exercises, sensory strategies, and mealtime routines, as reported by 129 respondents. Complete frequency distributions for all topics addressed in feeding therapy are reported in Figure 3. Of 129 respondents, over half reported that the home training is very easily understood and a quarter reported it is somewhat easily understood. Of 128 respondents, over half reported they were very comfortable using the home training they are provided while over a quarter reported they were somewhat comfortable. See Figure 4 for complete frequency distributions for caregiver comfort level using provided home training.

Figure 1

Home Training Topics Identified as Important to Address (n=135)

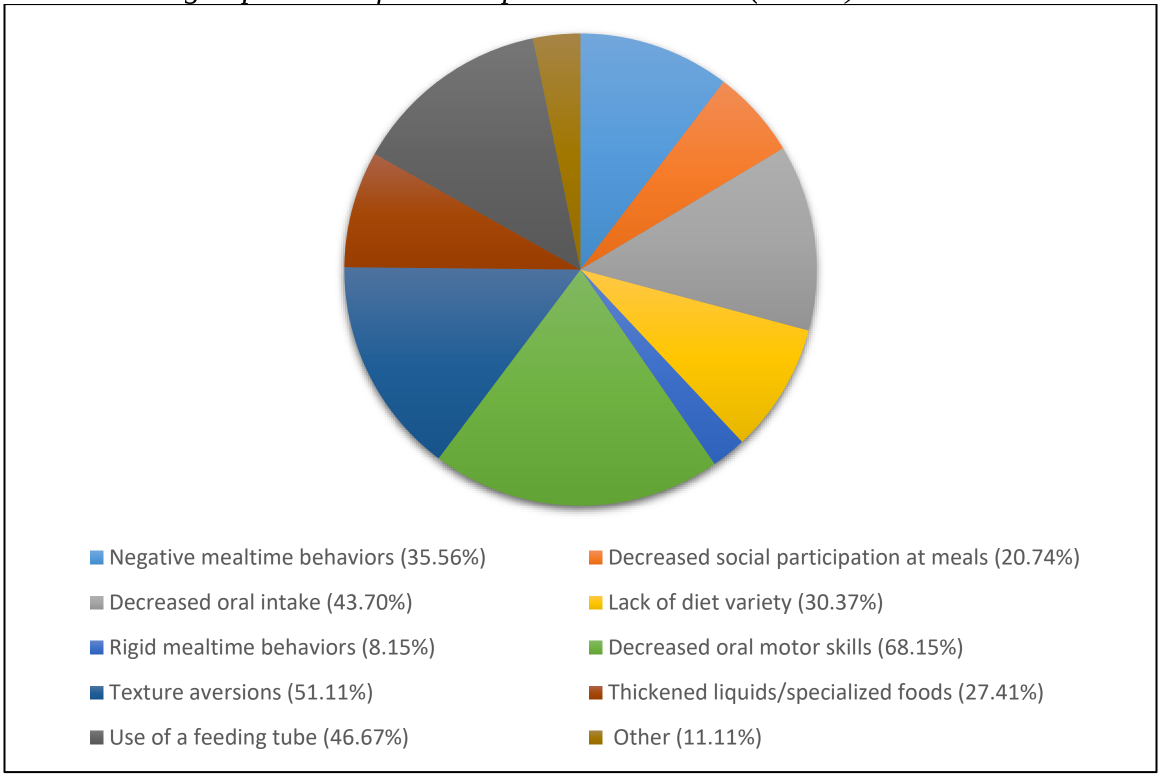


Figure 2

Methods of Home Training Received (n=130)

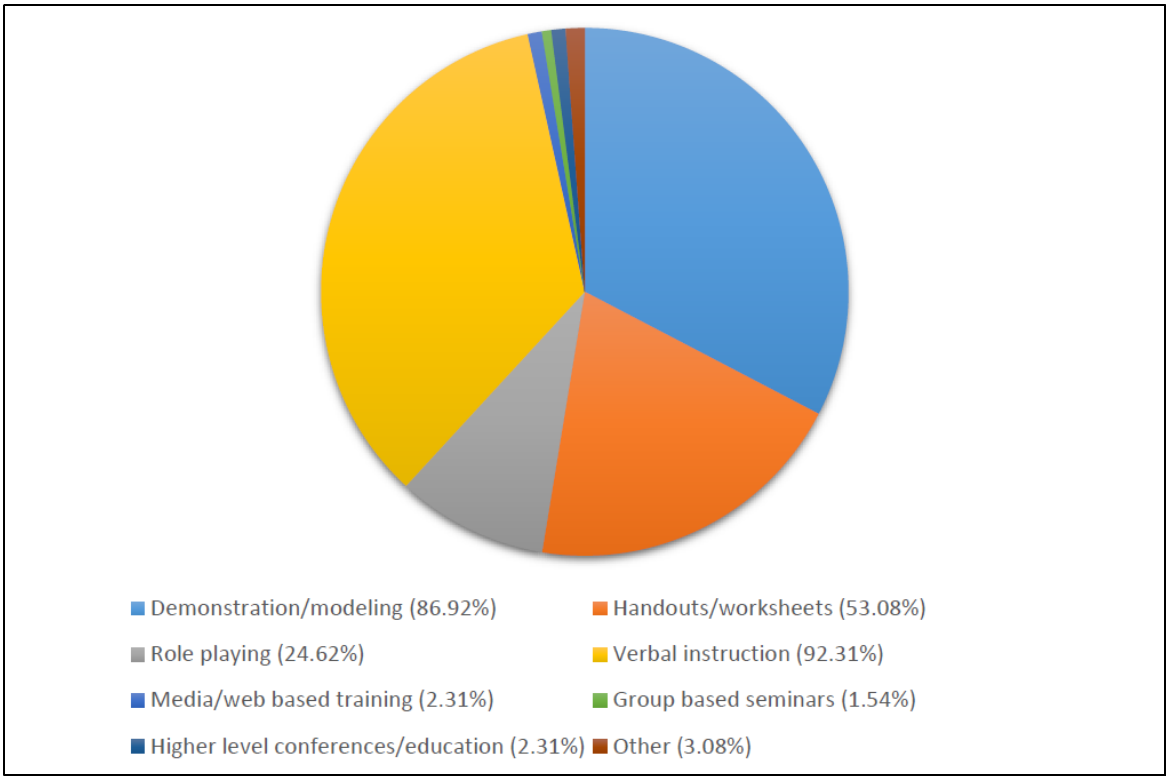


Figure 3

Home Training Topics Received (n=129)

