

**IMPACT OF PEDIATRIC FEEDING DIFFICULTIES AND SUPPORT FOR
CAREGIVERS**

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy

by

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Certification of Approval

I certify that I have read *Impact of Pediatric Feeding Difficulties and Support for Caregivers* by Judy Le, Melissa Le, Tiffanie Tang, and Rosalie Whyte, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Abstract

The purpose of this research was to understand the impact of pediatric feeding difficulties on caregivers, the current supports that caregivers utilize, and additional supports that caregivers desire to help them manage the feeding difficulties of their children. A mixed-methods design was utilized to gather details about the feeding experience from the quantitative and qualitative perspectives. For the quantitative portion, demographics were collected, and the Feeding Impact Scale was utilized. For the qualitative portion, caregivers were asked open-response questions about their experience. Results include that families are moderately impacted and caregivers are moderately to highly impacted as a result of children's feeding difficulties, caregivers desire additional resources and education, and are interested in the opportunity to connect with other caregivers who share the same experience. Occupational therapists can help fill current gaps and meet caregivers' needs through targeting caregiver stress, providing education specific to feeding difficulties, facilitating peer support groups, and advocating for caregivers' needs. This would support improved occupational engagement of caregivers in caregiving and non-caregiving occupations and can allow for an improved feeding experience.

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Impact of Pediatric Feeding Difficulties and Support for Caregivers

In establishing a consensus definition and conceptual framework on pediatric feeding disorders, Goday et al. (2019) defined them as “impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction” (p. 124). Pediatric feeding disorders are estimated to impact 25% of typically developing children, and 80% of children with disabilities (Manikam & Perman, 2000). While the effects of feeding difficulties on children are important, caregivers are also impacted by their child’s feeding difficulty. Various impacts of feeding difficulties on caregivers include increased stress (Curtin et al., 2015) and decreased self-efficacy and overall wellbeing (Harris, Ria-Searle et al., 2018). Additionally, feeding difficulties that require the use of gastrostomy tubes may further increase caregiver stress due to increased time spent managing the child’s feeding routine (Didehbani et al., 2011). When caregivers are under stress, this can result in using maladaptive feeding strategies such as force-feeding or bribing (Martin et al., 2013). These methods of feeding can result in a cycle of mealtime behaviors that do not improve, despite any short-term gains that they may provide. To disrupt the cycle of a negative feeding experience for children and caregivers, we believe more research should be dedicated to caregivers of children with feeding difficulties.

Our study investigated the overall impact of feeding difficulties on caregivers, the resources that they currently use for support, and the additional support that caregivers want to manage the feeding difficulties of their children. We believe that by increasing support for caregivers, they will be able to decrease stress, increase self-efficacy, and improve overall well-being, which will improve feeding outcomes for children and

caregivers. However, feeding difficulties need to first be understood in the context of the support caregivers have and desire, to understand the supports that will be most preferred by caregivers. As occupational therapists consider the experience of caregivers in their interventions, this is important for occupational therapists to understand so they use effective client-centered approaches (American Occupational Therapy Association [AOTA], 2014; Nichols et al., 2018).

Significance to Occupational Therapy

Theoretical Framework

The theoretical framework we used for our study was the Person-Environment-Occupation-Performance model (Baum et al., 2015). In this model, occupational performance is impacted by the relationship between the person, their environment, and an occupation. These elements contribute to performance which significantly impacts the ability to engage in meaningful occupations.

In our study, we focused on the experience of the caregiver. Caregivers must be able to identify their child's hunger cues and have the adequate knowledge to feed their child with feeding difficulties. Additionally, stress, self-efficacy, and overall well-being impact the caregiver's ability to perform in occupations of caregiving. Occupations of the caregiver include preparing and providing meals for children. Caregivers of children with feeding difficulties must also ensure that their children are eating an adequate amount and variety of foods (Harris, Ria-Searle et al., 2018). The feeding environment consists of many factors, including cultural feeding practices, socioeconomic status, social support, and education on feeding difficulties and how to respond to them. Additionally, any

assistive devices such as feeding tubes and where feeding takes place such as at home, school, and clinics are part of the feeding environment.

Performance is an outcome of a dynamic process that leads to participation and well-being (Baum et al., 2015). A caregiver's engagement in meaningful occupations of caregiving is dependent on their performance in feeding their child with feeding difficulties. If the feeding experience is negative and a caregiver is unable to feed their child, the caregiver's feelings about themselves, the feeding experience, and their ability to feed the child could be impacted. The complex relationship between the caregiver, the occupations of caregiving, and the feeding environment could impact the overall occupational performance of a caregiver. A deficit in any of these areas can cause a deficit in occupational performance. Therefore, the PEO-P model can be applied to the feeding experience of caregivers.

AOTA and AOTF Research Initiatives

While there are many professionals involved in the treatment of pediatric feeding difficulties, occupational therapists are uniquely positioned to understand the experience of caregivers and provide interventions. As noted by the AOTA, one reason that occupational therapists are so well suited to this field is that they focus on both the caregiving experience and social and environmental aspects of feeding (Nichols et al., 2018). With occupational therapy interventions and resources focused on caregiver well-being, caregiver self-efficacy can be increased. Additionally, promoting children's independence in feeding can strengthen the family dynamic. Our study aligns with the initiatives from the AOTA on improving the feeding experience for caregivers by seeking to understand the support and resources that caregivers prefer.

The American Occupational Therapy Foundation (AOTF) has identified family and caregiver needs as a research priority (AOTF, 2021). To understand family and caregiver needs, the AOTF has identified two areas for occupational therapists. There is a need for additional research on evidence-based measures and interventions and a focus on promoting health and well-being for individuals with conditions and families involved. Currently, there is not a network of occupational therapists focused on family and caregiver needs. However, occupational therapists can fill this gap because of their ability to understand the caregiver experience, as well as the social and environmental aspects of feeding (Nichols et al., 2018). The next steps include dedicating funding to train occupational therapists to research the evidence of family and caregiver needs, finding effective interventions and strategies for caregivers, and facilitating successful engagement in occupations outside of time spent caregiving (AOTF, 2021). Our study aligns with the initiatives from the AOTF to understand the needs of caregivers and suggest evidence-based interventions to support caregivers and families.

Need, Purpose, and Aims

Caregivers are integral in managing their child's feeding difficulties, and as a result, can experience increased stress (Curtin et al., 2015) and decreased self-efficacy and well-being (Harris, Ria-Searle et al., 2018). While occupational therapy organizations such as the AOTA and AOTF recognize the need for interventions focused on caregiver support (AOTF, 2021; Nichols et al., 2018), first we must understand the impact of feeding difficulties in the context of the support caregivers currently use and desire. Then, we can suggest support for caregivers that are the most beneficial to their needs.

The purpose of this research was to understand the impact of feeding difficulties on caregivers, the current supports that caregivers utilize, and additional supports that caregivers need to help them manage the feeding difficulties of their children. The anticipated outcomes of this research were to gain an understanding of the caregiver experience and insight into the types of support that caregivers prefer. The target population of this research was primary caregivers of children with feeding difficulties, including those caused by oral-motor problems, food allergies, gastrointestinal disorders, behavioral issues, and sensory issues. We were interested in understanding what the impact of feeding difficulties is on caregivers, what support is available to caregivers, and what additional support might be beneficial. We hypothesized that caregivers are impacted as a result of managing their child's feeding difficulty and that caregivers may prefer a peer support group to connect with other parents of children with feeding difficulties.

Literature Review

Caregiver Experience

The lived experiences of parents with children who have feeding difficulties are different from that of parents of children with typical feeding experiences (Winston et al., 2010). Several themes that emerged from the literature were time constraints, perceived expectations and roles, and parental emotions and their impact on self-efficacy.

Time Constraints

Winston et al. (2010) conducted a mixed-methods study to gain a greater understanding of caregivers' perceptions of their occupations when caring for a child with feeding difficulties. Study interventions included administering surveys and

conducting interviews in participants' homes. Outcomes were measured using a Parental Stress Scale and a Life Satisfaction Index scale. The results indicated that a significant amount of time is spent managing different issues and that caring for a child with feeding difficulties creates additional tasks that parents must incorporate into their daily routines. This may be due to the complexity of feeding when extra steps are necessary during mealtime due to the physical or cognitive needs of the child. For instance, Winston (2015) conducted a qualitative study to examine the lived experience of caregivers of young children with feeding difficulties. The researchers interviewed five caregivers and found themes of distress and complexities of feeding. One participant explained that a child who is fed through a gastrostomy tube will require special formula, equipment, and must stay on a specific schedule. To maintain a consistent schedule, caregivers must schedule their day around feeding and mealtimes, and this required planning then affects daily routines and schedules for the whole family. Forgetting one piece of the gastrostomy tube will set mealtimes back by three hours. Consequently, caregivers' daily schedules are dependent on the experiences of their child's feeding behavior. Any unforeseen events or mishaps will cause the parents to have to rearrange their entire schedule for the day.

Crowley et al. (2012) also described caregiver time constraints due to special dietary needs for a child. He conducted a qualitative study to observe the caregiver's experience when having to implement a special diet for her child while balancing the needs of the family. The researchers administered phone interviews with 22 caregivers. Outcomes were measured using Nvivo 7 to categorize descriptive themes. The results indicated that meal planning, grocery shopping, and meal preparation are stressful

experiences for caregivers due to the child's special dietary needs (Crowley et al., 2012). Caregivers are faced with restrictive food choices, sensory processing difficulties, and oral-motor delay concerns which require the caregiver to have a working knowledge about food sources due to allergens and how to manage the nutritional adequacy of the remaining diet. Additionally, Winston (2015) and Winston et al. (2010) reported that caregivers spend extra time navigating through the healthcare system—attending therapy visits, physician services, scheduling appointments related to the child's feeding concerns, and advocating for the child daily.

Perceived Expectations and Roles of Caregivers

Similar to feeding, caregiving is viewed in terms of society's expectations, cultural influences, and social interactions. Studies have found that caregivers of oral feeders and non-oral feeders were concerned with the idea of maintaining an expected way of feeding that was attributed to societal and cultural influences (Winston, 2015; Harris, Jansen et al., 2018). Harris, Jansen et al. (2018) conducted a quantitative study that examined the role of caregiver concern in nonresponsive feeding of fussy children. The study recruited 208 caregivers who participated in a survey that measured the frequency of fussy eating behavior and feeding practices using a Feeding Practices and Structure questionnaire. Harris, Jansen et al. found that caregivers set high expectations that did not meet the needs of the child during mealtime due to their perceptions of societal norms. Consequently, if caregivers were unable to fulfill these expectations, they would feel judged by those around them. Additionally, Crowley et al. (2012) found that caregivers felt that it was their role as good caregivers to effectively manage their child's eating habits, develop existing skills when it comes to food provision, and please the

entire family. Overall, caregivers' perceived expectation of their role and what a typical mealtime experience is like may negatively impact the caregiver. If a caregiver experiences an unsuccessful mealtime, intrusive feelings such as disappointment or shame may impact the caregiver's self-perception.

Caregiver Emotions and Self-Efficacy

Unsuccessful mealtimes negatively impact caregivers' emotions. Winston et al. (2010) reported caregiver emotions after an unsuccessful mealtime which included feeling frustrated, guilty, overwhelmed, stressed, and less confident. The study found that caregivers of children with feeding difficulties reported lower scores of satisfaction in leisure and recreation than caregivers of children who are typically developing. Additionally, the results revealed that the source of stress caregivers endured was due to the child's special feeding needs and dealing with a system that was unresponsive to their needs. When caregivers felt less confident about their strategies during mealtime, it affected self-perception and self-efficacy. Adamson and Morawska (2017) conducted a cross-sectional mixed methodology study that examined the practices of caregivers of children with feeding and behavioral challenges. They recruited 105 caregivers who participated in observations and completed several surveys—such as the Parenting Scale, Parenting Tasks Checklist, and the Parent and Toddler Feeding Assessment—which assessed child feeding behavior, parenting mealtime strategies, and caregiver self-efficacy. The results indicated that mealtime-specific self-efficacy was poorer amongst caregivers of children with feeding difficulties. Therefore, caregivers who felt ineffective during mealtime often felt less effective in their role as a caregiver overall.

Moreover, unsuccessful feeding experiences leave caregivers feeling ineffective and negatively impact caregiver self-efficacy (Adamson & Morawska, 2017; Harris, Jansen et al., 2018). Consequently, difficulty in the feeding experience may result in decreased occupational performance and caregivers using maladaptive strategies which perpetuate feelings of inadequacy (Harris, Jansen et al., 2018). For instance, caregivers managed noncompliant mealtime behavior and resistance through physical prompting, force-feeding, distraction, and discipline. Winston et al. (2010) presented supporting evidence that caregivers of children with feeding difficulties reported more unhelpful mealtime parenting strategies: offering alternative food options, promising a reward, distracting the child, or coaxing and pleading. Overall, when caregivers engage in unhelpful or maladaptive mealtime strategies, they subsequently feel inadequate and disappointed. Caregivers may feel as though they do not have the skill or ability to successfully fulfill their role as a caregiver.

Styles of Support for Caregivers

Interventions

According to Howe and Wang (2013), programs that teach parenting strategies can also improve children's mealtime behaviors. Howe and Wang conducted a systematic review of occupational therapy-based feeding interventions for children 5 years and younger. The interventions in this review included behavioral interventions, parent-focused educational interventions, and physiological interventions. Parent-focused educational interventions focused on providing parents and caregivers with information and recommendations to facilitate the feeding process. This intervention was found to be moderately to strongly effective in improving children's physical growth and

development, increasing the feeding competence of children and their primary caregivers, and improving parent-child interactions. Parent-focused educational interventions were effective when the goals were structured to improve maternal support, parenting skills, mother-child interaction, and the feeding competency of mother and child.

According to Zongrone et al. (2018), behavior change intervention recognizes the importance of self-efficacy during the intervention and focuses on improving maternal self-efficacy, knowledge, intent, skills, and motivation. This study assessed the effectiveness of behavior change intervention in increasing maternal self-efficacy of complementary feeding and examined if mothers with higher maternal self-efficacy gained more from the intervention than mothers with lower maternal self-efficacy. Behavior change intervention focuses on the self-efficacy of an individual as the determining factor for behavior change in nutrition interventions. Complementary feeding consists of feeding nutrient-dense foods such as green leafy vegetables and eggs in addition to breastfeeding to 6-month-old infants to promote growth and development. Mothers who participated in behavior change interventions were shown to have higher maternal self-efficacy of complementary feeding scores than those who received standard counseling on nutrition. The results indicate that self-efficacy influences caregiver behavior and increases their ability to feed children complementary foods. Therefore, interventions should be framed to address social, contextual, and environmental factors that promote self-efficacy.

Social Support

Assets-based Feeding Help Before and After Birth is an intervention that provides a combination of proactive peer support, behavioral change, social support, and

restructuring of the environment (Ingram et al., 2019). This intervention is a women-centered approach that utilizes listening skills to focus on the positive capabilities of individuals and communities rather than their needs, deficits, and problems. It also focuses on peer support to give social support to those who share common experiences. Ingram et al. (2019) conducted a randomized control trial that examined the experiences of women with infants aged 4–21 months who received this peer support intervention for infant feeding. After receiving this intervention, women reported that they valued learning about the available community resources and the opportunity of receiving support from others with similar experiences. They also reported feelings of reassurance in knowing where to go for advice and support.

Williams and Hankey (2014) conducted a cross-sectional quantitative study that examined how interpersonal relationships relate to health-related quality of life of 299 caregivers of children with food allergies. Web-based questionnaires were utilized to assess the caregiver's demographics, child allergy characteristics, the extent of social support available to the caregivers, the negative social experiences related to caregiving, and their health-related quality of life. Social support encompasses resources of another individual, social connectedness, perceived quality of support, and enacted support. Social negativity includes conflict, interference, and insensitivity. The results showed that caregivers reported better health-related quality of life with high levels of perceived social support, while high levels of social negativity had a detrimental effect on the caregiver's health-related quality of life. As caregiver well-being is an important factor of family functioning and child adjustment, social support should be taken into consideration when designing interventions and support groups for parents.

Semi-structured interviews of 47 women were conducted by McLeish and Redshaw (2017) to examine the mothers' perceptions and experiences of peer support during pregnancy and early parenthood. The interviews focused on the mothers' experiences utilizing maternity services, and how they heard about and initiated participating in peer support. It also examined the types of parental support and their impacts, if there was a difference between receiving support from a professional or a peer, how mothers felt about ending the peer support, and if they had any recommendations for any changes. Evidence collected from the interviews suggested that peer support can reduce mothers' experiences of low mood and anxiety by helping them overcome feelings of isolation, disempowerment, and stress, as well as supporting improvements in mothers' feelings of self-efficacy, self-esteem, and parenting competence. As peer support is differentiated from professional support by the benefits it provides, we explored which style of support parents of children with feeding difficulties prefer.