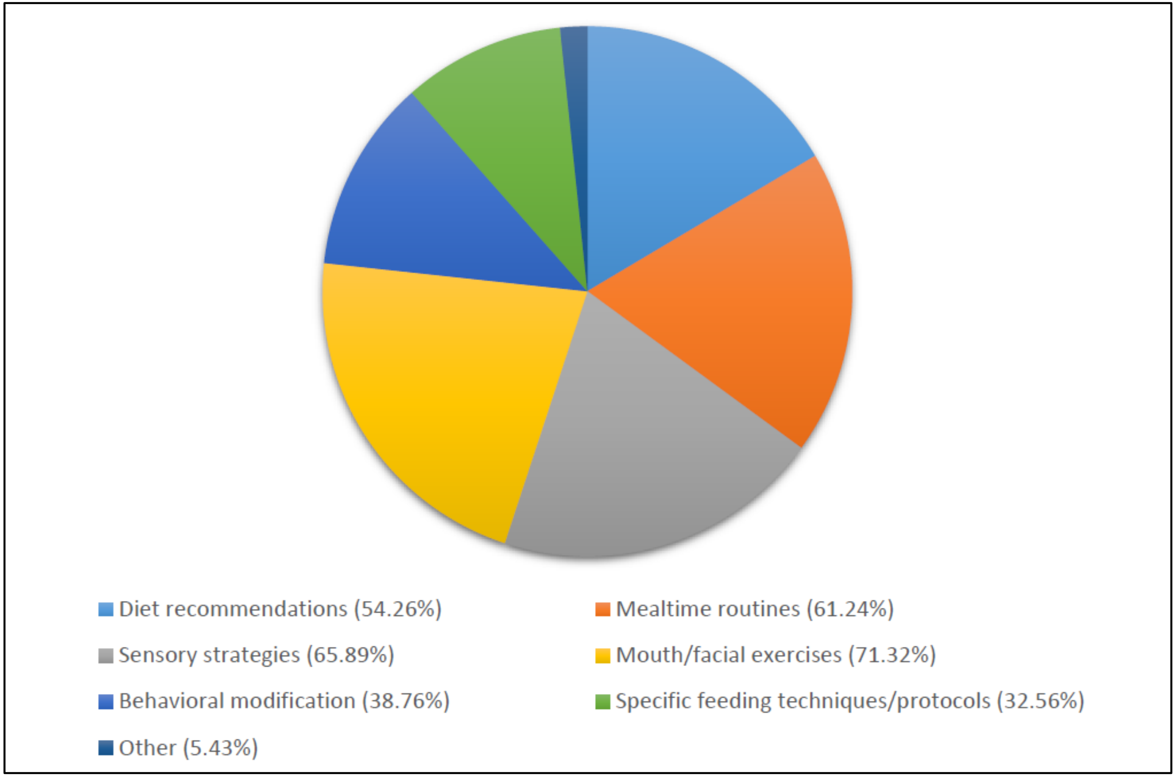
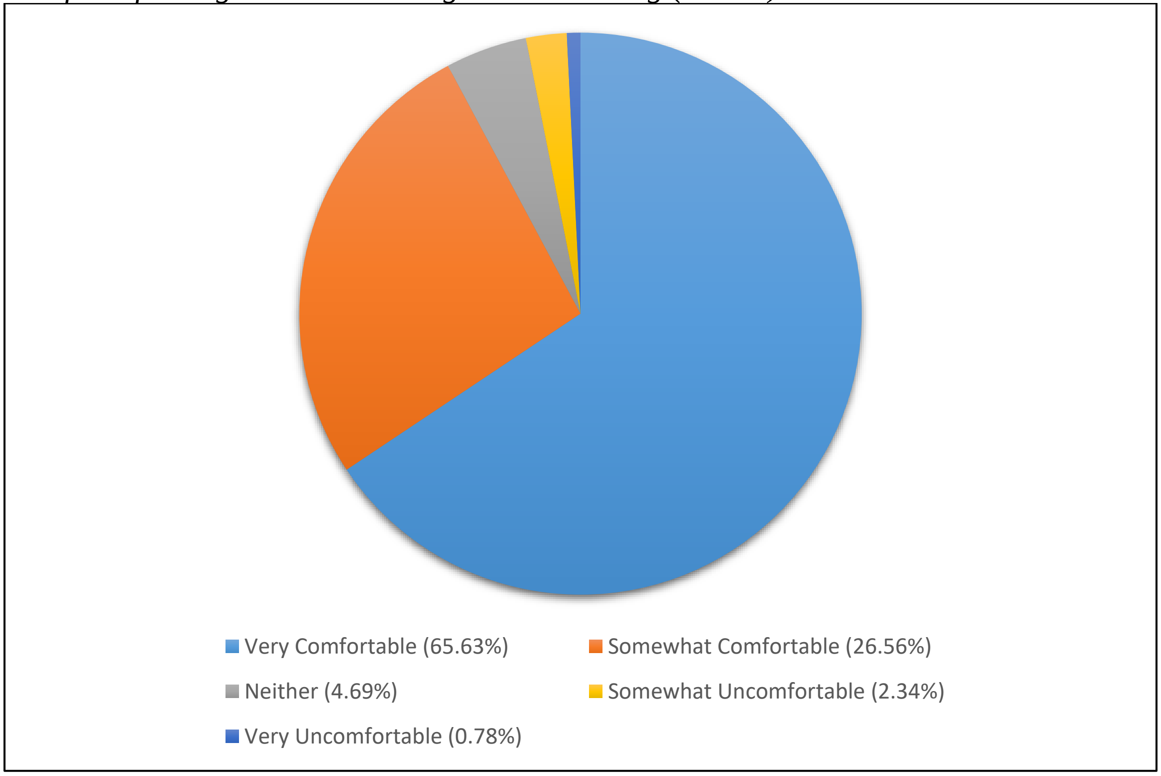


Figure 4

Comfort of Caregivers When Using Home Training (n=128)



Caregiver Perspective Related to Home Training

The remaining survey questions sought to examine the caregiver perspective in relation to their feelings and perceived barriers and additional supports related to treating their child with a feeding delay or disorder. The top four barriers to implementing home training, as reported by 126 respondents, were (a) feelings of frustration or being overwhelmed when using home training for feeding, (b) limited time affecting family mealtimes, (c) impact on relationship with the child who is receiving feeding therapy, and (d) impact on relationship with other children in the family. Frequency distributions for all potential barriers are presented in Figure 5. The same respondents reported needing additional support to implement home training often (31.75%) and seldom (38.10%). The top four additional resources that would help with implementation of home training, as reported by 120 respondents, were (a) additional support from current therapist(s) and professional(s), (b) additional support from other parents experiencing the same issues, (c) additional support from spouse, and (d) additional support from extended family members. Four respondents commented in the other section, regarding additional resources, that visits in their home would be beneficial to implementing home training for feeding. Frequency distributions for all potential additional resources are listed in Figure 6. Of those 120 respondents, 40% reported they would be very likely to use an online resource to supplement home training for treating their child's feeding delay or disorder, while 28.33% reported they would be somewhat likely to use an online resource, and 26.67% were not sure if they would use an online resource.

Figure 5

Potential Barriers (n=126)

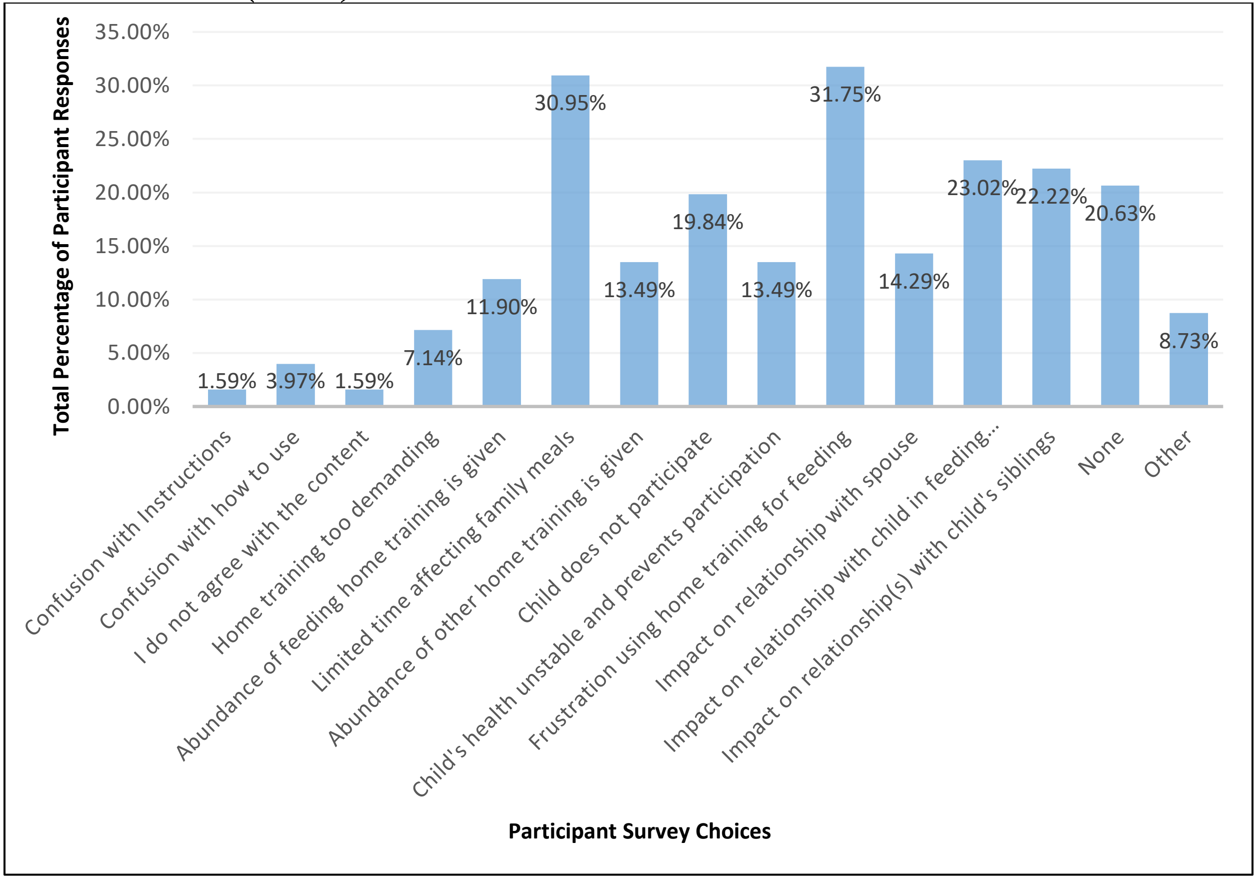
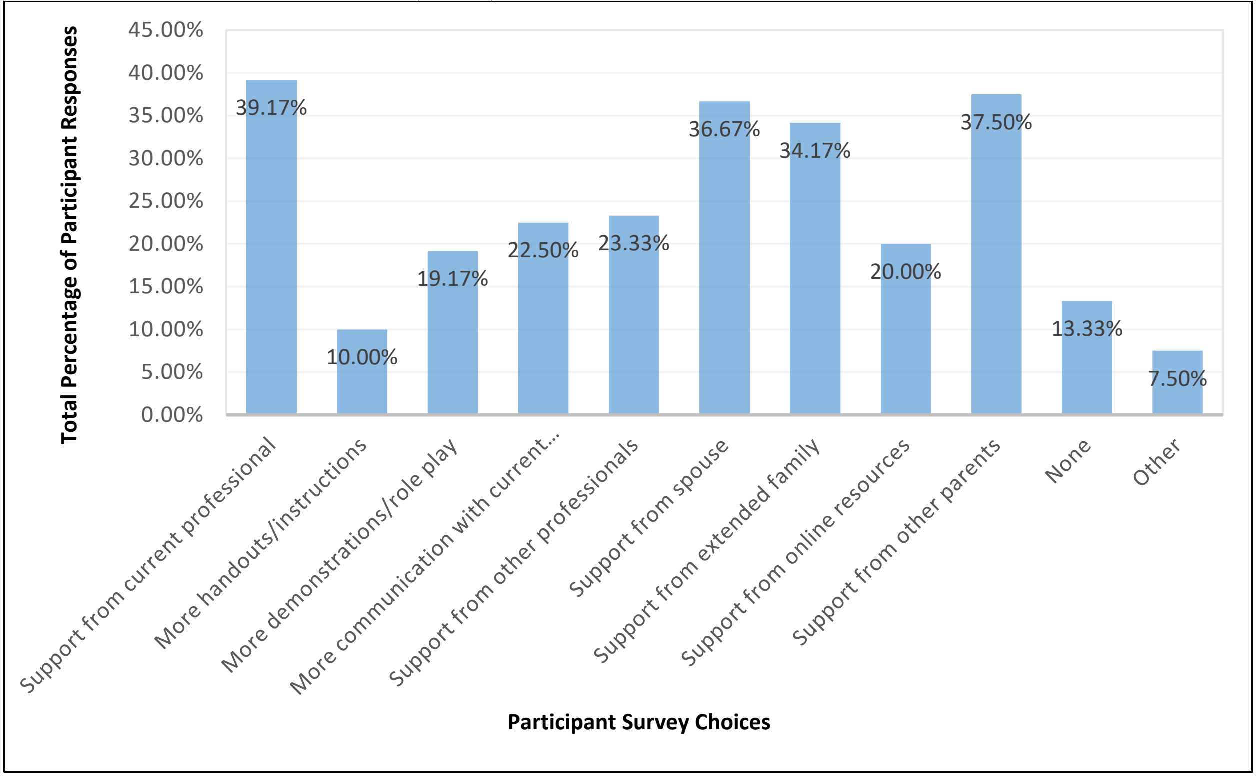