Carpenter and Garfinkel (2021) utilized an online survey with primarily Likert scale questions to conduct a quantitative study of 108 caregivers. The study examined caregivers' perspectives of the training families received to support their child's feeding difficulties, and how family mealtimes may be affected by such issues. The caregivers reported that they feel confident, nervous, and hopeful when receiving home training, and they feel frustrated, nervous, and overwhelmed when not receiving home training. The majority of the caregivers reported feeling supported by their feeding professional but also reported the need for additional support from their spouse and extended family members, other parents experiencing similar situations, their current feeding

professionals, and in-home visits. Overall, caregivers reported receiving current and evidence-based interventions, feeling supported, that their child's feeding difficulties were affecting family relationships, a desire to connect with caregivers of children with feeding difficulties, and needing coping and stress management strategies. These results indicate a need for additional support and follow-up for caregivers in various forms.

Gaps in Knowledge

Preferred Styles of Support for Caregivers

While each study contributes knowledge to the effectiveness and significance of parental support and intervention for parents of children with feeding difficulties, there is a lack of evidence that examines which style of support and interventions parents prefer. Our study sought to understand parents' perspectives on their preferred types of support to design interventions that are beneficial to them. To do so, we wanted to understand what support parents currently have and what can be done by occupational therapists to fulfill their lacking needs.

Lack of Caregivers' Perspectives

Although parents are receiving interventions and programs dedicated to improving mealtime behaviors, there is a gap between whether parents can retain the material and apply it with their children effectively (Howe & Wang 2013). Without consistency and support, parents often give up the advice that was offered to them, even when it is best for their child (Crowley et al., 2012). This impacts the parents' ability to respond to their child's feeding difficulty. In addition, mothers felt difficulty in accessing resources to meet the unique feeding needs of their children (Rogers et al., 2011). While there are interventions and programs for parents, we are looking to fill in the disparities

that are not met through increasing evidence for preferred parental support. Interventions that utilize social support have been effective in helping parents learn from those in similar situations and share common experiences (Ingram et al., 2019). Additionally, when parents perceive high levels of social support, their health-related quality of life is improved (Williams & Hankey, 2014) and peer support helped improve mothers' feelings of self-efficacy, self-esteem, and parenting competence (McLeish & Redshaw, 2017). Before implementing peer support for parents of children with feeding difficulties, it is important to understand the impact of feeding difficulties on parents in the context of available and desired support. Once there is an understanding of what types of support parents want, the preferred support method can be tailored to fit the parents' needs.

Methodological Gaps

There are methodological gaps in the existing studies. For instance many studies only include mothers as their target population (Crowley et al., 2012; Ingram et al., 2019; Martin et al., 2013; McLeish & Redshaw, 2017; Rogers et al., 2011; Winston, 2015; Winston et al., 2012). We are interested in all primary caregivers of children with feeding difficulties, including mothers, fathers, grandparents, and others. Primary caregivers are our population of interest because they are directly impacted as a result of managing their child's feeding difficulty. Additionally, some studies include children with specific disabilities who have feeding difficulties (Fung et al., 2002; Rogers et al., 2011) and other studies focus on specific feeding difficulties such as those that occur during breastfeeding (Ingram et al., 2019) or due to food allergies (Williams & Hankey, 2014). While children with disabilities are impacted more often than typically developing children (Manikam & Perman, 2000), feeding difficulties impact all populations; therefore, we did include

children with disabilities and typically developing children in our study. Additionally, feeding difficulties can be due to a variety of causes, and our study included feeding difficulties caused by oral-motor problems, food allergies, gastrointestinal disorders, and behavioral and sensory issues.

Methodology

Recruitment of Target Population

We created a flyer containing information about the purpose of our survey, the amount of time the survey takes, an entry to a raffle, and our contact information (See Appendix A). We emailed the flyer and study information to the Occupational Therapy Association of California (OTAC), children's hospitals, and occupational therapists for distribution to caregivers of children with feeding difficulties to participate in our online survey. OTAC distributed the survey by sending an email to OTAC members. OTAC members consist of students and practicing occupational therapists who can distribute the flyer and questionnaire to their clients. We also contacted groups via word of mouth and through support groups for caregivers of children with feeding difficulties. One way that we accessed this population was through contacting caregivers of children with feeding difficulties who receive therapy services at the Center for Developing Kids located in Pasadena, California.

Our target population is caregivers of children 0-18 years old with a parent-reported feeding difficulty including behavioral, oral motor, sensory, food allergies, gastrointestinal disorder, or other difficulties listed by the parent. After completing the demographics portion for screening purposes, caregivers could then complete the next section of the survey which includes the Feeding Impact Scale (Estrem et al., 2020).

Inclusion and Exclusion Criteria

To be included in data analysis, participants need to have a child with a feeding difficulty or past feeding difficulty. Participants self-report that their child has a feeding difficulty, and their child may or may not have a formal diagnosis. Participants were excluded from data analysis if their child requires mechanical ventilation or supplemental oxygen, if they are not the primary caregiver of the child with a feeding difficulty, or if open response questions were not completed. Any responses completed in a language other than English, incomplete responses, or with the same answer for all Feeding Impact Scale items or open responses questions were also excluded from data analysis. Children diagnosed with anorexia and bulimia nervosa were excluded from data analysis, since our target population of this study was children with feeding difficulties, and eating disorders do not fit into this category. Exclusion criteria were updated during the study to account for a large number of unreliable responses (See Limitations).

Mixed-Methods Design

For this project, we utilized a mixed-methods design. A quantitative and qualitative section was included in one Google form and sent to the target recruitment populations (see Appendix B). By utilizing a mixed-methods design, we acquired relevant statistics as well as the personal experiences of those in our study. This design aligns with previous studies in which the feeding experience of caregivers is a primary focus (Winston et al., 2010). A mixed-methods design allows the comparison of quantitative and qualitative data to find similarities between the two data sets and confirm findings. This method of collecting quantitative and qualitative data together is a convergence model (Creswell & Plano-Clark, 2007). By gathering details about the

feeding experience from the quantitative and qualitative perspectives, we were then able to compare findings from both sections. This enabled us to acquire a more comprehensive perspective of caregivers' feeding experience.

Quantitative Methodology

In the quantitative portion of our survey we collected demographic information and Feeding Impact Scale scores (Estrem et al., 2020). The demographic portion consisted of information designed to obtain background knowledge about the sample. This information provides context to our data such as the generalizability of our results to the general population. We collected demographic information about caregivers such as the area they live in and their relationship to the child with feeding difficulties. We collected demographic information about children such as if they have a feeding disorder diagnosis, additional details of the feeding difficulty, and any care related to the feeding difficulty.

Additionally, the quantitative portion of our survey involved completing the Feeding Impact Scale, a measure which assesses the impact of a child's feeding problem on the caregiver and family. We chose this measure instead of a parental self-efficacy or stress measure to better understand the overall impact of a child's feeding difficulty on caregivers. The Feeding Impact Scale is a 25-item Likert scale. Psychometric properties such as reliability and validity help researchers determine if a tool is consistent and measures what it intends to (Kielhofner & Coster, 2017). The psychometric properties of the Feeding Impact Scale include good to excellent internal consistency and weak to moderate convergent validity. Internal consistency refers to how well the items of the measure correlate with each other and convergent validity refers to how well the Feeding

Impact Scale correlates with other measures intended to quantify the impact of a child's feeding difficulty on a caregiver and family. The authors of the scale attribute the weak to moderate convergent validity to a lack of standard measures for comparison. Once more measures like this are developed, more accurate convergent validity can be determined. We received permission from the authors of the scale to use it for research purposes and to adapt it to an electronic format (see Appendix C). Collecting demographic and Feeding Impact Scale scores helped us understand the feeding experience of caregivers from a quantitative perspective.

Qualitative Methodology

The qualitative portion of our study aligns with phenomenological research which seeks to understand the lived experience of caregivers of children with feeding difficulties. The qualitative portion of the survey aims to explore the lived experiences, types of support, and the desired support of caregivers of children with feeding difficulties. The questions were formatted as an open response where participants could disclose any information they felt comfortable sharing. Questions include an open-ended question about their doctor's understanding of the feeding difficulty. It was asked to create a full picture of caregivers' current lived context of support such as if the caregivers feel supported and understood by their healthcare provider. Next, we asked questions about the caregivers' perception of the impact of their child's feeding difficulty on their overall emotional health. Overall, the advantage of the open-ended portion of the survey was to collect a descriptive narrative of what each caregiver is experiencing and how this impacts their emotional health and well-being.

Data Analysis

Quantitative Data Analysis

Excel spreadsheet and SPSS were utilized to analyze the demographic data of the participants. We used descriptive statistics to analyze frequency distributions, percentage values, and measures of central tendency; which are represented in tables and graphs (see Appendix D). For caregivers, we looked at demographic factors such as where they live, their relationship to the child with a feeding problem, and the impact of a child's feeding problem on the caregiver. For the child, we looked at their feeding disorder diagnosis, additional details of the feeding difficulty, and care related to the feeding difficulty. Frequency distribution showed how many caregivers and children are within each demographic category (Taylor & Kielhofner, 2017).

Percentages represented the caregivers or children in each demographic category. Measures of central tendency include the mode, median, and mean of the caregiver's Feeding Impact Scale scores and demographics for children and caregivers.

Qualitative Data Analysis

Qualitative data analysis includes the caregivers' responses to open-ended questions. To analyze these, we conducted a content analysis to categorize responses into common themes or codes. Inductive coding was utilized to allow common themes to emerge from the data without the influence of pre-existing codes. A line-by-line manual analysis was performed. First, we read the qualitative responses and created an original set of codes to begin categorization. Then, we analyzed the data line-by-line and categorized responses into original codes. Additional codes were added for responses that did not align with existing codes. Then, we read the responses line-by-line to confirm that

the codes applied to the data and that the responses were sufficiently categorized by the codes. Each open-ended question was analyzed following this method and assigned a set of codes to describe the responses to that question. Additionally, the frequencies of codes will be calculated and incorporated in the quantitative results section (see Appendix F).

Ethical and Legal Considerations

Vulnerable Populations

Children are considered a vulnerable population for research (Shivayogi, 2013). Since we are interested in the caregivers' perspective, we are not working directly with the vulnerable population of children. Caregivers may feel emotional distress for the topic of interest but questions are not required to be answered and caregivers can choose to stop at any point of the survey. Distressing questions can be skipped without any further questioning. Caregivers could be feeling high amounts of stress due to their managing their child with feeding difficulties and from the lack of support they are feeling. However, since this is a short survey, taking approximately 30 minutes of the caregivers' time, it will limit the amount of time parents are exposed to the survey content and questions.

Anonymity

The survey was sent via Google Forms and did not require participants to sign in with their email address to access the survey. We did not collect an email address or any identifying information from participants. If names were specified in the participant's responses, they were removed to maintain anonymity. To encourage participation, we offered participants the chance to win a \$25 Amazon gift card in a raffle. Anonymity was maintained as the raffle is associated with a different Google Form. By having a separate

form, the email addresses collected to contact the winner of the raffle were not associated with the survey responses. Additionally, email addresses were deleted after the raffle. Our survey and raffle responses are password protected and only the researchers and collaborators of the project have access to the Excel spreadsheet.

Informed Consent

Participants of our study provided informed consent (see Appendix F). Informed consent is a process in which participants agree or disagree to partake in a study, and it consists of three components—information, comprehension, and voluntariness (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Our consent form contained information such as the purpose of our research, information about the researchers, the voluntary participation process, the study procedures, and confidentiality precautions. After reading the informed consent form, participants were given the option to select “disagree” if they no longer wanted to take part. Comprehension of the informed consent form was implied by answering this question. This question was required and all survey responses were checked for an “agree” response before data analysis. Participation and all questions included in our study were optional, voluntary, and participants could withdraw from participation at any time, as described in the informed consent form.

Institutional Review Board Approval and Special Permissions

In alignment with Stanbridge University Institutional Review Board (IRB) approval, our study will be carried out according to the United States Code of Federal Regulations applicable to studies that involve human subjects. Ethical principles in conducting research will be adhered to and all personnel involved in conducting the

study have completed the Collaborative Institutional Training Initiative ethics training. The study was approved by Stanbridge University's IRB (see Appendix G). Moreover, all submissions and modifications followed the IRB directions and guidelines. By doing so, the ethical integrity of the study was maintained. We acquired agreement from the Center of Developing Kids in Pasadena, California due to significant recruitment and future interest in collaboration pending the results of this study (see Appendix H).

Results

Quantitative Analysis

Demographics

Eleven participants ($n = 11$) were asked twelve questions regarding the child's demographics. The first question asked whether the child had feeding difficulties. 90% ($n = 9$) participants answered "yes." The second question asked whether the child was diagnosed with a feeding disorder. As shown in figure D1, 40% ($n = 4$) of participants indicated that their child does not have a formal feeding disorder diagnosis. The third question asked the nature of the child's feeding difficulties. As shown in figure D2, 63.64% of the children of the study participants indicated that the nature of their child's feeding problem is "sensory" ($n = 7$), while 36.36% ($n = 4$) indicated "oral motor" as the nature of the feeding problem. The fourth question asked the quantity of food the child consumes. As shown in figure D17, 40% ($n = 4$) claim that their child eats "20+" types of food. The fifth question examined if the child has any diagnosis other than a feeding disorder. As shown in figure D3, 69.2% ($n = 9$) of participants indicated that their child has a diagnosis other than a feeding disorder that include attention deficit hyperactivity disorder, anxiety, hypotonia, mosaicism, autism, spina bifida, Chiari malformation,

hydrocephalus, and selective mutism. Question six asked if the child is currently receiving feeding therapy and which providers are on the child's therapy team. As shown in figure D18, 40% (n = 4) of participants claimed occupational therapists are on their child's therapy team. The seventh question asked if the child had received feeding therapy in the past if they are not currently receiving feeding therapy. As shown in figure D19, 30% (n = 3) claimed no, 30% (n = 3) claimed yes, and 40% (n = 4) had no response. Question eight asked if the child has ever received nutrition non-orally. As shown in figure D4, 70% (n = 7) of participants indicated no, 20% (n = 2) indicated NG-tube, and 10% (n = 1) indicated G-tube. The ninth question examined if the child is receiving supplemental oxygen or mechanical ventilation and all participants indicated no. Question ten asked at what age the child's feeding difficulties emerged and all participants indicated 0–3 years. The eleventh question assessed the age of the child. As shown in figure D20, the age range was 10 months to 18 years old. Question 12 asked the gender of the child. As shown in figure D21, 60% (n = 6) of participants indicated that their child's gender is male, and 40% noted their child is female.

Four questions measured parent demographics. The first question asked where the caregiver lives. Shown in figure D14, 80% (n = 8) stated that they live in California. 10% (n=1) in Illinois, and 10% (n = 1) in Washington. The second question asked whether the location of residence was considered rural, suburban, or urban. Shown in figure D15, 50% (n = 5) of participants identified their area as "suburban" while the other 50% (n = 5) identified their area as "urban." The last couple of questions asked about the relationship to the child with feeding difficulties and whether the participant is the primary caregiver. As shown in figure D16, 90% (n = 9) of participants identified

themselves as the “mother” of the child with feeding difficulties and 10% (n = 1) of participants identified themselves as the “father.”

Feeding Impact Scale

The Feeding Impact Scale is a 25-item Likert scale which seeks to determine the total impact of a child’s feeding difficulty on their parent and family. While this assessment considers parents as the target population, our study includes all primary caregivers of children with feeding difficulties. Each item is on a scale of 1-5, with higher scores indicating a higher level of impact. Each item is described below, including mean, mode, standard deviation (SD), minimum, and maximum scores (see Appendix D). There is a total feeding impact score for both the parent and family sections of the assessment. These scores are also described by mean, mode, SD, minimum, and maximum scores for the sample population.

Questions 1 through 13 on the Feeding Impact Scale focus on the family and measures the total impact that a child’s feeding difficulty has on their family. In our study, 10 participants answered the Feeding Impact Scale portion for families. Question 1 asked if families have to plan ahead when eating somewhere other than their home. The mean score was 4, mode was 5, SD was 1.05, minimum was 2, and maximum was 5. Question 2 considered if family mealtime is longer due to the child’s feeding problem. The mean score was 3.40, mode was 4, SD was 1.58, minimum was 1, and maximum was 5. Question 3 asked if other caregivers, including babysitters or grandparents, have a difficult time feeding the child. The mean was 3.70, mode was 5, SD was 1.49, minimum was 1, and maximum was 5. Question 4 sought to understand if the number of appointments that the child has affects the family. The mean was 3.00, mode was 3, SD

was 1.33, minimum was 1, and maximum was 5. Question 5 asked if the child's feeding difficulty affects their siblings. Out of the nine scores for this question, the mean was 3.11, mode was 1, SD was 1.69, minimum was 1, and maximum was 5. Question 6 asked if the care required for the child's feeding difficulty impacts the family financially. The mean was 2.80, mode was 3, SD was 1.40, minimum was 1, and maximum was 5. Question 7 asked if there is more stress in the family due to the child's feeding. The mean was 3.90, mode was 5, SD was 1.20, minimum was 2, and maximum was 5. Question 8 sought to understand if family members do not want to watch the child due to their feeding difficulty. Out of the nine scores for this question, the mean was 2.33, mode was 2, SD was 1.22, minimum was 1, and maximum was 5. Question 9 asked if the family avoids social activities due to the child's feeding. The mean was 2.10, mode was 1, SD was 1.20, minimum was 1, and maximum was 4. Question 10 considered if it is easy for families to find babysitters for their child. Out of the nine scores for this question, the mean was 3.67, mode was 3, SD was 0.87, minimum was 3, and maximum was 5. Question 11 asked if the extended family understands the child's feeding needs. The mean was 3.33, mode was 4, SD was 1.22, minimum was 1, and maximum was 5. Question 12 considered if the family enjoys eating in a restaurant. The mean was 3.20, mode was 3, SD was 1.14, minimum was 2, and maximum was 5. Question 13 sought to understand if mealtimes are pleasant for the family. The mean was 3.40, mode was 4, SD was 0.97, minimum was 2, and maximum was 5. The Total Feeding Impact- Family Score showed a mean of 40.70, a mode of 51, SD of 9.79, minimum of 26, and maximum of 51.

10 participants answered the Feeding Impact Scale portion for parents. The parent portion of the Feeding Impact Scale starts on question 14. This question assessed the amount of effort that a child requires during mealtime when compared to their peers. The mean score was 4.40, mode was 5, SD was 0.97, minimum was 2, and maximum was 5. Question 15 assessed the caregivers' perception of whether others understand their child's feeding needs. The mean score was 4.30, mode was 4, SD was 0.67, minimum was 3, and maximum was 5. Question 16 sought to understand if caregivers worry about how long it will take for their child's feeding to improve. The mean score was 3.50, mode was 2, SD was 1.27, minimum was 2, and maximum was 5. Question 17 assessed if feeding their child requires caregivers to have extra patience. The mean was 4.80, mode was 5, SD was 0.42, minimum was 4, and maximum was 5. Question 18 sought to understand if caregivers need to prepare a different meal for their child due to their feeding difficulty. The mean score was 4.50, mode was 5, SD was 0.85, minimum was 3, and maximum was 5. Question 19 sought to determine if caregivers are concerned about their child's daily nutritional requirements. The mean score was 3.90, mode was 5, SD was 1.29, minimum was 1, and maximum was 5. Question 20 considered if caregivers worry daily about their child's feeding. The mean was 3.40, mode was 2, SD was 1.43, minimum was 2, and maximum was 5. Question 21 asked if caregivers worry about how their child's feeding affects their health. The mean was 3.50, mode was 4, SD was 1.43, minimum was 1, and maximum was 5. Question 22 asked if feeding takes the child more than 20 minutes. The mean was 4, mode was 5, standard deviation was 1.33, minimum was 2, and maximum was 5. Question 23 asked if caregivers worry about the impact of their child's feeding on development. The mean was 3.60, mode was 3, standard

deviation was 0.97, minimum was 2, and maximum was 5. Question 24 asked if caregivers feel frustrated that they are unsure of the amount of food their child will eat. The mean was 2.60, mode was 3, standard deviation was 1.07, minimum was 1, and maximum was 4. Finally, question 25 asked if there is more stress in caregivers' lives due to their child's feeding. The mean was 4.00, mode was 4, standard deviation was 1.15, minimum was 1, and maximum was 5. Overall, the Total Feeding Impact- Parent Score was a mean of 46.50, mode of 37, SD of 6.69, minimum of 37, and maximum of 56.

Qualitative Analysis

Explanation of Feeding Impact Scale Responses

The final question of the Feeding Impact Scale asks participants if they would like to explain any of their responses. Two participants chose to provide further explanation and the resulting themes were stress, having to pick restaurants that serve a child's preferred foods, and sensory aversions to non-preferred foods. Concerning stress, one participant said "I used to feel a lot of stress when my daughter was younger . . . There is probably a constant low-level of stress in my life due to feeding issues." Another caregiver discussed how their family needs to plan in advance which restaurants to attend due to their child's food and sensory preferences, stating "We have to pick restaurants that have burgers, meatballs, or chicken nuggets, otherwise there's not really any meal he would pick. He has a huge sensory aversion to eggs, rice, yogurt and things of similar consistency."

Fit of Doctor's Advice to Child's Needs

Caregivers brought up the concern of their child's feeding difficulties with their doctors with only one participant having not discussed it. Four participants stated that

their doctors understand the nature of their child's feeding difficulty and four participants stated that their doctors do not understand the nature of their child's feeding difficulty. One participant stated, "I take all advice with a grain of salt." Another participant expressed that their pediatrician did not take their concerns seriously, so they had to bring up the issue during every appointment. The doctor blamed the child's eating habits on pickiness rather than an eating concern. One participant said, "I think he accepts it for what it is but doesn't offer much advice. His main concern is her growth and weight. The fact that she is very big for her age seems to make him less concerned about her feeding challenges." When asked about how well the doctor understands the nature of their child's feeding problem, a participant stated, "probably not well . . . I feel like we are all learning and trying to figure it out together and on equal levels." Other participants stated that their doctor's understanding was, "well enough," "very well," and "quite well." When asked if the doctor's advice fit what you need, a participant stated, "yes."

Mealtime Resources

Caregivers identified a variety of resources they wish they had during mealtime or for their child with feeding difficulties. A common theme was that participants had a desire for more knowledge about feeding difficulties. For instance, a participant mentioned "early childhood signs in terms of distinguishing a picky eater vs a child is responding sensitive to eating." Another participant expressed "I wish I could download my feeding knowledge into my husband's brain." One participant expressed a desire for a handbook, while another participant wished to learn about shared experiences, stating they would like to have access to "other stories that are similar to ours and how they progressed in a positive way." Most caregivers in our sample had a desire for

professional help when it came to difficulties during mealtime. Some participants expressed a need for an “in home feeding therapist instead of clinic where mealtimes don’t naturally occur” or “a chef and someone else to feed my son.” One participant expressed a desire for “someone to guide me on what [I] am doing wrong. I don't want to handicap him by continuing to feed him.” Another participant mentioned “more professionals who really knew what was going on/how to help us. More access to in-home therapy so they could understand/see what a day in the life is really like.”

Overall Impact of Feeding Difficulty on Emotional Health

Majority caregivers in our sample reported that the impact of their child’s feeding problem on their overall emotional health was stressful. One participant said, “adds somewhat [to] daily stress, but does not challenge my ability to see a bright future”. Five participants expressed “it’s stressful,” “very stressful” and “very impactful because ‘triple feeding’ has taken over my life.” While one participant expressed “previously, I was an emotional wreck! I probably still have residual trauma and early memories with my child (first 3 years) are all colored by this stress and experience.” A few participants shared feelings of frustration. A participant stated “...once he started on real food . . . now I have even less time.” Another participant expressed “I also HATE cooking now which I used to love.” While one participant simply stated “irritability.” Two participants share that they felt exhausted and experienced *anxiety*. Two participants experienced anxiety, one shared “this is hard. Between the anxiety and feeding stuff he says some really mean things during mealtimes which makes them less enjoyable for all.” Another participant shared “there is a lot of anxiety.” Of the two participants who stated they felt exhausted, one mentioned that “I can hardly shower or sleep,” and the other stated “I’m exhausted.”

One participant provided insight into the feeling of guilt, sharing that their child's feeding difficulties "just makes me wonder if I should have pushed her to eat more variety earlier. But she's very stubborn and probably wouldn't have."

Caregiver Support Group

Eight caregivers in our sample expressed interest in a support group for caregivers of children with feeding difficulties. One participant said, "support groups are really helpful and effective. You don't feel so alone and other people may be able to help you with tips on what has worked for their child." Another participant mentioned their participation in a feeding support group and internet groups and said, "the advice/help I got from other parents was much more valuable than that coming from the doctors/therapists. So, I think these types of groups are great!" Participants mentioned both internet and in-person groups as support group settings that they would participate in. Two participants were not interested in a support group. One participant mentioned that their child is an adult, so a caregiver support group is no longer necessary. Another participant said that they are "too busy prepping meals" to participate in a caregiver support group.

Participants expressed what kind of content they would like to receive from a caregiver support group. Three caregivers were interested in tips and advice from other caregivers. Caregivers would like to know what has worked for other caregivers and their children and value caregivers' advice. One participant mentioned specific problems related to feeding difficulties be addressed, such as behavioral issues and oral motor difficulties.

Additional Information

Five participants wanted to share additional information about the experience of being a caregiver to a child with feeding difficulties. One participant expressed the desire for a comfortable mealtime experience for their child during mealtimes and said, “I didn’t push it because I wanted enjoyable mealtimes and for her to not stress about food.” For this caregiver, maintaining a comfortable mealtime experience is more important than other aspects of managing feeding difficulties such as introducing new foods or behavioral strategies.

Two participants expressed the need for more education on the topic of feeding difficulties. One participant said, “getting day cares on board with special dietary needs is like pulling teeth . . . more education in those arenas would likely be very helpful for parents of children with feeding challenges.” Another participant mentioned the need for more education for caregivers and friends and family:

Most of us parents were thrown into this world suddenly. People are at least familiar with things like cancer or diabetes before a loved one has it; but most of us didn't even know there was such a thing as "not eating". So, I think it is really hard to find support and help because it just isn't understood or known about by our family and friends.

Another theme was the need for more training for professionals. One participant expressed “more pediatricians need to be better trained in discovering tongue and lip ties when checking baby in the hospital” and another said that “getting the right team and services [is] difficult.” Sometimes, if a child’s doctor does not understand the feeding

difficulty, it is difficult to obtain referrals to therapists or specialists that would be able to adequately address the child's needs.

Two caregivers also expressed the need for more awareness on the topic of feeding difficulties:

I think there needs to be more raised awareness on this topic. I have come to noticed that some parents believe or assume that their child is a picky eater when perhaps its stemming from something else. I think it's important to help broaden the horizon for parents and show them that just because a child may [stumble] across a feeding problem doesn't necessarily mean they won't have a bright future.

Discussion

This mixed methods study explored the impact of feeding difficulties on caregivers, what supports are available to caregivers, and what additional support can be beneficial. Overall, we found that caregivers' emotional well-being and occupational engagement are impacted due to the feeding difficulties of their child. The current support that caregivers are receiving includes doctors, occupational therapists, and family members. However, caregivers reported that they would like to have more resources and education for both professional healthcare workers as well as family members. Additionally, caregivers reported that they would like caregiver education and connecting with others with similar experiences.

Feeding Difficulties

Based on the demographics collected from the Feeding Impact Scale and survey, caregivers reported that the nature of the feeding difficulties can be attributed to feeding difficulties such as sensory, oral motor, or mixed feeding difficulties. The diversity of the

feeding difficulties reflect how challenges in feeding can be multifaceted in terms of how caregivers can be impacted regardless of the type of feeding difficulty and diagnoses.

While there were various feeding difficulties reported, the uniformity of the impact on the caregivers was evident in our results. Caregivers reported that their child had limited food repertoire with under 20 foods in their diet. This can lead to additional stress in planning ahead to attend restaurants and cooking.

Impact on Caregivers

Overall, there was a moderate impact on the family and a moderate to high impact on the caregiver due to the child's feeding difficulties. The impact on the caregiver presents as increased stress, frustration, anxiety, exhaustion, and guilt which leads to poor emotional well-being. As a result, the caregivers' ability to effectively engage in occupations is negatively impacted. For instance, caregivers reported that the time needed to meal prepping, feeding, and planning social activities attributed to time constraints daily activities such as showering, sleeping, and other leisure activities. Due to the impact of the feeding experience with a child with feeding difficulties, caregivers reported that they no longer enjoyed the task of cooking. These findings support our hypothesis that caregivers are impacted as a result of their child's feeding difficulties.

Additional Resources and Education

Caregivers reported that they would like additional resources and education for healthcare professionals, family members, and themselves. Our respondents often stated that doctors' advice often does not fit their needs. This points to a gap in the healthcare professionals' understanding of the impact of feeding difficulties on caregivers and the wide range of challenges that children with feeding difficulties have. Caregivers also

stated that they would like more resources and education for others in contact with their child such as daycare workers, family members, and friends. For instance, caregivers reported having a difficult time finding babysitters and once they did, the babysitter had difficulty feeding their child and understanding their needs. Caregivers want to feel understood by others and have others understand the needs and challenges of their child's feeding difficulties. Additionally, caregivers reported wanting more resources and education for themselves that include early childhood signs for feeding difficulties, professional assistance, and opportunities to share experiences with others. This points to a need for in-home therapy and peer support groups for caregivers. According to the Feeding Impact Scale, caregivers are not overwhelmed with current appointments but some experience time constraints due to food preparation and mealtime. Participating in peer support groups would be beneficial for caregivers' stress, however the caregivers' time constraints should be factored into the frequency of any potential support group.

Conclusion

The purpose of this research was to understand the impact of feeding difficulties on caregivers, the current support that caregivers utilize, and additional resources that caregivers desire to help them manage the feeding difficulties of their children. Along with managing their child's feeding, caregivers desire support to manage their stress and for education. From our findings, our hypothesis was supported, as caregivers expressed desire for a peer support group. There is a need for additional resources to address the impacts of feeding difficulties on caregivers' occupational engagement. Caregivers expressed that they experience feelings of anxiety, stress, and frustration, which affect their ability to care for their child and to engage in other caregiving and

non-caregiving occupations. This implication of our research aligns with the AOTF research initiative of addressing the engagement of caregivers in non-caregiving occupations to promote occupational balance (AOTF, 2021). The scope of occupational therapy is in a unique position to address caregiver stress and help promote occupational engagement and balance.

Having an occupational therapist on the interdisciplinary team can help address the complex aspects of children's feeding difficulties and facilitate successful engagement in the occupation of feeding. Additionally, occupational therapists have the ability to advocate and promote the caregivers' needs to engage in the occupation. One way that an occupational therapist can fill this gap is through early intervention, as 100% (n=11) participants stated that feeding difficulties emerged prior to 3 years old. Early intervention can focus on parent education about the signs of feeding difficulties and parental support. These are areas of need that occupational therapists can fill as evidenced by our findings

Limitations

There are limitations of this study that should be addressed in the future. The diversity represented in our sample is low: 80% of study participants reside in California, 50% of participants live in urban areas, 50% of participants live in suburban areas, and 90% of participants are mothers to children with feeding difficulties. Originally, a large-scale and multi-state recruitment method was planned, and we were going to access the target population through social media posts and posts on websites for occupational therapists. However, this was changed due to a large number of unreliable responses. We believe that this occurred due to the advertisement of a raffle on our recruitment flyers.

After this problem occurred, we updated exclusion criteria and removed unreliable responses from data analysis accordingly. Exclusion criteria included responses that stated “no” to having a feeding difficulty, “yes” to the child requiring supplemental oxygen, and “no” to the participant being the primary caregiver of the child. Additionally, responses were excluded from data analysis if they had incomplete answers to the Feeding Impact Scale or open-response questions, had the same score for all items of the Feeding Impact Scale, were written in a language other than English, or the written answers were incoherent. Anorexia nervosa and bulimia nervosa diagnoses were also excluded since caregivers of children with eating disorders were not the target population. We decided to move forward with a smaller scale recruitment, mainly through feeding therapists, to capture more reliable responses. Existing social media and website posts were deleted. While this resulted in a smaller sample size and limited diversity, we believe that the data and findings presented are reliable.