Figure 6

Potential Additional Resources (n=12)



One hundred and eighteen respondents reported the top three topics of home training that have positively impacted mealtimes with their child were mouth and facial exercises (55.93%), sensory strategies (55.08%), and mealtime routines (50.85%) and that the home training has been very (35.59%) or somewhat (31.36%) positive in influencing a change in their child's behaviors at mealtimes. One hundred and seventeen respondents reported the home training was neither positive nor negative (34.19%) or was very (28.21%) and somewhat (27.35%) positive with influencing the relationship with their child. The respondents often (50.43%) felt it necessary to alter the home training to meet the needs of their family. One hundred and nine respondents reported feeling nothing (23.85%), hopeful (21.10%), nervous (21.10%), in control (18.35%), and confident (16.51%) when they did alter the home training. While 116 respondents reported feeling hopeful, overwhelmed, nervous, confident, and happy (25.00%) when given home training, 114 respondents reported feeling frustrated and overwhelmed when not given home training. Complete frequency distributions for feelings when given and not given home training are reported in Figures 7 and 8. One hundred and eleven respondents reported feeling hopeful (58.56%), happy (47.75%), confident (37.84%), empowered (36.04%), and in control (27.93%) when they were able to use the home training they received, and 110 respondents reported feeling frustrated (59.09%), overwhelmed (35.45%), and guilty (30.91%) when they were unable to use the home training they received.

Figure 7

Caregiver Feelings when Given Home Training (n=116)