Demographics such as income and ethnicity were not collected in an effort to remain sensitive to the sample population. However, it cannot be determined if the sample population represents the population as a whole. Additionally, we are unsure if the resources afforded by families with higher incomes influence the impact of feeding difficulties on caregivers and the resources that they desire. We recommend collecting this information in future studies and seeking to understand what differences might be present based on socio-economic status. Understanding where the largest gaps are in terms of resources and support for caregivers can help occupational therapists target their interventions where they are most needed.

Additionally, due to the small sample size, the statistical power of this study is low. However, this was a mixed-methods study, and qualitative results were included to inform us about the lived experiences of caregivers and parents of children with feeding difficulties. We recommend that quantitative and qualitative results be interpreted together to understand the impact of feeding difficulties on caregivers and the additional support that caregivers desire.

Finally, feeding difficulties and disorders were self-reported by caregivers. With children who are more medically complex, feeding difficulties are only a portion of the stress. Therefore, it is difficult to isolate how feeding difficulties impact caregivers' overall level of parenting stress.

While participants reported that their child had a feeding difficulty, 40% reported a formal feeding disorder diagnosis. Potentially, other children in the sample might also have a formal feeding disorder diagnosis and feeding disorders might have been under-reported by our participants. If this study was completed in a hospital or feeding clinic, feeding disorders could be confirmed via chart review or consultation with a child's doctor or feeding therapist.

Also, the impact of feeding difficulties on caregivers was determined by self-reported answers. We recommend that additional measures be used to supplement self-reported responses in future studies. Researchers can observe a mealtime to gain a better understanding of what this experience is like for caregivers and children. A more in-depth follow-up interview would also provide additional details about caregivers' experiences. However, due to COVID-19, observation and in-person follow-up interviews were not available as options. In the future, we recommend that these options be considered.

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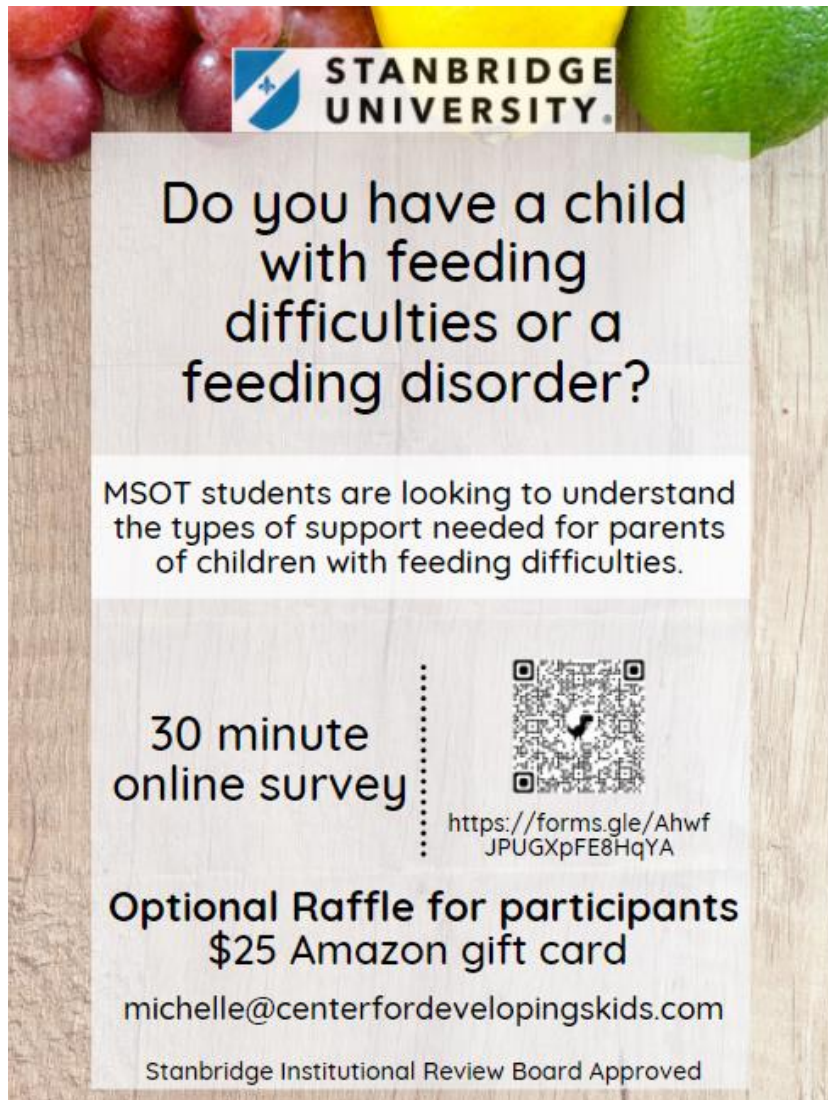
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- Zongrone, A. A., Menon, P., Pelto, G. H., Habicht, J. P., Rasmussen, K. M., Conostas, M. A., Vermeylen, F., Khaled, A., Saha, K. K., & Stoltzfus, R. J. (2018). The pathways from a behavior change communication intervention to infant and young child feeding in Bangladesh are mediated and potentiated by maternal self-efficacy. *The Journal of Nutrition*, 148(2), 259–266. <https://doi.org/10.1093/jn/nxx048>


Appendix A**Recruitment Materials**A recruitment flyer for a study on feeding difficulties. The flyer is set against a background of fresh produce, including red grapes, a yellow lemon, and a green lime, all resting on a wooden cutting board. At the top left, the Stanbridge University logo is visible, featuring a blue shield with a white cross and the text "STANBRIDGE UNIVERSITY." in black. The main text of the flyer is centered and reads: "Do you have a child with feeding difficulties or a feeding disorder?" Below this, it states: "MSOT students are looking to understand the types of support needed for parents of children with feeding difficulties." Further down, it offers a "30 minute online survey" and includes a QR code. To the right of the QR code is the URL "https://forms.gle/AhwfJPUGXpFE8HqYA". Below the QR code and URL, it mentions an "Optional Raffle for participants" with a "\$25 Amazon gift card". At the bottom, the contact email "michelle@centerfordevelopingskids.com" is provided, followed by the text "Stanbridge Institutional Review Board Approved".

STANBRIDGE UNIVERSITY.

Do you have a child with feeding difficulties or a feeding disorder?

MSOT students are looking to understand the types of support needed for parents of children with feeding difficulties.

30 minute online survey



<https://forms.gle/AhwfJPUGXpFE8HqYA>

Optional Raffle for participants
\$25 Amazon gift card

michelle@centerfordevelopingskids.com

Stanbridge Institutional Review Board Approved

Note. Example of flyers with study information used for recruitment purposes. Various flyers were used, with the same text and various backgrounds. Flyers were sent to OTAC for distribution to its members and occupational therapists for distribution to their clients. Flyers were sent to feeding support groups via word of mouth and parents of children with feeding difficulties receiving services at Center for Developing Kids in Pasadena, CA.

Appendix B

Survey: Demographics, Feeding Impact Scale, and Open-Response Questions

Figure B1

Impacts on Parents of Children with Feeding Difficulties

Parent Information

The following questions are about the parent/primary caregiver of the child with feeding difficulties.

What state do you live in?

Choose ▼

Do you consider where you live to be rural, suburban, or urban?

Rural

Suburban

Urban

What is your relationship to the child with feeding difficulties?

Mother

Father

Grandparent

Other: _____

Are you the primary caregiver?

Yes

No

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Note. Demographics questions of interest about caregivers' information.

Figure B2

Impacts on Parents of Children with Feeding Difficulties

Child Information

The following questions are about your child with feeding difficulties.

Does your child have a feeding difficulty?

Yes
 No

Does your child have a feeding disorder diagnosis? If yes, please specify.

Your answer _____

What is the nature of your child's feeding problem? Please check all that apply.

Oral motor
 Food allergies
 Gastrointestinal disorder
 Behavioral
 Sensory
 Other: _____

How many foods does your child currently eat?

0-5
 5-10
 10-15
 15-20
 20+

Does your child have any diagnoses other than a feeding disorder? If yes, please specify.

Your answer _____

If your child is currently receiving feeding therapy, which providers are on your child's therapy team? Select all that apply.

Occupational therapist
 Speech language pathologist
 Registered dietician
 Psychologist
 Gastroenterologist
 Allergist
 N/A (not currently receiving feeding therapy)
 Other: _____

Note. Demographics questions of interest about children's information.

Figure B3

If your child is not currently receiving feeding therapy, have they received feeding therapy in the past?

Yes

No

Has your child ever received nutrition non-orally?

No

G-tube

NG-tube

Other: _____

Is your child receiving supplemental oxygen or mechanical ventilation?

Yes

No

At what age did your child's feeding difficulties emerge?

0-3 years

4-6 years

7-9 years

10 years +

How old is your child in years? (Please use months if under 1 year).

Your answer _____

What is your child's gender?

Male

Female

Prefer not to say

Other: _____

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Note. Demographics questions of interest about children’s information.

Figure B4

Impacts on Parents of Children with Feeding Difficulties

Impact on Parent and Family

The following questions are from the Feeding Impact Scale (Estrem et al., 2020) and are about the impact on the parent and family of having a child with a feeding difficulty. The researchers have permission to use the Feeding Impact Scale for research purposes.

Citation:
Estrem, H. H., Pados, B. F., Park, J., Thoyre, S., McComish, C., & Nguyen, T. (2020). The Impact of Feeding on the Parent and Family Scales (Feeding Impact Scales): Development and Psychometric Testing. *Journal of nursing measurement*, JNM-D-20-00008. Advance online publication. <https://doi.org/10.1891/JNM-D-20-00008>.

We have to plan ahead when eating somewhere other than our home.

1 2 3 4 5

Strongly disagree Strongly agree

Family mealtime is longer because of my child's feeding.

1 2 3 4 5

Strongly disagree Strongly agree

Other caregivers (grandparents, babysitters) have difficulty feeding my child.

1 2 3 4 5

Strongly disagree Strongly agree

The number of appointments my child has affects our family.

1 2 3 4 5

Strongly disagree Strongly agree

My child's feeding affects his/her siblings.

1 2 3 4 5

Strongly disagree Strongly agree

My child's feeding care affects my family financially.

1 2 3 4 5

Strongly disagree Strongly agree

There is more stress in my family because of my child's feeding.

1 2 3 4 5

Strongly disagree Strongly agree

Note. Feeding Impact Scale questions.

Figure B5

Family members do not want to watch my child because of his/her feeding needs.

1 2 3 4 5

Strongly disagree Strongly agree

My family avoids social activities due to my child's feeding needs.

1 2 3 4 5

Strongly disagree Strongly agree

We can easily find a babysitter for our child.

1 2 3 4 5

Strongly agree Strongly disagree

My extended family understands my child's feeding needs.

1 2 3 4 5

Strongly agree Strongly disagree

My family enjoys eating in a restaurant.

1 2 3 4 5

Strongly agree Strongly disagree

Mealtime is pleasant for my family.

1 2 3 4 5

Strongly agree Strongly disagree

My child requires more of my effort at mealtime because of the way he/she eats than other children his/her age.

1 2 3 4 5

Strongly disagree Strongly agree

I feel other people do not understand my child's feeding needs.

1 2 3 4 5

Strongly disagree Strongly agree

I worry about how long it will take for my child's feeding to get better.

1 2 3 4 5

Strongly disagree Strongly agree

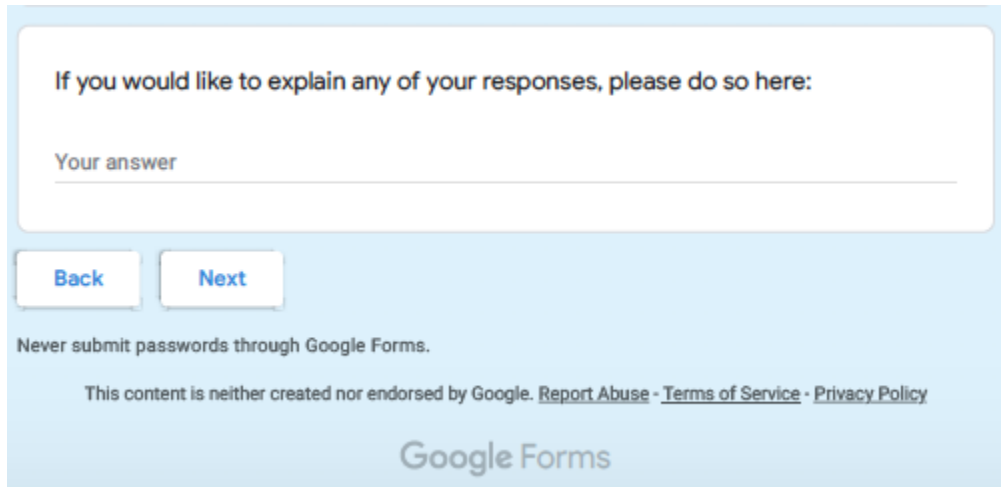
Note. Feeding Impact Scale questions.

Figure B6

Feeding my child requires extra patience.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
I have to prepare a special meal for my child because of his/her feeding needs.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
Meeting my child's nutritional requirements is a daily concern.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
I worry daily about my child's feeding.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
I worry that my child's feeding affects his/her health.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
Feeding my child takes more than 20 minutes.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
I worry the way my child eats will affect his/her development.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
I feel frustrated that I do not know how much my child will eat.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree
There is more stress in my life because of my child's feeding.					
	1	2	3	4	5
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Strongly agree

Figure B6Note. Feeding Impact Scale questions.

Figure B7



If you would like to explain any of your responses, please do so here:

Your answer

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Note. Feeding Impact Scale questions.

Figure B8

Impacts on Parents of Children with Feeding Difficulties

Open-response Questions

The following questions are written by the Stanbridge University research team. The following questions are open-response questions about the experience of having a child with feeding difficulties, what current support is available, and additional support that may be beneficial.

What people and resources do you use for emotional support to manage the challenges of feeding your child? Please check all that apply.

- Spouse
- Significant other
- Family
- Friends
- Structured support group (disability or feeding specific)
- General parent support group
- Healthcare professionals
- Other: _____

How well does your doctor understand the nature of your child's feeding problem? Does your doctor's advice fit what you need?

Your answer _____

What resources do you wish you had during mealtime/for your child with feeding difficulties?

Your answer _____

How would you describe the impact of your child's feeding problems on your overall emotional health?

Your answer _____

Would you participate in a parent support group for parents of children with feeding problems? If yes, what content would you like this group to focus on? What form would you be interested in (internet group, in-person)?

Your answer _____

Is there anything else you wish to share about your experience of feeding your child with feeding problems?

Your answer _____

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Note. Open-response questions.

Appendix C

Permission to use Feeding Impact Scale in an Electronic Format

From: **Estrem, Hayley H.** <estremh@uncw.edu>

Date: Tue, Feb 2, 2021 at 6:48 PM

Subject: RE: Form Submission - General Contact - Use of Feeding Impact Scale for student thesis research

To: michelle@centerfordevelopingkids.com <michelle@centerfordevelopingkids.com>

Hi Michelle,

I'm glad to hear you are using the Feeding Impact Scales in your work. It is okay to use a google form to collect data if your IRB approves use of google forms for the project; however, I wonder if they would be okay with that. It may be better to use Microsoft forms, Qualtrics, or RedCAP, but that would depend on what your institution relies on for data security. Some sites have added it to the electronic charting. So long as you don't change any wording and keep scoring the same, cite it and all that, putting it into electronic format is totally fine. Also, if you are interested in the normative data, we are still writing that up but we have the analysis complete – it should be on the horizon.

Let me know if you need anything, I'm happy to help!

Hayley Estrem

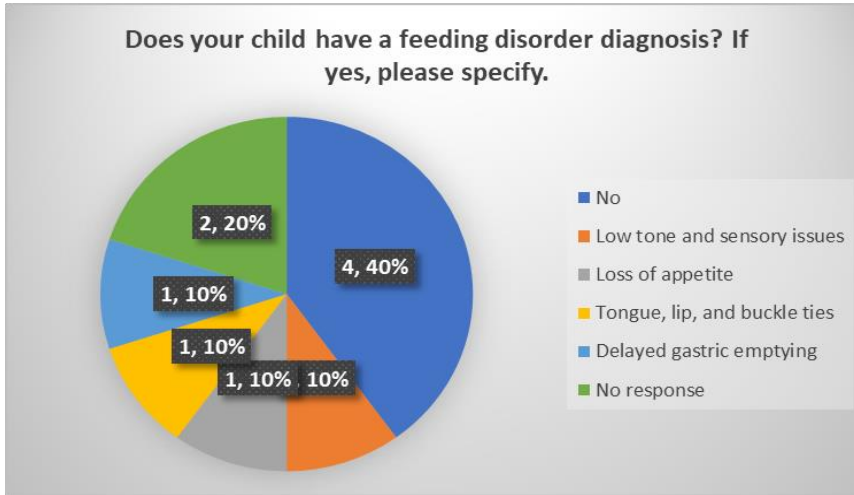
Hayley Henrikson Estrem

Note. Permission from Hayley Estrem, Feeding Impact Scale author, to adapt the Feeding Impact Scale to an electronic format, Google Forms. Stanbridge University IRB approved the use of a Google Form for obtaining data. All wording and scoring remained the same and authors have been properly attributed.