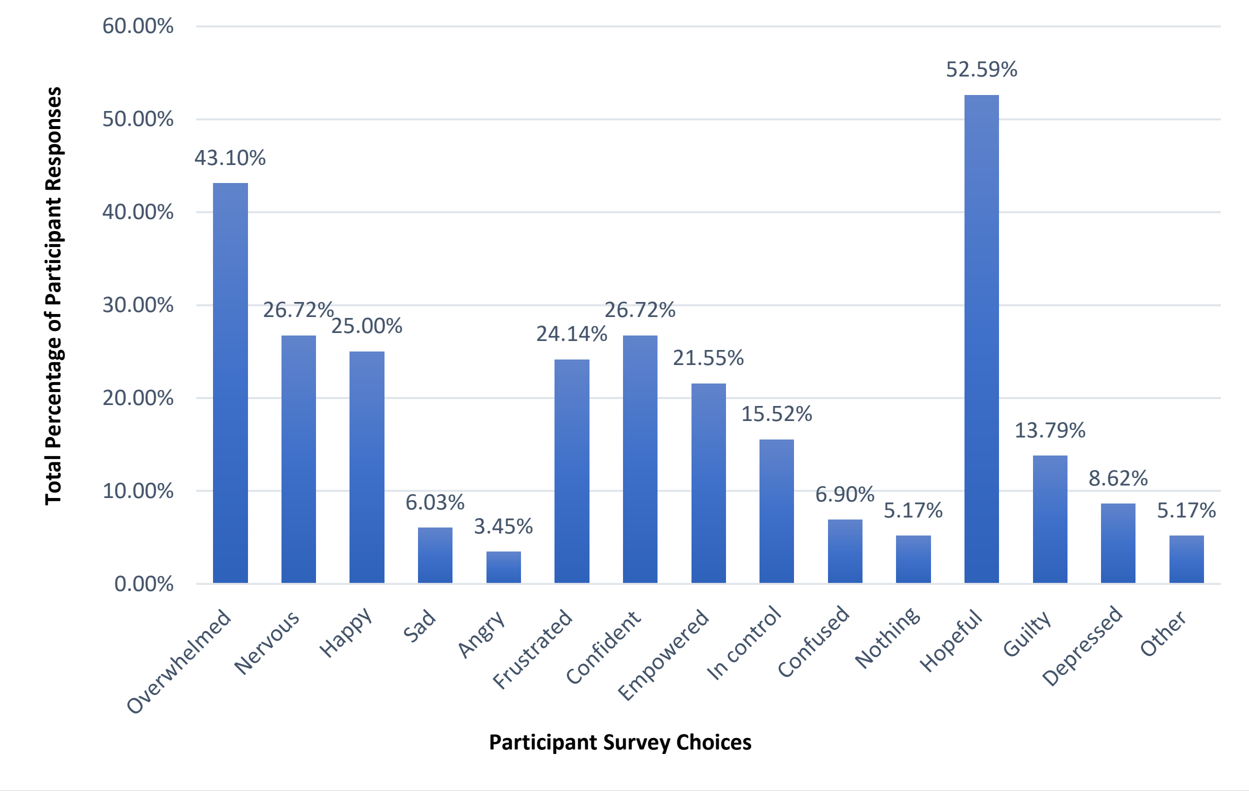
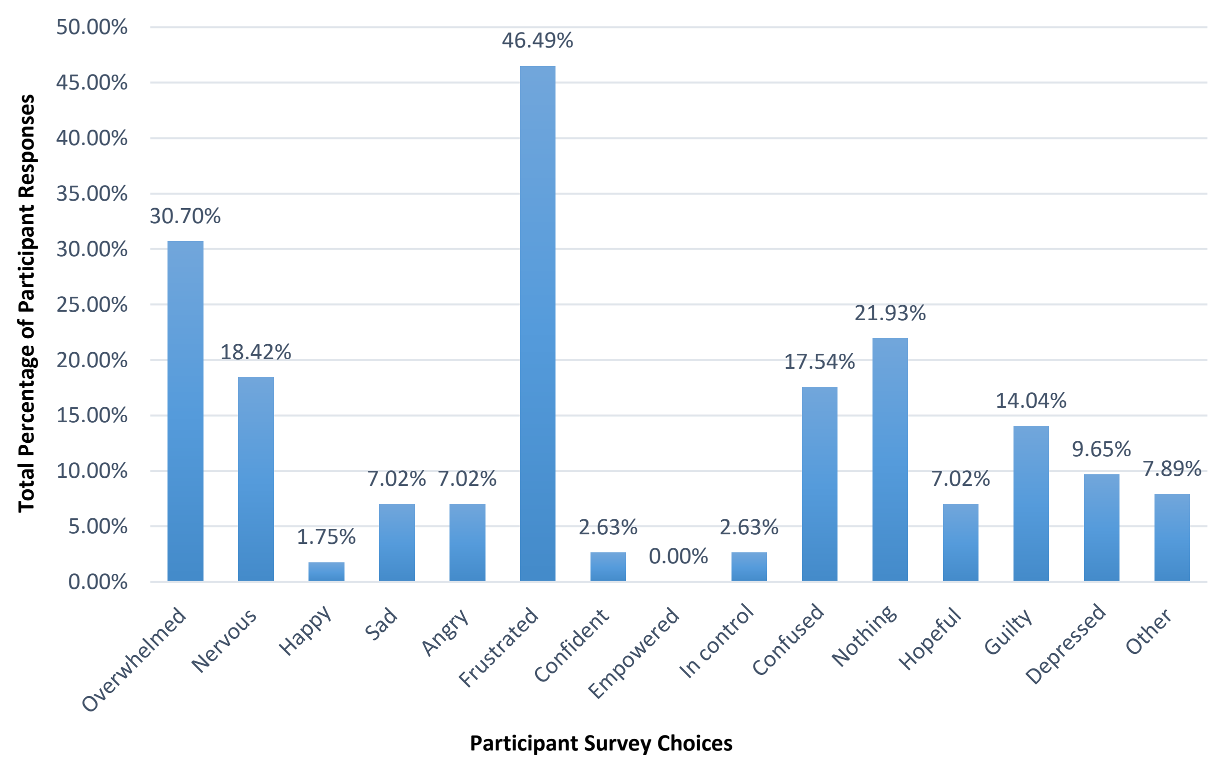