Appendix D

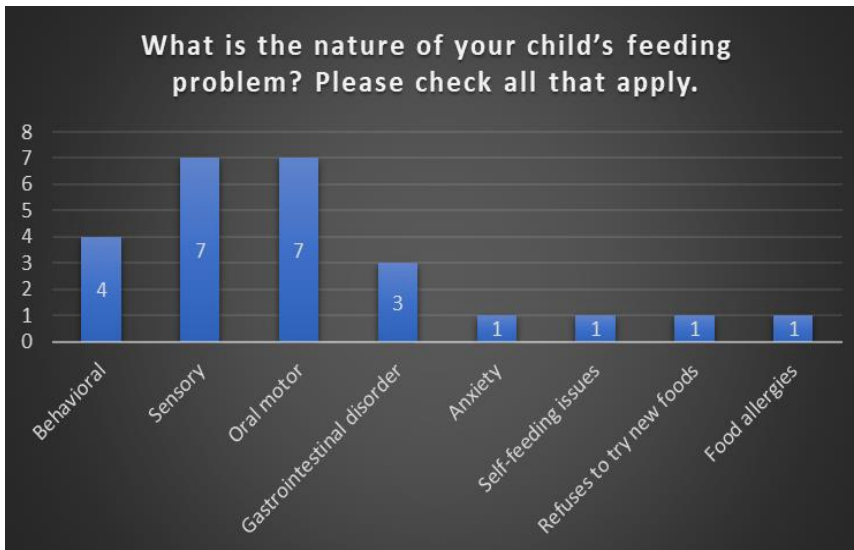
Quantitative Results: Demographics and Feeding Impact Scale Analysis

Figure D1

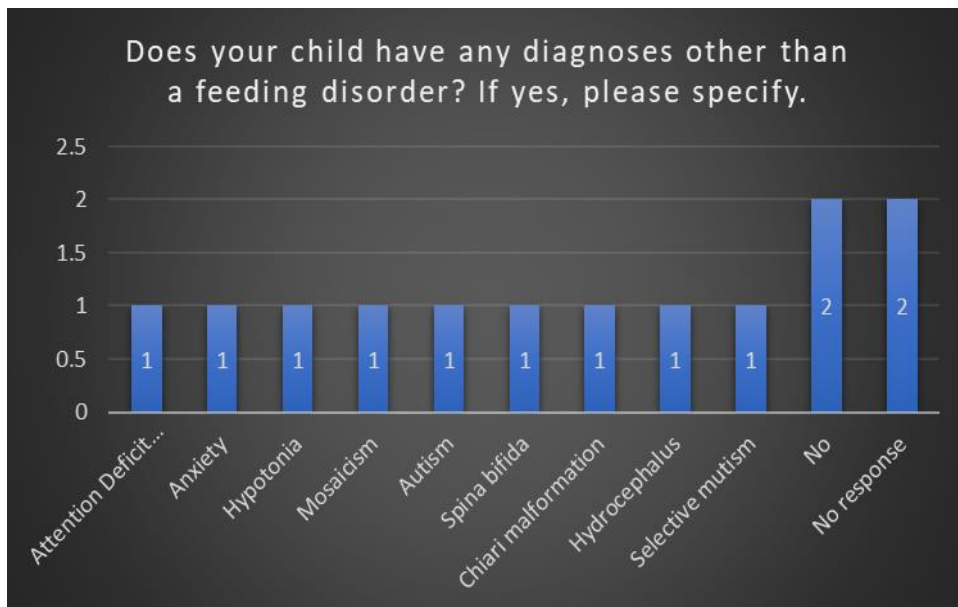


Note. Feeding disorder diagnosis. According to Figure D1, most participants indicated that their child does “not” have a feeding disorder diagnosis (n = 4; 40%).

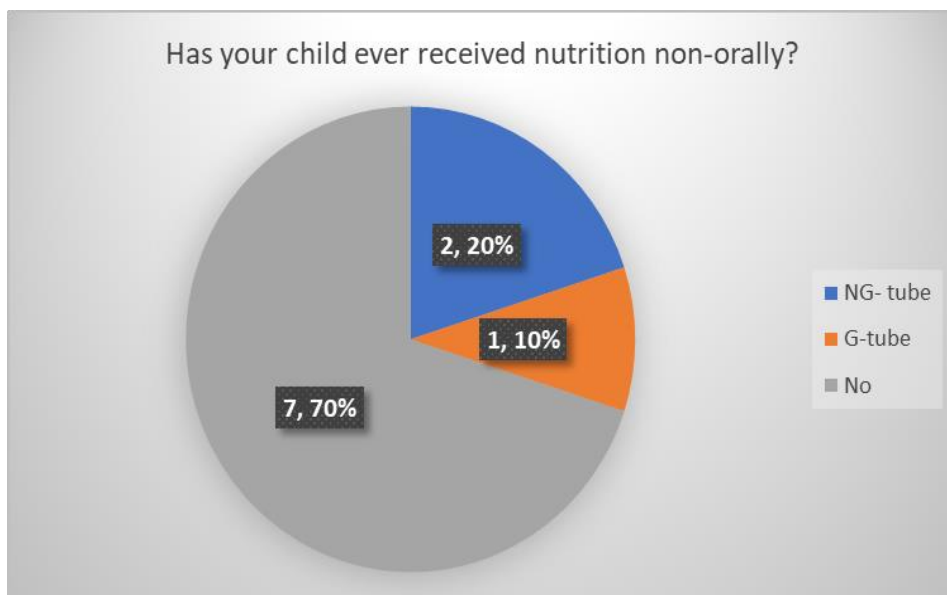
Figure D2



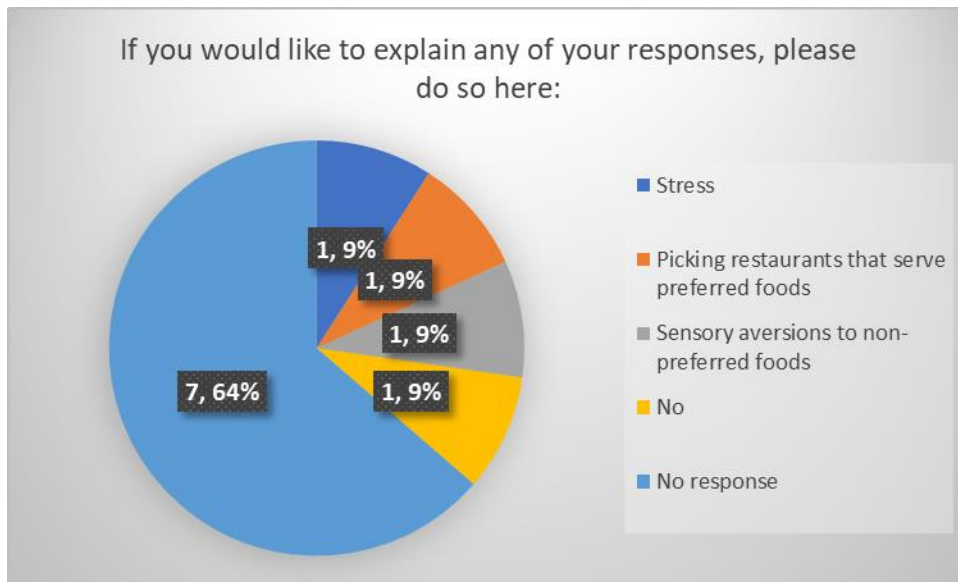
Note. Classifying the nature of the feeding difficulty. According to Figure D2, some of the participants indicate that the nature of their child’s feeding problem is “sensory” (n = 7; 63.64%), and “oral motor” (n = 7; 64.64%).

Figure D3

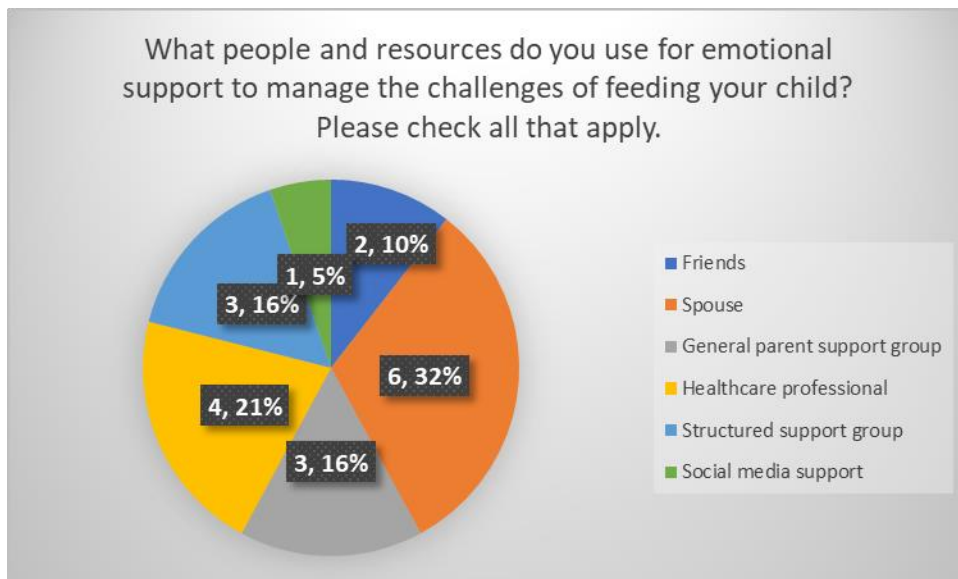
Note. Other diagnoses. According to Figure D3, most of the children of study participants have a specific diagnosis other than a feeding disorder (n = 9; 69.2%).

Figure D4

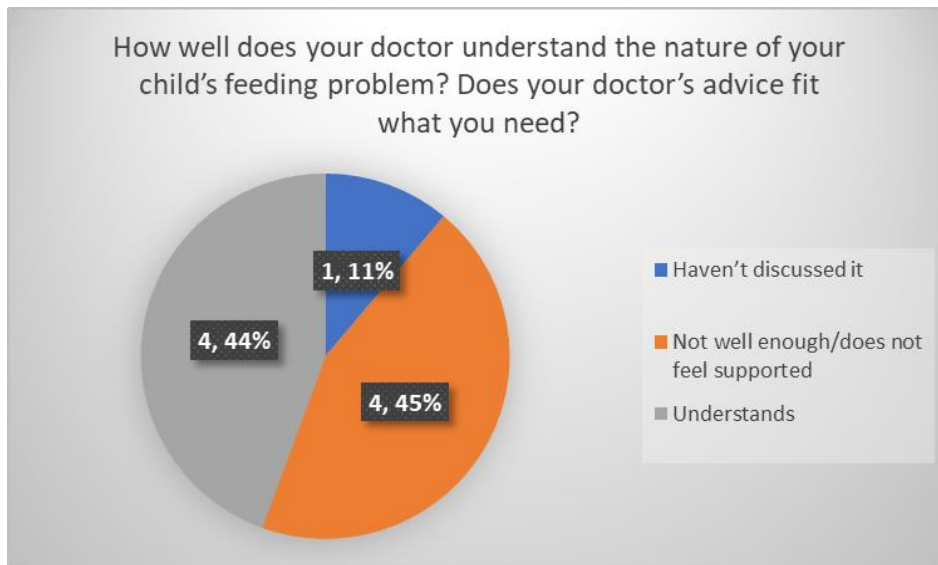
Note. Non-oral nutrition. According to Figure D4, most children of study participants have 'not' received nutrition non-orally (n = 7; 70%).

Figure D5

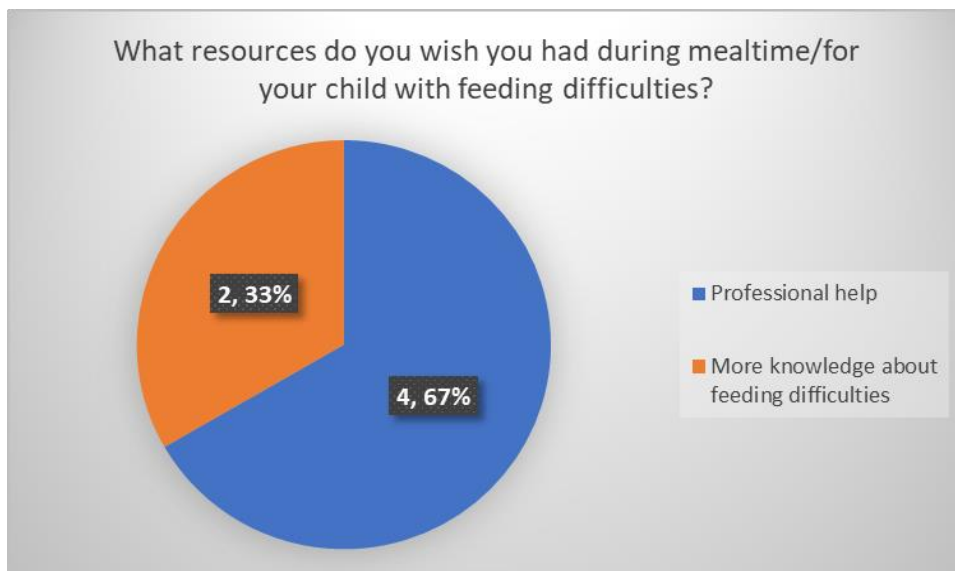
Note. Explanation of responses. According to Figure D5, most participants did not respond to this question (n = 7; 63.6%).

Figure D6

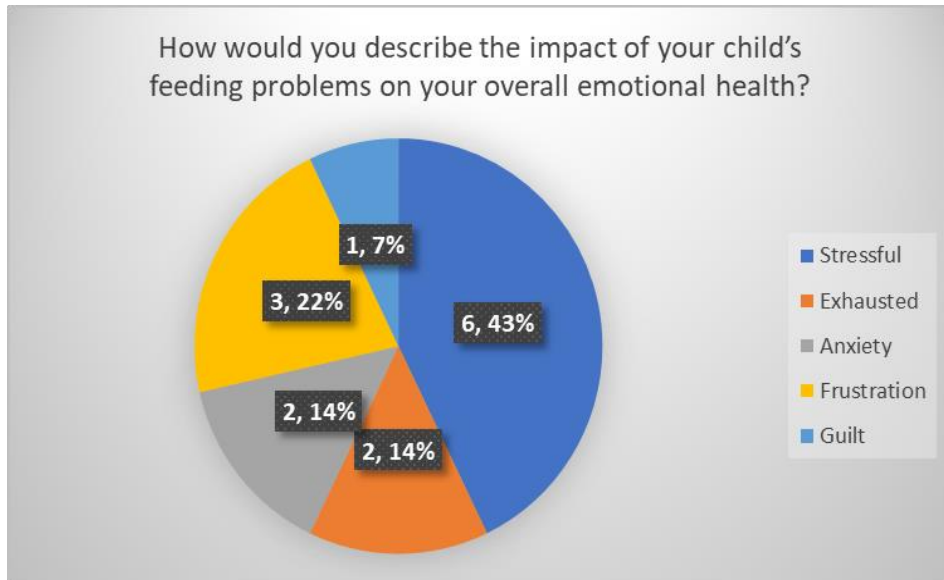
Note. People and resources used for emotional support. According to Figure D6, most study participants use their spouse for emotional support to manage the challenges of feeding their child (n = 6; 31.6%).

Figure D7

Note. Doctors' understanding of the feeding difficulty. According to Figure D7, some study participants claim that their child's doctor "does not understand well enough" (n = 4; 44%) while others feel their doctor "understands" (n = 4; 44%).