Figure 8

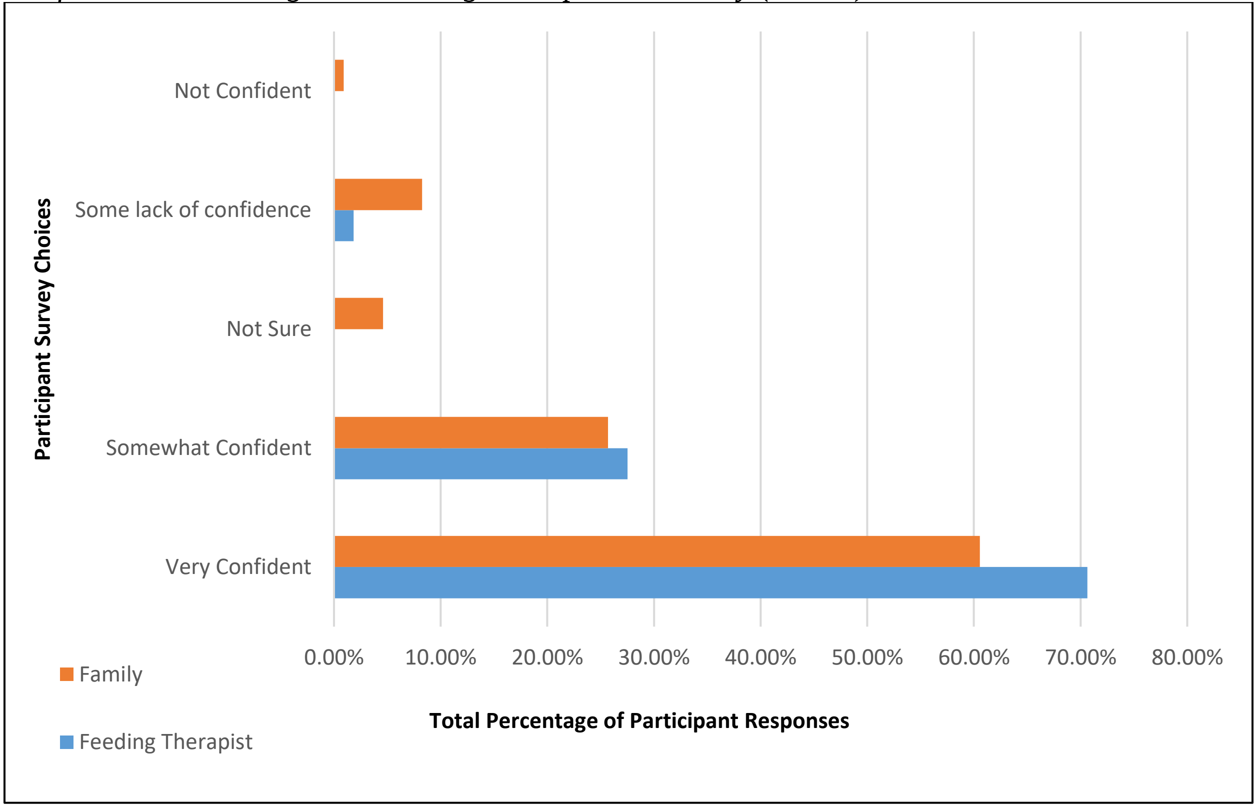
Caregiver Feeling when Not Given Home Training (n=114)



Of 109 respondents, 70.64% reported feeling very confident in their ability to advocate for their child’s feeding needs with their feeding therapist, 60.55% reported feeling very confident in their ability to advocate, and 25.69% reported feeling somewhat confident advocating for their child’s feeding needs with their family members and other caregivers. A comparison of confidence levels with advocacy is reported in Figure 9. Those 108 respondents who were able to speak up for their child reported feeling confident (39.81%), in control (31.48%), empowered (28.70%), nervous (27.78%), and frustrated (21.30%) when they did advocate for their child.

Figure 9

Confidence Advocating with Feeding Therapist vs. Family (n=109)



One hundred and eight respondents reported frequently (73.15%) hearing from their feeding professional regarding their understanding of the home training they were given and that they were very involved (73.15%) in communicating with their child’s feeding professional to set and modify goals as well as discuss their child’s progress. These respondents also reported feeling very comfortable (74.07%) communicating with their feeding professional about the home training they received, and 87.96% reported feeling supported by their feeding professional.

Additional Comments

The respondents were provided with an opportunity to elaborate on how they felt supported or not supported by their feeding professional and were invited to add additional commentary in relation to their child’s feeding delay or disorder at the end of the survey. The majority of the respondents provided commentary on either feeling supported or not supported, while a few provided general additional commentaries about their child’s feeding delay or disorder. This will be explored further in the discussion section.

Discussion

The Use of Home Training

Several survey questions supported current research trends related to describing the home training that was currently being given to the families. Many types of the feeding interventions and protocols that exist in the current literature feature some form of parent training and were supported through participant responses. Descriptive statistics revealed that the main methods of home training being distributed to families are verbal instruction, demonstration, and worksheets and handouts. The primary topics being addressed and the types of professionals working with these children support previous research indicating that an interdisciplinary team and multicomponent plan approach are most beneficial to treating pediatric feeding disorders (Lukens & Silverman, 2014; Owen et al., 2012; Sharp et al., 2016; Sharp et al., 2017). Overall, the caregivers reported feeling hopeful, nervous, and confident when given home training and feeling frustrated, overwhelmed, and nervous when not given home training. These feelings help support the need for home training as a vital component of treating children with feeding delays or disorders.

Additional Supports

While the majority of the respondents reported feeling supported by their feeding professionals, they also reported frequently needing additional support. The respondents indicated that they would benefit from additional support from their spouse and extended family members, their current feeding professional, other parents experiencing similar situations as their own, and visits in their home.

Support from Spouse

The majority (89.5%) of the respondents for this study were mothers. In the United States, many mothers often stay at home with children, and these numbers increase when a child has a disability (Steinfeld & Frias, 2014). Although this was not specified in the survey questions, there is a difference in the perception of what support means, and it can be formal or informal (Tadema & Vlaskamp, 2009). Formal supports are services provided by professionals, while informal supports include social supports from family members and friends (Tadema & Vlaskamp, 2009). A potential barrier that the respondents frequently identified was the effect home training has on the relationship between the caregiver and the child receiving the therapy as well as the relationship between the caregiver and the siblings to the child with a feeding delay or disorder. As seen in previous research examining the perspective of mothers raising children with feeding delays or disorders, these mothers often experience feelings of increased stress (Rogers et al., 2011; Suarez et al., 2014), which could lead to the increase in responses that additional support from a spouse or extended family members may be beneficial. These caregivers may be identifying that they need informal support from family members. One respondent reported, “Family [and] friends don’t understand my child’s diagnosis. No one else helps with mealtime or feeding. People think I can starve him and he will eat.” Family and friends who support these caregivers by helping to consistently implement home training as well as allow more time for the caregivers to spend with other children in the home would be seen as an additional informal support.

Support from Current Feeding Professional

The majority of the respondents reported feeling supported by their current feeding professional, frequently communicating with the professional about the home training received, being very involved communicating with them about their child’s goals and progress in feeding therapy, and feeling very comfortable communicating with them. Yet, with all of these positive responses, these respondents also reported that receiving additional support from their current feeding professional would be beneficial.

There may be many reasons why the need for additional support from the current feeding professional is present.

One reason for the increase in these responses may be attributed to feelings of support when a family chooses to alter the home training to meet their needs. Half of the respondents reported needing to alter the home training and feeling hopeful and nervous when they altered the home training. Primarily, the respondents felt happy and confident when they were able to use the home training given but felt frustrated and overwhelmed when unable to do so. If the caregivers alter the home training and are then unable to use what has been altered, they may experience negative feelings and, thus, feel the need for additional support from their feeding professional.

An additional reason for the increase in these responses may be driven by the desire for home training also to address parental stress and coping skills. One respondent reported, "I often [felt] like we [got] too many recommendations at once. It was overwhelming," while another respondent stated "feeding 'stuff' is really hard to parent through." Two respondents stated, "I think a part of home training should be to give parents coping skills," and that they would like "additional support from anyone who could add more time to my day." Occupational therapists have the responsibility to offer family-focused interventions and are able to facilitate participation in occupations, such as feeding and eating, for the whole family. Implementing family-centered care in this manner can help to improve the relationships between all the family members involved (Wilkes-Gillan & Bourke-Taylor, 2017). Occupational therapists who offer formal support to the family unit are another vital component of home training to treat pediatric feeding delays or disorders.

An additional reason for the increase in these responses may be the desire to have visits conducted in the home to provide a different level of care for the child. Through additional commentary, the respondents identified having the feeding professional conduct sessions in the home as an additional resource or support. This would achieve not only a more holistic and family-centered treatment approach, but also support for the family in succeeding in their natural environment. Another concern expressed by the respondents was that their child does not always participate in home training in the home. One respondent stated, "during therapy he participates & responds to the games and techniques [but] at home he refuses to participate; nothing works." This creates a separate issue to be addressed in the child's treatment plan and may help justify the need for home visits.

A final reason for the increase in these responses may be a desire to have additional advocacy to increase support from extended family members. The respondents reported feeling confident, in control, and empowered when able to advocate for their child with a feeding delay or disorder. Almost all of the respondents reported feeling very to somewhat confident in their ability to advocate for their child with their current feeding professional. This number dropped by approximately 12% when the respondents were asked if they felt confident to advocate for their child with family members and other caregivers. This decrease in confidence may lead one to decide that the primary caregiver may be seeking additional support from the current feeding professional to ensure consistency in treatment for the child and to validate the primary caregivers concerns for the child with a feeding delay or disorder.

Support from Other Parents

Another area for additional support identified by the respondents was the desire to have more support from other parents experiencing similar situations with their child with a feeding delay or disorder. The majority of the respondents were recruited from social media support groups related to pediatric disorders that affected feeding and eating, showing that online support groups are used frequently. These groups are established by other parents who often do not wish to have therapists as members of the group, indicating they are informal supports and lack structure. However, a little over half of the respondents stated they would be somewhat or very likely to use an online resource to supplement treating their child's feeding delay or disorder. Informal supports are often not valued as highly as formal supports (Tadema & Vlaskamp, 2009), leading occupational therapists to consider creating and using online resources as a formal support for these families. If more online resources and formal supports were available that were created and lead by trained professionals while offering a safe space for parents to communicate together, it may help achieve this desire for additional support from other parents with children with feeding delays or disorders.

Relationship with Child

Most of the respondents reported that home training, in general, made a positive impact on their relationship with their child, and many reported that working on mouth and facial exercises, sensory strategies, and mealtime routines positively impacted their child's behavior at meals. Other respondents reported home training had neither a positive nor negative impact on their relationship. This distinction in responses could be attributed to the increased levels of stress experienced by the caregivers and the possible negative feeling that may be associated with this stress. When examining the barriers listed, many of the respondents reported that barriers impacted not only the relationship with the child with a feeding delay or disorder affected, but also the relationship with the other children in the household. This might be why caregivers are requesting additional support from extended family members, so that they might have more time to spend with their children. One caregiver stated that home training was "sometimes too time consuming because of other children and schedules," while another stated "we prioritize feeding homework rotationally with his various other priorities." Caregivers may be seeking additional supports in order to spend time with their children that do not involve home training to strengthen those relationships.

The relationship between the caregiver and child may also be affected well before a feeding delay or disorder has been identified if the child exhibited difficulty with attachment and bonding at an early age. This survey showed that half of the respondents' children receiving feeding therapy were between 1–3 years of age. If a child was experiencing feeding difficulties as an infant, those difficulties may have impacted the bonding and attachment phase of development. Early bonding and attachment rely heavily on the ability of the child and caregiver to communicate openly with each other, and, if an infant's cues are misinterpreted, it could lead to the beginnings of maladaptive attachment (Wilkins, 2010). If an infant was withdrawn from feeding at an early age, the caregiver may have reacted differently because of stress from the child's feeding issues, thus leading to an attachment so close it borders on obsession or a distanced attachment, both affecting the relationship with the caregiver and child (Wilkins, 2010). It is possible that the negative feelings expressed through this survey when not given home training or when looking at the relationship with the child at meals are present because of increased parental stress and how attachment and bonding were affected in infancy.

Feeling Supported

The respondents were provided with an opportunity to elaborate on how they felt supported or not supported by their feeding professional and were invited to add additional commentary in relation to their child's feeding delay or disorder at the end of the survey. Three significant data points that emphasized feeling supported by their feeding professional emerged: the ability of the professional to adapt and modify treatment to meet the needs of the child, good communication through phone calls and texts outside of treatment sessions, and being a quality listener. These are reflected in the respondents' following statements: "Everyone is willing to modify their approach based on our conversation," "she listens and modifies training based on what we are seeing with my son's progress," and "she reaches out between sessions." When making comments, a few of the respondents emphasized not feeling supported by their feeding professional when there was limited to no contact with their feeding professional. This is reflected in the respondents' following statements: "We don't speak often" and "we do not see our feeding person frequently enough."