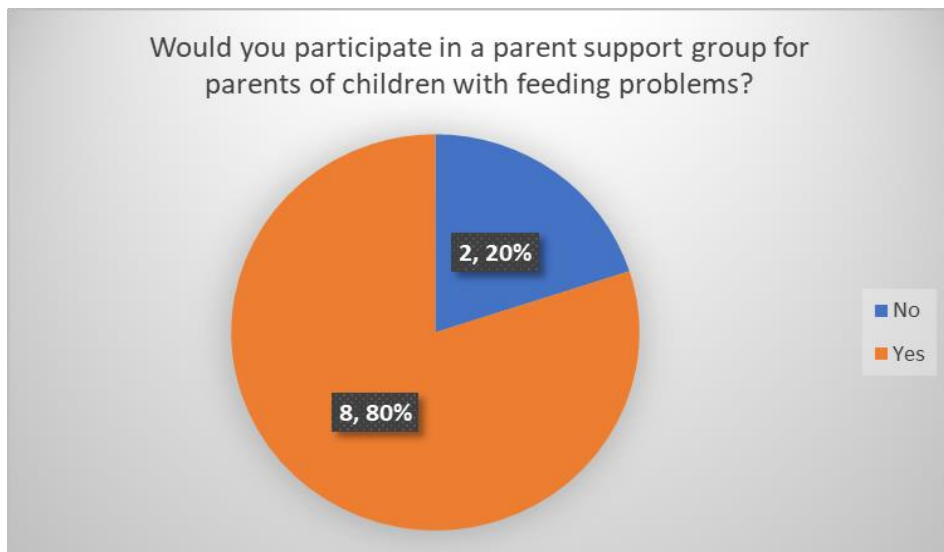
Figure D8

Note. Resources needed during mealtime/for the child with feeding difficulties. According to Figure D8, most study participants wish they had "professional help" during mealtime/for the child with feeding difficulties (n = 4; 67%).

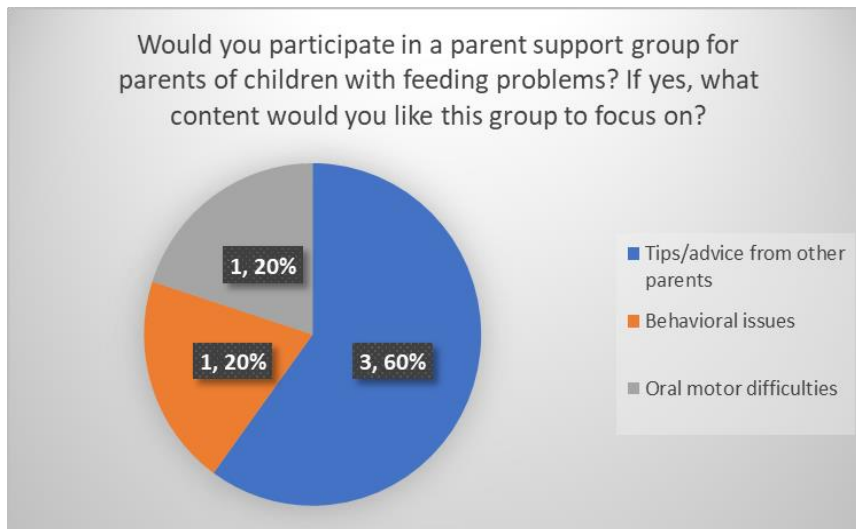
Figure D9

Note. Impact of child's feeding difficulties on caregivers' overall emotional health.

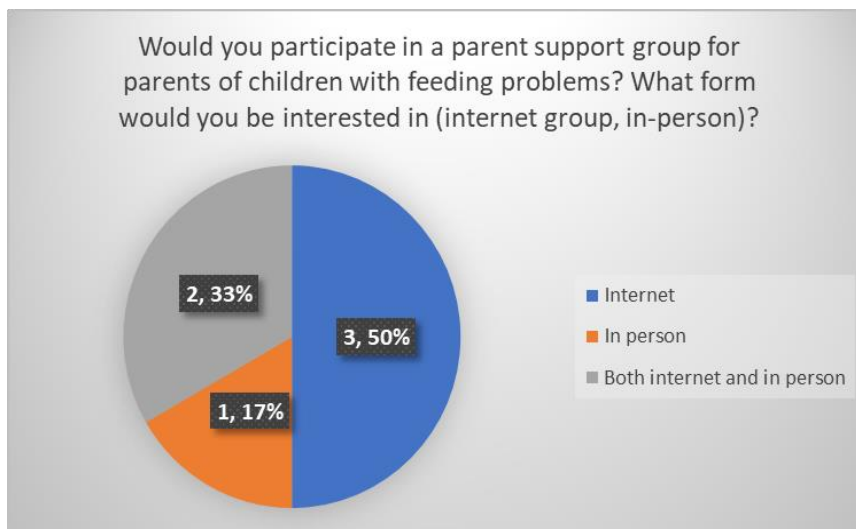
According to Figure D9, most study participants claim that their child's feeding difficulties are "stressful" on their overall emotional health (n = 6; 42.9%).

Figure D10

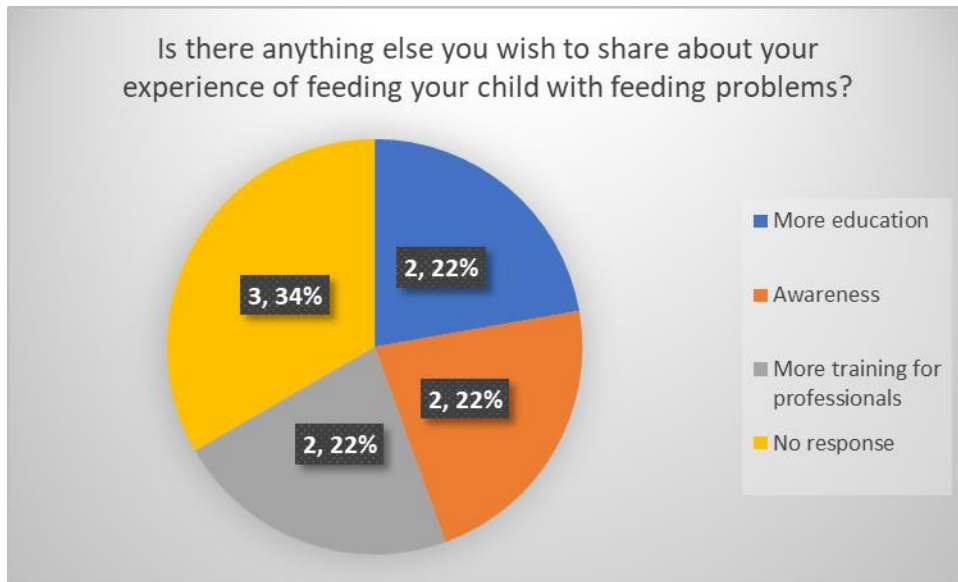
Note. Potential participation in a support group. According to Figure D10, most study participants would participate in a support group for parents of children with feeding problems (n = 8; 80%).

Figure D11

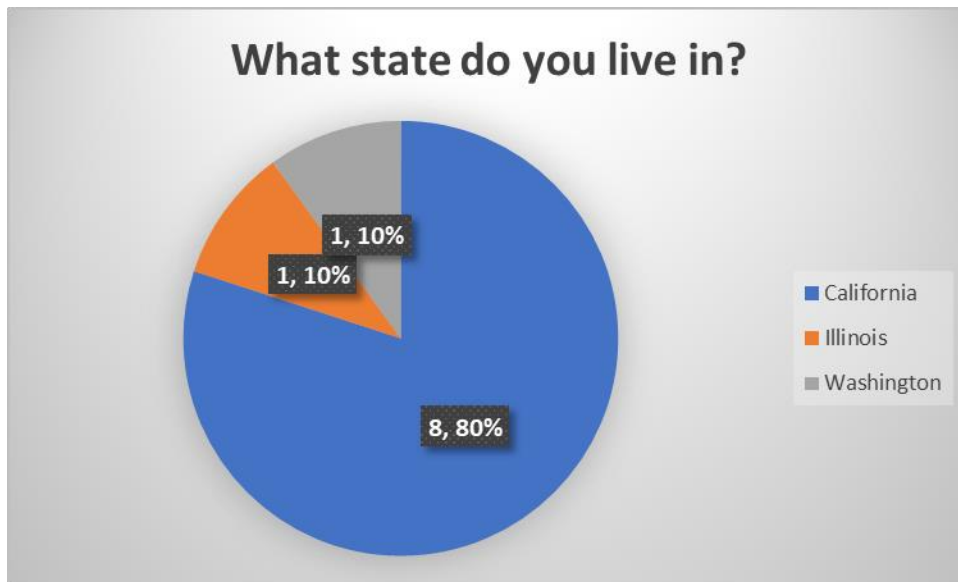
Note. Desired focus for a support group. According to Figure D11, most study participants from the above support group for parents of children with feeding problems [Figure 10] would like the group to focus on “tips/advice from other parents” (n = 3; 60%).

Figure D12

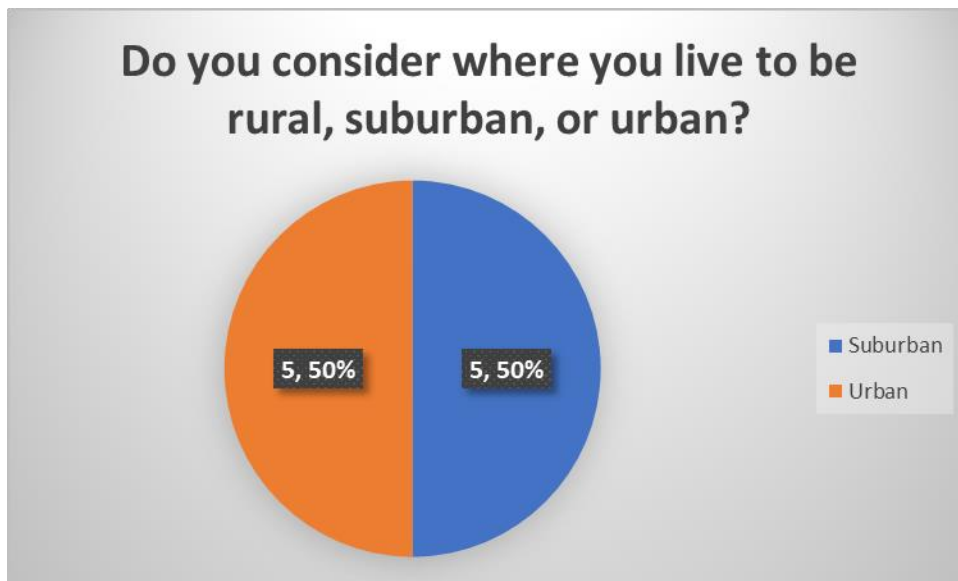
Note. Desired form of a support group. According to Figure D12, most study participants from the above support group for parents of children with feeding problems [Figure 10] would like for it to be conducted on the “internet/virtual” (n = 3; 50%).

Figure D13

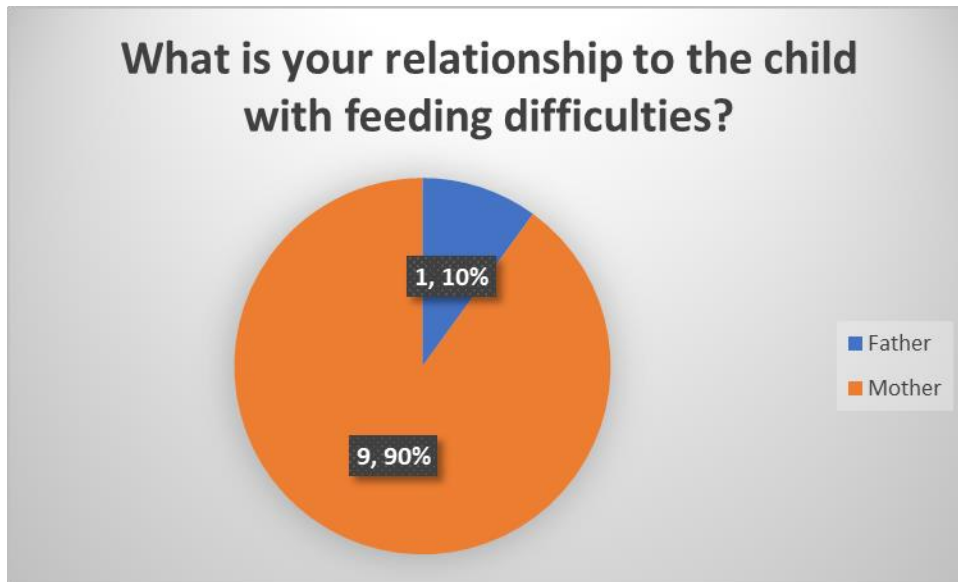
Note. Additional information about caregivers' experiences. According to Figure D13, some study participants would like "more education" (n = 2; 22%), "awareness" (n = 2; 22%), and "more training for professionals" (n = 2; 22%) when sharing experiences of feeding the child with feeding problems.

Figure D14

Note. States that participants live in. According to Figure D14, most study participants live in the state of “California” (n = 8; 80%).

Figure D15

Note. Classification of locations that participants live in. According to Figure D15, some study participants live in an area where they consider “suburban” (n = 5; 50%) or “urban” (n = 5; 50%).

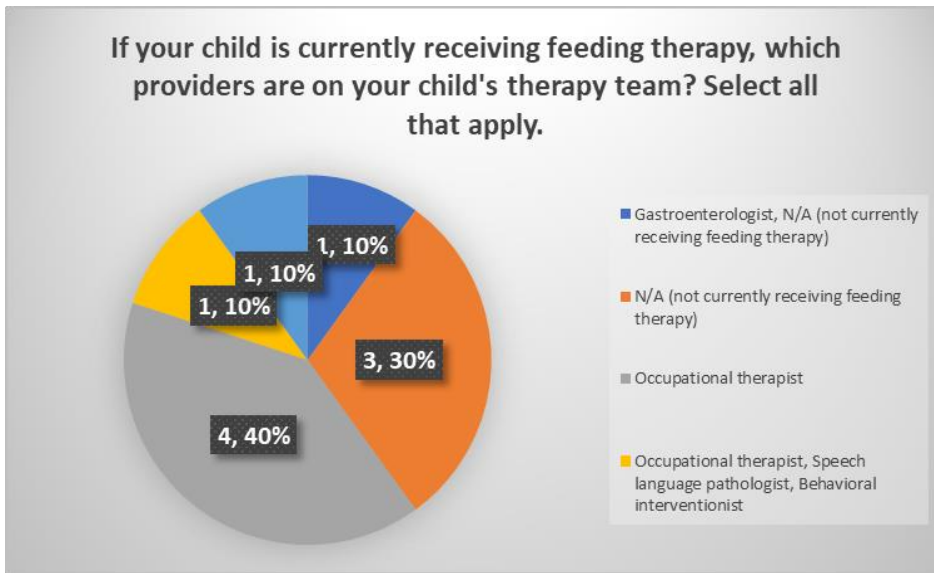
Figure D16

Note. Parental status of the caregiver. According to Figure D16, most study participants stated they are the mother of the child with feeding difficulties (n = 9; 90%).

Figure D17

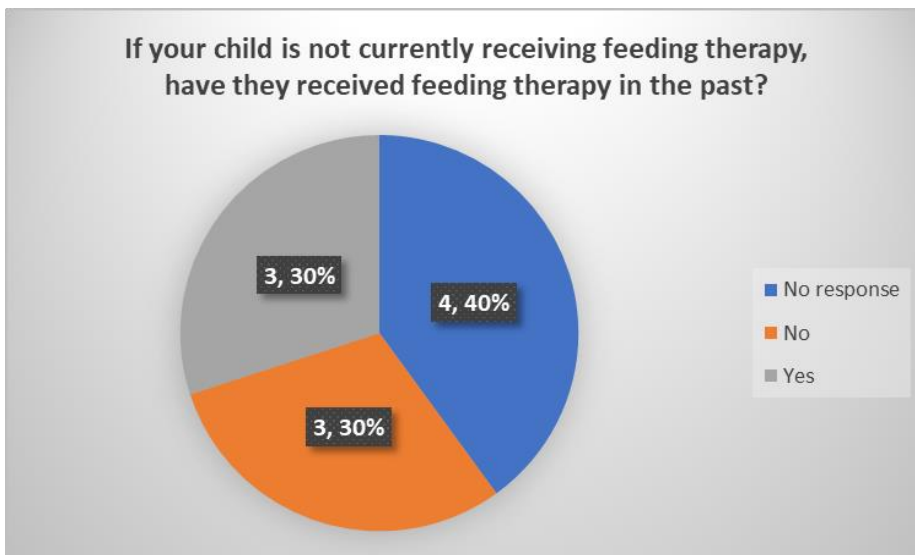
Note. Current number of foods that children of study participants eat. According to Figure D17, most study participants claim their child eats “20+” foods (n = 4; 40%).

Figure D18



Note. Providers on the child’s therapy team. According to Figure D18, most study participants stated that occupational therapists are on their child’s therapy team (n = 4; 40%).