Respondent commentary related to the child's feeding delay or disorder also revealed the following: the need for different professionals to communicate collaboratively on a child's feeding concerns, the need for home training to also cover coping skills for parents, and the need for feeding therapy to start when the child is at a younger age. This is reflected in the respondents' following statements: "It is very hard sometimes when therapists don't agree or read each other's reports" and "therapy [was] not supported at a young enough age to make a difference." Knowing how early attachment and bonding can be impacted at an early age further strengthens the needs for early identification and intervention of feeding delays or disorders as well as parental support.

Implications for Occupational Therapy Practice

The results indicate a need for continued support and follow up for these caregivers in different forms. As feeding and eating is a co-occupation between caregivers and the child with a feeding delay or disorder, occupational therapists have an obligation to support this important relationship and occupation (AOTA, 2014; Olson, 2004). The need for occupational therapists to listen, communicate, and practice holistic, individualized, and family-centered care is vital and adds to the positive feelings associated with being supported. This data shows a glimpse of traits that should be exhibited by professionals that may help alleviate some of the stress caregivers experience. It may be necessary to incorporate more topics of family training to address parental stress and health as well as family training techniques with more than just the primary caregiver of the household to help each family unit feel successful with their child's treatment and home training. It would also be beneficial to have an understanding of local support groups that may help address the caregiver's stress and give them an opportunity to connect with others experiencing the same issues. Occupational therapists can also create opportunities for families to connect with each other through community support groups or groups that are hosted in addition to the child receiving feeding therapy.

The incorporation of visits in the family's home or use of telehealth as a supplemental service could offer more support in the natural environment. AOTA has already started to implement telehealth services in other practice areas and currently recognizes telehealth as an "application of evaluative, consultative, preventative, and therapeutic services delivered through communication and information technologies" (Cason, 2012, p. CE-1). Telehealth has the unique advantage to improve access to services and specialists to facilitate collaborative and coordinated care (Cason, 2014) and would provide needed support in treating children with feeding delays or disorders in their homes.

The ability to streamline the early referral process would be beneficial to these families as well. Two major ways of being able to increase the early referral process would be through education to primary care professionals and for occupational therapists to join the primary care arena as described in the primary health care model. First, occupational therapists can educate those primary care professionals on the role of occupational therapy in primary care (Donnelly et al., 2013), specific information related to feeding delays and how to identify those delays, the integration of an occupational therapist to the primary care team, and the potential services an occupational therapist could bring to the team (Donnelly et al., 2013). Education like this can be done in many ways, including presentations, participating in educational rounds for the professionals, brochures, and information booths (Donnelly et al., 2013). Second, occupational therapists can join the primary care team working in doctors' and pediatricians' offices. Working in this position would meet the definition of primary care set by the Affordable Care Act to "address most of the needs of patients over a period of time, including family and community" (Metzler et al., 2012, p. 266). With occupational therapists working in this position, these early delays could be addressed more quickly than in the current referral process and in a holistic model incorporating the family as an active member of the decision-making team. Occupational therapists would be providing family-centered care, which would be billable and create a cost savings over time (Dahl-Popolizio et al., 2017). Occupational therapists have a unique set of skills that make them a valuable member of the primary care team, and they should continue to build and strengthen those alliances to ensure the inclusion of referrals through coordinated care (Metzler et al., 2012).

Study Limitations

One limitation of this study was the length of this survey as well as the intensity of responses for the questions, which may have caused several of the respondents to drop out at various points, as 187 individuals began the survey and only 108 completed it. Another limitation is that one of the exclusionary questions asked the parents if their child had been diagnosed with a feeding delay or disorder, and this question was set up through the SurveyMonkey software to exclude those participants who answered 'no.' Many times, caregivers are unsure or have not been explicitly told by a doctor that their child does, indeed, have a feeding delay or disorder, yet they are referred to and participate in feeding therapy. Parents experiencing increased stress could have potentially missed this information when it was given to them by their child's doctor. If this question had been worded differently or included a 'not sure' option and allowed for the participants to continue in the survey, it may have increased the overall response rate. Another limitation of this study was the lack of definition of what support means to each individual. If the question regarding what additional supports and resources might be helpful to the respondents included a further definition of informal or formal support, there may be a different variation of the answers and different descriptions of what exactly would be most helpful to the caregivers. Another limitation of this study is that the survey was created by the investigator and not standardized. A final limitation of this study was a technical error in the online survey. A single question was not activated for the survey and 10 participants did not answer that question, resulting in a different participant number in the demographic results.

Future Research

Future research should examine the use of home visits or telehealth as a supplemental service to feeding treatment and how this does or does not affect the overall outcome of home training for the child and family. The majority of the respondents for this survey were recruited through social media sites set up as support groups for caregivers with children who have feeding delays or disorders. Knowing how these sites and groups are used as support systems, what kinds of support are offered and/or gained, and what parents may be looking for in an online support group could help guide future practice and caregiver support resources. Since this study looked at quantitative data to define the caregivers' perceptions, it would be beneficial to conduct a mixed methods study to gain more robust information regarding caregiver perceptions. Finally, knowing what other professionals and parents know about early feeding delays and how to identify them could help guide the early referral process in order to begin treatment of feeding delays or disorders at an earlier age.

Conclusion

A survey was conducted to examine the caregivers' perspectives of home and caregiver training received and used to aid in treating their child's feeding delay or disorder and how this training has affected mealtimes with their child. The results revealed (a) that caregivers are receiving current and evidenced-based methods of home training to supplement treating their child's feeding delay or disorder, (b) that caregivers feel supported but feel they need more support, and (c) that relationships in the family are adversely affected. This survey also revealed caregivers of children with feeding delays or disorders are seeking more connections with other caregivers experiencing the same situations as they are and have identified a need for personal stress management and coping skills not offered as home training. Home training to help treat a child's feeding delay or disorder is a vital component of feeding treatment and helps support holistic and family-centred treatment models. Continuing to provide these treatment models is the way for feeding treatment to advance, and it can continue to do so by offering more family-focused treatment topics addressing the co-occupation of parenting, relationships and parent-child interactions, caregiver burden and stress management, and increased caregiver support in various forms.

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