Figure D19



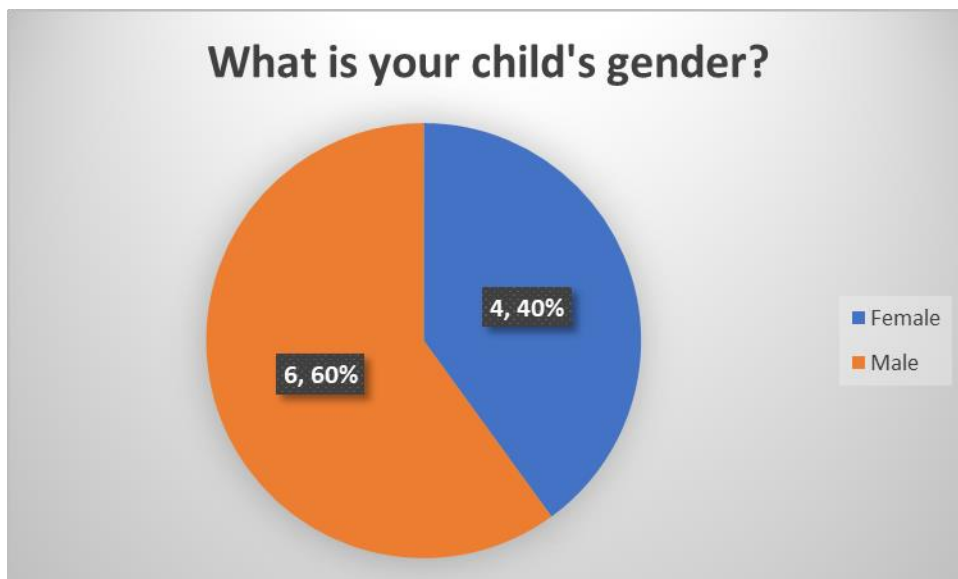
Note. Past feeding therapy. According to Figure D19, some study participants claim “no” (n = 3; 30%) and others “yes” (n = 3; 30%) that their child has received feeding therapy in the past.

Figure D20



Note. Age of children of study participants. According to Figure D20, some children of study participants are “2 years old” (n = 2; 20%) and others “3 years old” (n = 2; 20%) of age.

Figure D21



Note. Gender of children of study participants. According to Figure D21, most children of study participants are ‘male’ (n = 6; 60%).

Table D1

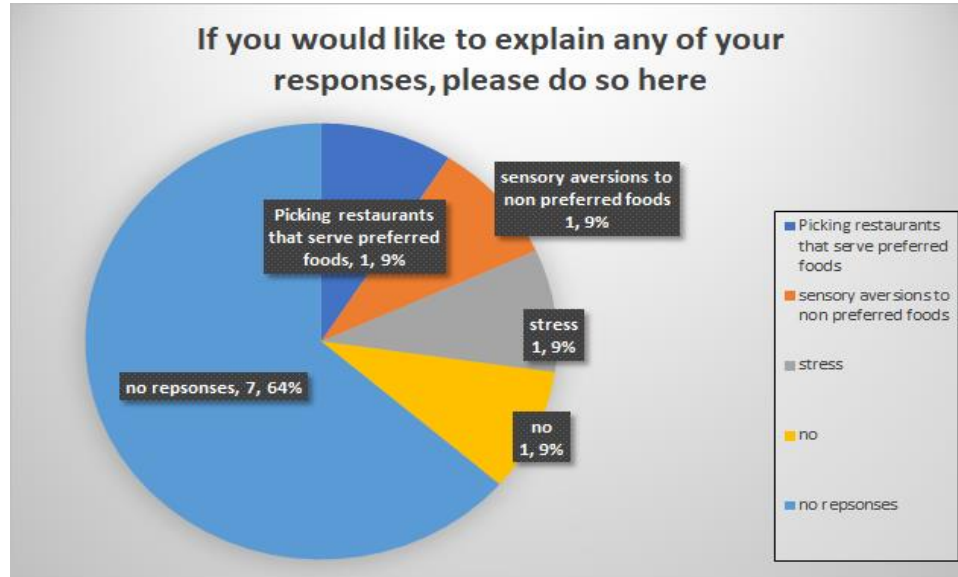
Question	Feeding Impact	Valid	Missing	M	Mod	SD	Min	Max
1	We have to plan ahead when eating somewhere other than our home.	10	0	4.00	5	1.05	2	5
2	Family mealtime is longer because of my child's feeding.	10	0	3.40	4 ^a	1.58	1	5
3	Other caregivers (grandparents, babysitters) have difficulty feeding my child.	10	0	3.70	5	1.49	1	5
4	The number of appointments my child has affects our family.	10	0	3.00	3 ^a	1.33	1	5
5	My child's feeding affects his/her siblings.	9	1	3.11	1 ^a	1.69	1	5
6	My child's feeding care affects my family financially.	10	0	2.80	3	1.40	1	5
7	There is more stress in my family because of my child's feeding.	10	0	3.90	5	1.20	2	5
8	Family members do not want to watch my child because of his/her feeding needs.	9	1	2.33	2	1.22	1	5
9	My family avoids social activities due to my child's feeding needs.	10	0	2.10	1	1.20	1	4
10	We can easily find a babysitter for our child.	9	1	3.67	3	0.87	3	5
11	My extended family understands my child's feeding needs.	9	1	3.33	4	1.22	1	5
12	My family enjoys eating in a restaurant.	10	0	3.20	3	1.14	2	5
13	Mealtime is pleasant for my family.	10	0	3.40	4	0.97	2	5
1-13	Total Feeding Impact - Family Score ^b	10	0	40.70	51	9.79	26	51
14	My child requires more of my effort at mealtime because of the way he/she eats than other children his/her age.	10	0	4.40	5	0.97	2	5
15	I feel other people do not understand my child's feeding needs.	10	0	4.30	4	0.67	3	5
16	I worry about how long it will take for my child's feeding to get better.	10	0	3.50	2 ^a	1.27	2	5
17	Feeding my child requires extra patience.	10	0	4.80	5	0.42	4	5
18	I have to prepare a special meal for my child because of his/her feeding needs.	10	0	4.50	5	0.85	3	5
19	Meeting my child's nutritional requirements is a daily concern.	10	0	3.90	5	1.29	1	5
20	I worry daily about my child's feeding.	10	0	3.40	2 ^a	1.43	2	5
21	I worry that my child's feeding affects his/her health.	10	0	3.50	4 ^a	1.43	1	5
22	Feeding my child takes more than 20 minutes.	10	0	4.00	5	1.33	2	5
23	I worry the way my child eats will affect his/her development.	10	0	3.60	3	0.97	2	5
24	I feel frustrated that I do not know how much my child will eat.	10	0	2.60	3	1.07	1	4
25	There is more stress in my life because of my child's feeding.	10	0	4.00	4	1.15	1	5
14-25	Total Feeding Impact - Parent Score ^c	10	0	46.50	37 ^a	6.69	37	56

Note. Feeding Impact Scale Scores. The mean, mode, standard deviation, minimum, and maximum are shown for each item on the Feeding Impact Scale. The scale is divided into family and parent sections.

Appendix E

Quantitative Results: Frequencies of Qualitative Coding Schemes

Figure E1



Note. The frequency of codes applied to an open-response question on the Feeding Impact Scale.

Figure E2

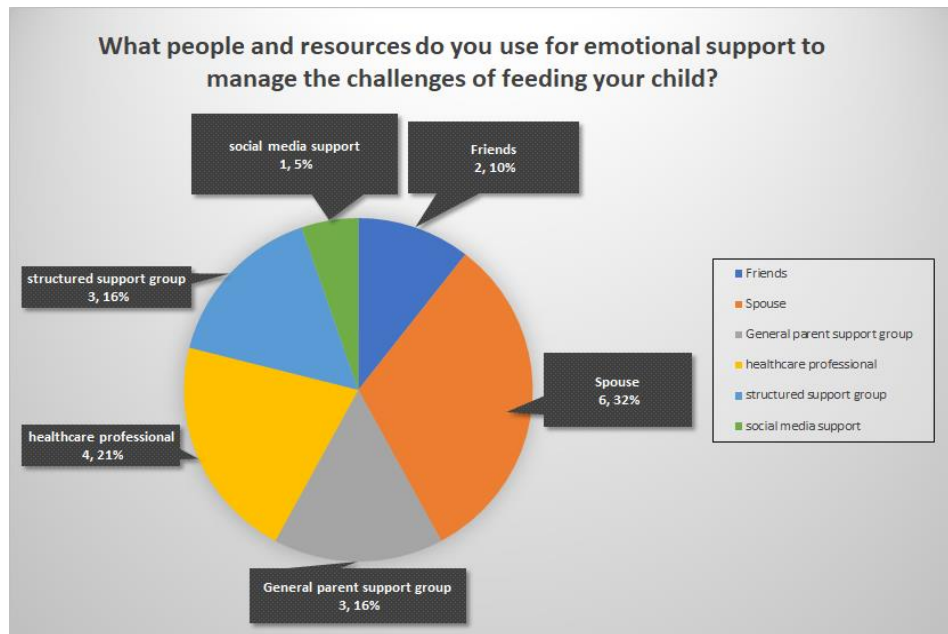


Figure E3

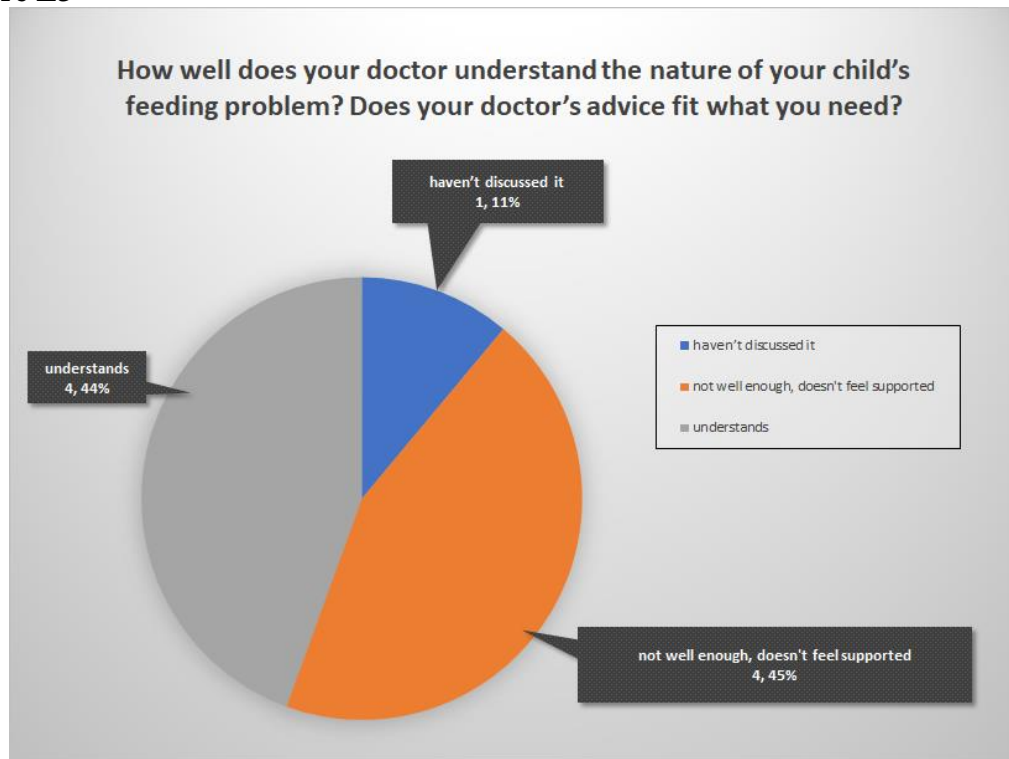


Figure E4

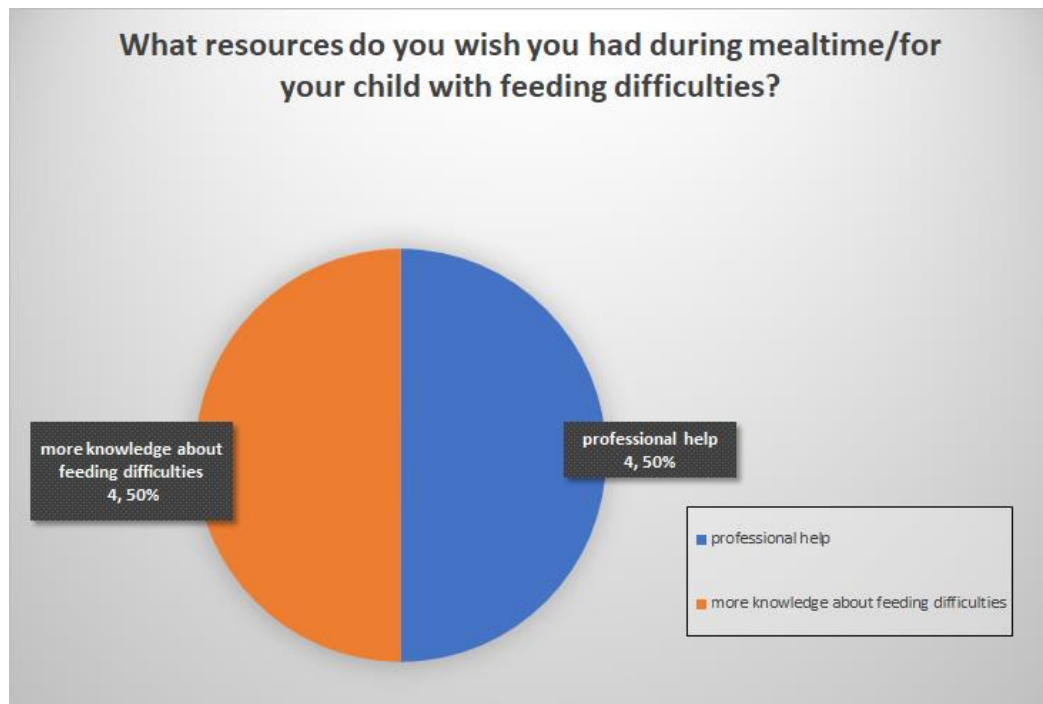


Figure E5

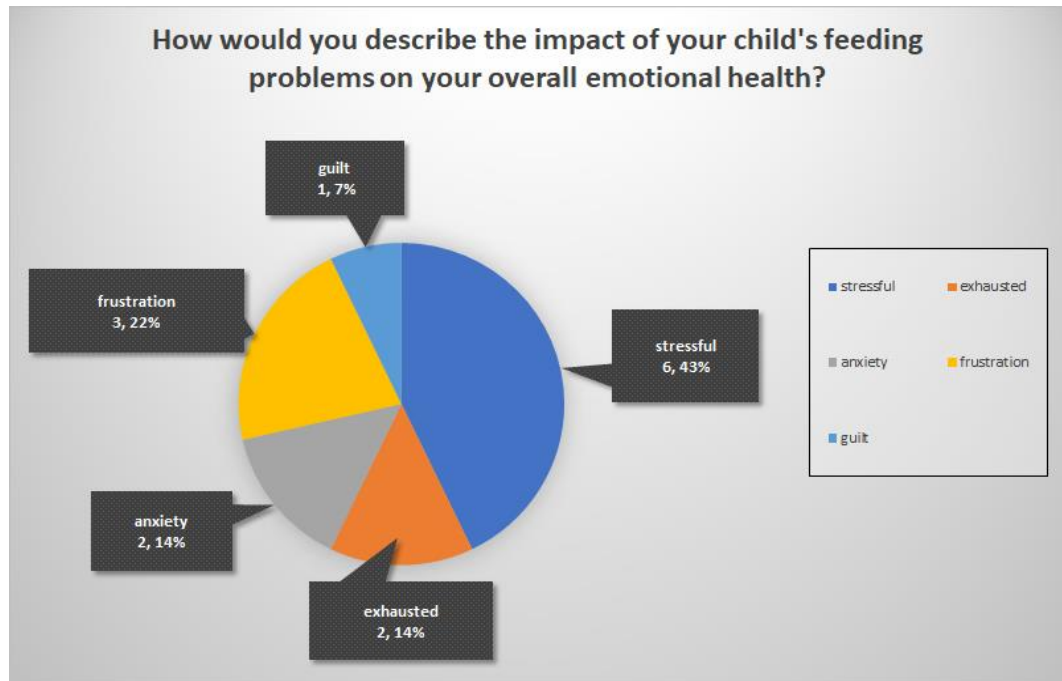


Figure E6

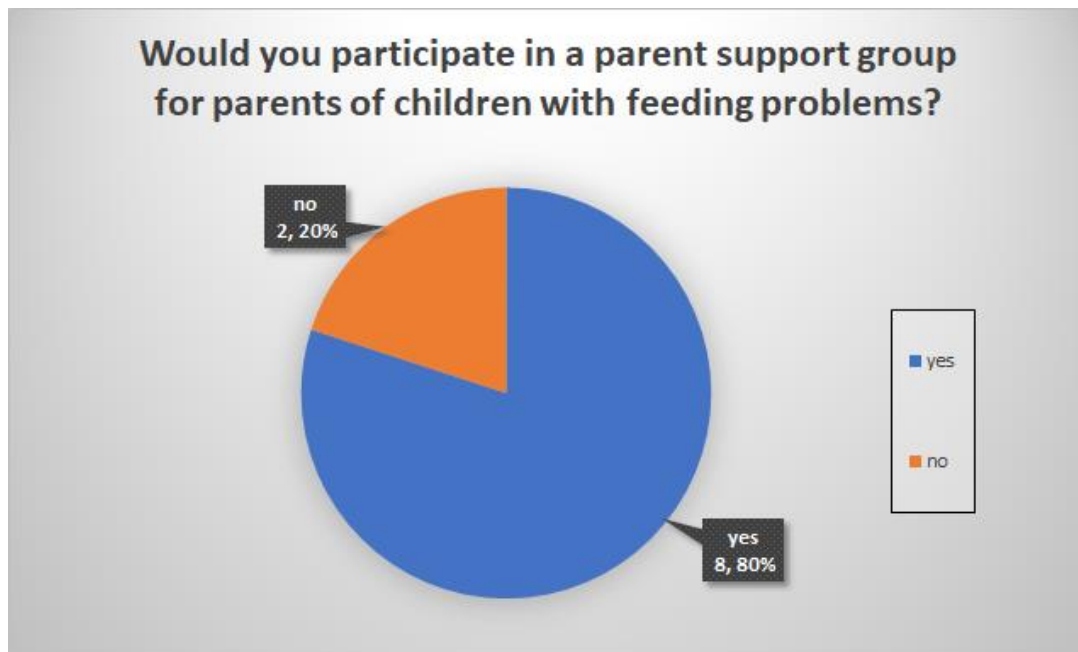


Figure E7

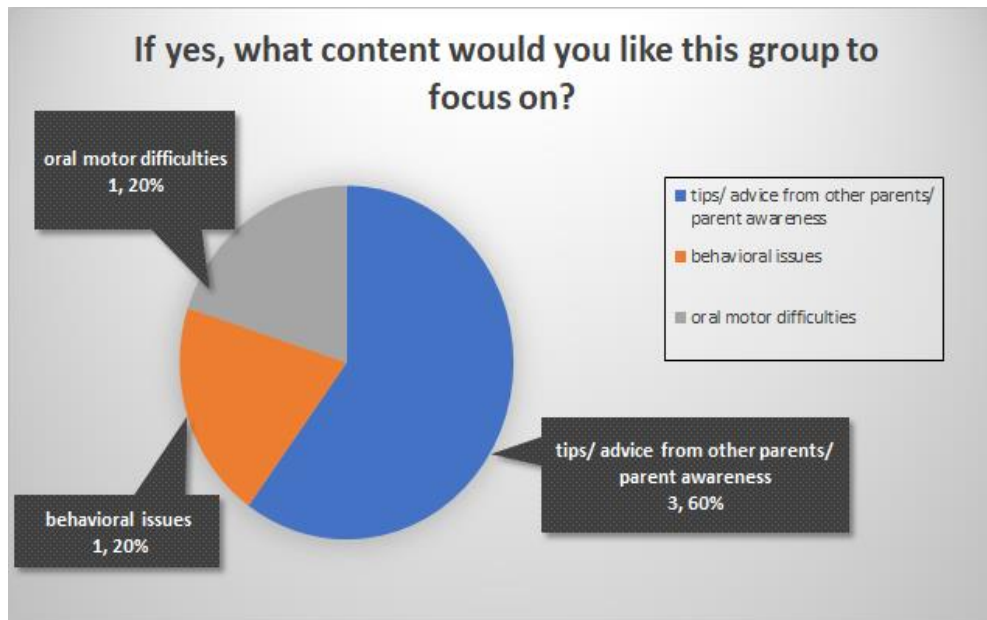


Figure E8

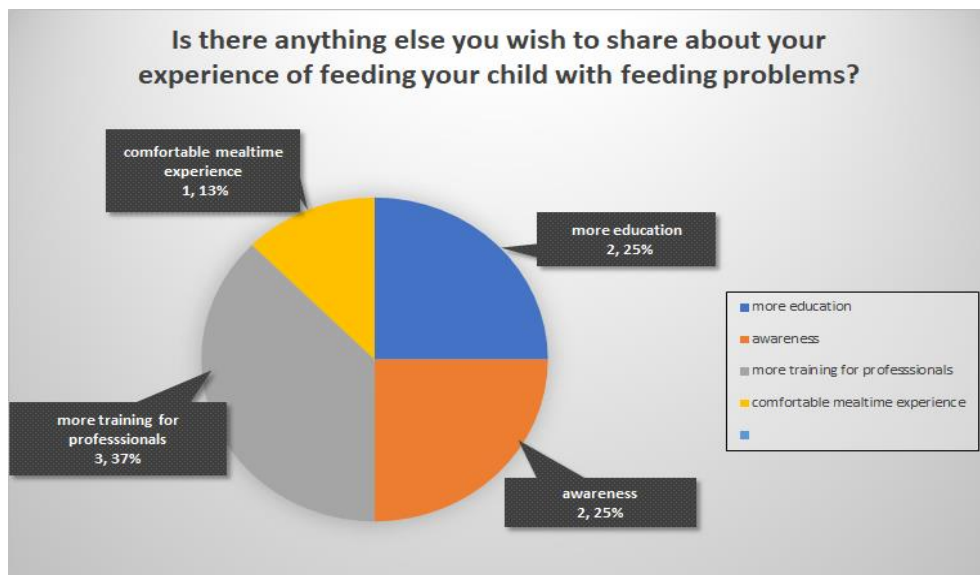


Figure E9

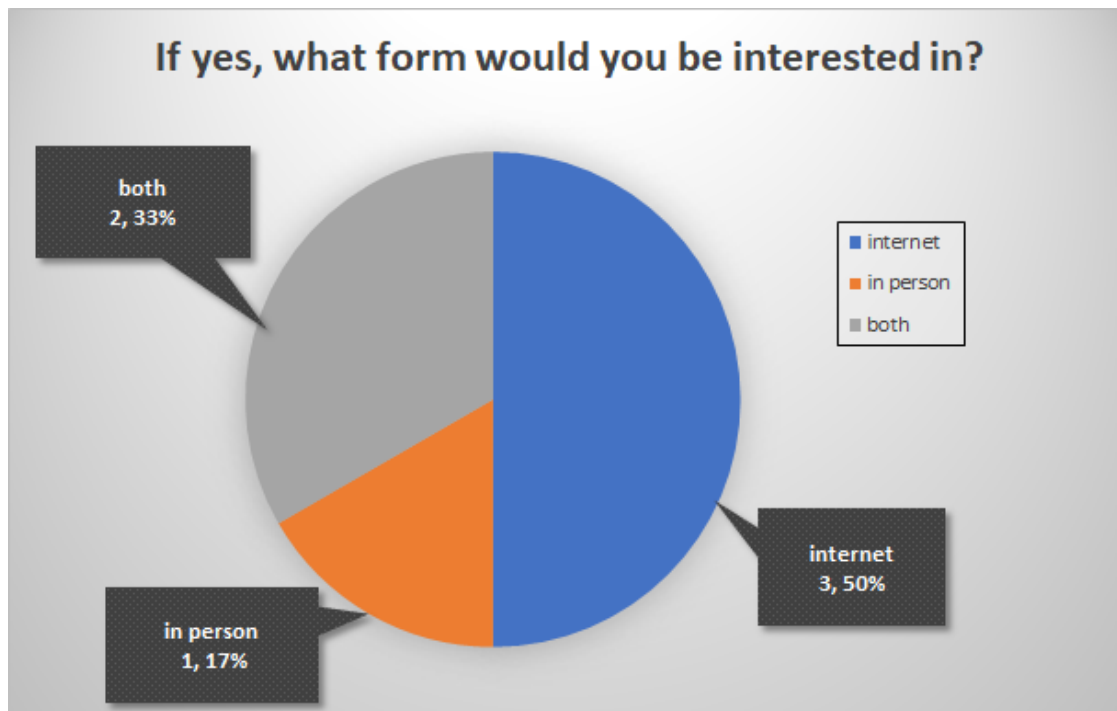
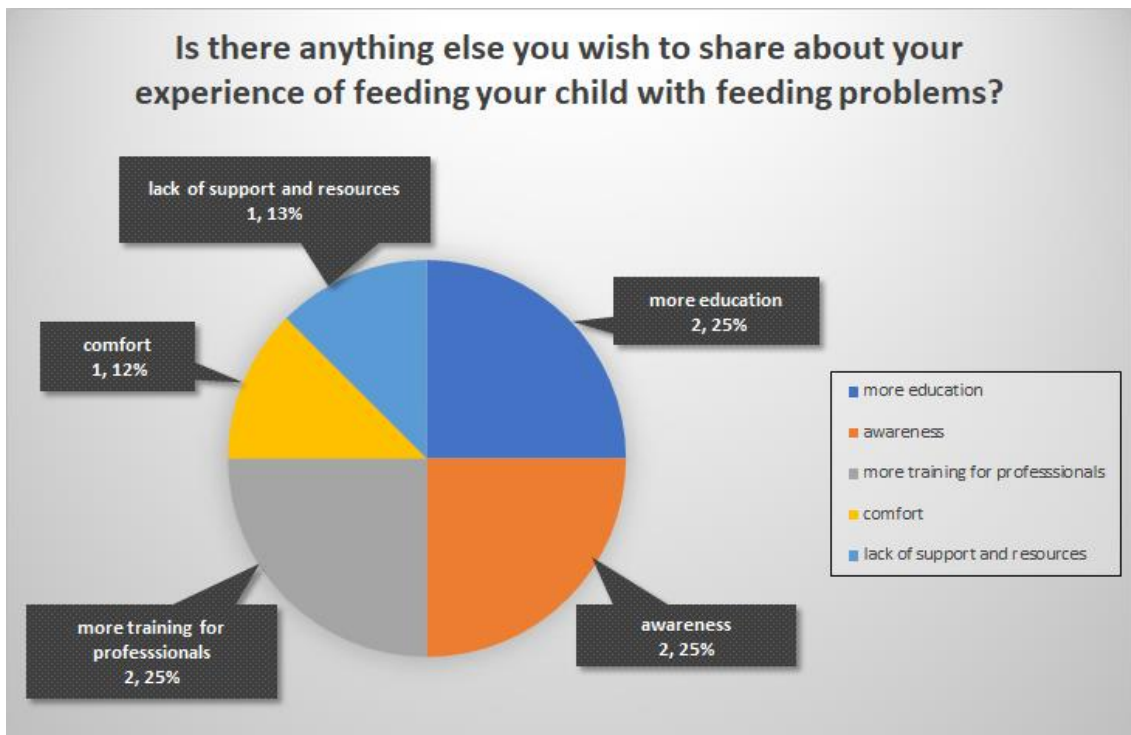


Figure E10



Appendix F

Informed Consent Form

Impacts on Parents of Children with Feeding Difficulties

Consent Form

The purpose of this research project is to understand the impact on parents of children with feeding difficulties, current support available, and additional support that may be beneficial. This is a research project being conducted by Masters of Science in Occupational Therapy students at Stanbridge University. You are invited to participate in this research project because you are the parent/caregiver of a child with a feeding difficulty.

Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw from participating at any time, you will not be penalized.

The procedure involves filling an online survey that will take approximately 30 minutes. Your responses will be confidential and we do not collect identifying information such as your name or IP address. The survey questions will be about demographics, the impact on the family and parent of having a child with a feeding difficulty, the current areas of support available, and what additional support may be beneficial. At the end of the survey, you will have the opportunity to enter your email address for a \$25 gift card raffle drawing. Email addresses will be stored separately from survey responses and will be deleted upon completion of the raffle.

We will take various precautions to protect the confidentiality of all subjects. All data is stored in a password protected electronic format. To help protect your confidentiality, the surveys will not contain information that will personally identify you. The results of this study will be used for scholarly purposes only and may be shared with Stanbridge University representatives.

If you have any questions about this survey, please contact michelle@centerfordevelopingskids.com. This research has been reviewed according to Stanbridge University Institutional Review Board procedures for research involving human subjects.

Researchers- Rosalie Whyte (Rosalie.Whyte@my.stanbridge.edu), Tiffanie Tang (tiffanekntang@gmail.com), Judy Le (judy1994@gmail.com), Melissa Le (Melissa.Le@my.stanbridge.edu). Advisor- Michelle Knight, OTR/L, SWC (michelle@centerfordevelopingskids.com)

* Required

ELECTRONIC CONSENT: Please select your choice below. Clicking on the "agree" button below indicates that: you have read the above information, you voluntarily agree to participate, and you are at least 18 years of age. If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button and close the survey. *

Agree

Disagree

Please type: AJ1GX9. (This is to verify you are a human.) *

Your answer _____

Where did you hear about our survey? *

Your answer _____

[Next](#)

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Google Forms

Note. Informed consent form that participants must complete and select agree to be included in data analysis.

Appendix G
IRB Approval

03/29/2021

Re: IRB Application Number MSOT10-08

Dear Ms. Knight,

The Stanbridge University Institutional Review Board has completed the review of your application entitled, "Impact of Having a Child with Feeding Difficulties and Parental Support." Your research protocol MSOT10-08 is formally accepted as completed and categorized as exempt.

Should you wish to make modifications to this approved protocol, please submit a modification form for IRB review and approval. No changes may take place without IRB approval.

Sincerely,

Dominique N. Wascher, Ph.D.
IRB Chair

Note. Stanbridge University IRB Approval. All study modifications, including recruitment changes and updates to inclusion and exclusion criteria, were submitted and approved by the IRB.

Appendix H

Site Agreement with Center for Developing Kids

Figure H1

Research Site Agreement Form
Master of Science in Occupational Therapy

AGREEMENT

Research Site: Center for Developing Kids

Research Site Address: 2555 E. Colorado Blvd, Ste 100, Pasadena, CA 91107

Title of Proposed Research: Impact of Having a Child with Feeding Difficulties and Parental Support

STANBRIDGE UNIVERSITY MASTER OF SCIENCE IN OCCUPATIONAL THERAPY DEGREE PROGRAM

Student Investigator(s) Name(s):

1. Rosalie Whyte
2. Tiffanie Tang
3. Judy Le
4. Melissa Le

Principle Student Investigator Name: Michelle Knight, MS, OTR/L, SWC

Email address: michelle@centerfordevelopingkids.com Phone Number: 626-695-6716


Duration of the study: 15 weeks

Authorization Effective Date: April 5 2021 Authorization Expiration Date: July 23, 2021

Allowed Number of Contact Hours: N/A The study will be completed by (date): July 23, 2021

Description of Research:

This study seeks to understand the impact on parents of having a child with feeding difficulties, the supports available, and to identify additional supports. Study will include an anonymous parent survey using the Feeding Impact Scale and open ended questions.

 **STANBRIDGE UNIVERSITY**

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Note. Site agreement with Center for Developing Kids due to significant recruitment of participants from the site and interest in future partnership pending results.


Figure H2

Research Site Agreement Form
Master of Science in Occupational Therapy

Intellectual Property Statement:
Stanbridge University reserves the right to use, publish, and disseminate the results of the research findings. The University shall provide the research site with a copy of the final research product at the earliest practicable time.

Thesis Advisor Contact Information:
Name: Michelle Knight
Email address: Michelle@centerfordevelopingkids.com Phone Number: 626-695-6716

RECRUITMENT PLAN
Means by which the researcher(s) will contact and/or recruit participants:
A flier with a link to the survey will be sent to occupational therapists working with children with feeding difficulties using social media, AOTA and OTAC forums, and online feeding therapy groups. Therapists can pass the information to parents of clients with feeding difficulties.

SITE REPRESENTATIVE AGREEMENT
I agree to the recruitment and data collection methods to be used in this study, and I authorize the investigator to conduct research at:
Facility Name/Research Site Name: Center for Developing Kids
Representative authorizing agreement: Michela Gabriele
Title: Director
Signature:  Date: 2/5/21



Note. Site agreement with Center for Developing Kids due to significant recruitment of participants from the site and interest in future partnership pending results.