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Thomas F. Fisher
Indiana University - USA, fishert@iu.edu

Anna Dusick
University of Wisconsin - Madison - USA, fishert@iupui.edu

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Case Study: Caregiver Perception of Pediatric Multidisciplinary Feeding Outpatient Clinic

Abstract

This study explores the perception of satisfaction of caregivers who attended a feeding clinic at a large pediatric hospital in the midwest. The clinic is designed for a multidisciplinary team to meet with the child and the caregiver. Thirty-five participants were involved in the study. Results indicated that most participants were satisfied with the clinic experience. However, there were areas of care not covered by the members of the feeding team, which indicates a need. It is suggested that this need could be filled by occupational therapists.

Keywords

feeding problems, pediatrics, multidisciplinary approach, occupational therapy

Cover Page Footnote

This manuscript would not have been possible without the contributions of Dr. Anna Dusick. Unfortunately, while collaborating on the manuscript, Anna became ill and subsequently passed away very quickly. She was passionate about occupational therapy for the six years that she practiced before deciding to enter medical school. She often shared with OT students, medical students, residents, and fellows, that because of her occupational therapy knowledge and skills, she was a better neurodevelopmental pediatrician. She would be satisfied that this study and the results are being shared with the community who is helping young children with the occupation of eating, feeding, and swallowing. The authors would like to recognize Natalie Brassard, MS, OTR; Laura Bergstrom, MS, OTR; Lauren Cleary, MS, OTR; and Ashley Hedges, MS, OTR. They were the student co-investigators at the time this study was conducted and provided the foundation for this manuscript.

Credentials Display and Country

Thomas F. Fisher, PhD, OT, FAOTA
Anna Dusick, MD, OT - USA

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Feeding, eating, and swallowing are part of an active, multisystem process that is reliant on an individual's oral motor functioning, physicality, oral sensation, position in space, and interaction with both living and non-living contextual factors (Caretto, Topolski, Linkous, Lowman, & Murphy, 2000). The American Occupational Therapy Association (AOTA) defines feeding as "the process of setting up, arranging, and bringing food [or fluid] from the plate or cup to the mouth; sometimes called self-feeding" (AOTA, 2008, p. 276). They define eating as "the ability to keep and manipulate food or fluid in the mouth and swallow it; eating and swallowing are often used interchangeable" (AOTA, 2008, p. 276). Swallowing is defined as "a complicated act in which food, fluid, medication, or saliva is moved from the mouth through the pharynx and esophagus into the stomach" (AOTA, 2008, p. 276).

Approximately 25% of otherwise normally developing children and up to 80% of children with developmental disabilities have problems with feeding, eating, or swallowing and are at risk for not developing successful feeding behaviors (Arvedson, 2008; Cornwell, Kelly, & Austin, 2010). Some examples of feeding problems include an inability to transition to solid food, insufficient caloric intake, and a limited range of food choice (Linscheid, 2006). The insufficient development of age appropriate reflexes, low muscle tone, weakness, postural instability, and inappropriate sensorimotor integration are all factors that may contribute to the development of a feeding problem

(Arvedson, 2008; Rudolph & Link, 2002). Indeed, abnormal bite and swallowing, insufficient tongue lateralization, lower jaw instability, and irregular biting can severely disrupt a child's ability to consume food safely and receive the necessary nourishment for growth and development (Arvedson, 2008; Rudolph & Link, 2002). Dysphagia, a common diagnosis in individuals with feeding difficulties, is defined as a "wide range of feeding and/or swallowing dysfunction in infants and children" (Miller & Willging, 2003, p. 442). Children may also develop feeding and swallowing issues secondary to medical issues, including gastrointestinal surgeries, burns, cancer, and/or developmental disabilities, such as cerebral palsy or autism. Some feeding and swallowing issues develop during active growth stages occurring from birth to age two years.

Feeding and eating are vital occupations. Occupation is described as a client's interests, goals, habits, routines, and everyday tasks necessary to support participation in everyday life (AOTA, 2008). The scope of occupational therapy practice includes the provision of services to children with developmental issues, such as feeding, eating, and swallowing (Stoner, Bailey, Angell, Robbins, & Polewski, 2006). Occupational therapy has been identified as a discipline commonly involved in specialized programs established primarily to address feeding and swallowing issues (Simonsmeier & Rodriguez, 2007).

Clinical settings can address feeding issues through a feeding program. A feeding program

involves a team of specialists from many disciplines providing recommendations and quality care for individuals with feeding difficulties (Miller et al., 2001; Simonsmeier & Rodriguez, 2007). Clinical feeding programs are often multidisciplinary, with the specialists involved using variations in assessment modalities and intervention strategies (Duval, Black, Gesser, Krug, & Ayotte, 2009; Rudolph & Link, 2002). The timely and effective management of pediatric feeding disorders is essential in order to prevent further health deterioration, such as esophagitis, respiratory complications, aspiration, weakness, and/or skin breakdown issues (Schwarz, Corredor, Fisher-Medina, Cohen, & Rabinowitz, 2001). Therefore, it is essential for the practitioners involved in a feeding program to have a professional understanding of the inclusion of evidence-based interventions from multiple theoretical frameworks. A clinical feeding team typically includes a pediatrician, a pediatric gastroenterologist, an occupational therapist (OT), a speech and language pathologist (SLP), and a registered dietician (RD) (Cooper-Brown et al., 2008).

OTs serve on the multidisciplinary feeding teams in hospitals, clinics, and schools. Occupational therapy practitioners have professional education in anatomy, physiology, neuroscience, human development and behavior, and the psychological and social sciences (AOTA, 2008). As a part of specialized services, OTs are able to evaluate clients as well as administer and interpret assessments (AOTA, 2008). Despite the

OT's traditional role on a feeding team of integrating sensorimotor experiences and recommending adaptive equipment and assistive devices for proper positioning and self-feeding, the responsibilities of the OT are not always fully understood by other professionals on the multidisciplinary team (Caretto et al., 2008; Wooster, Brady, Mitchell, Grizzle, & Barnes, 1998).

Caregiver and infant or child feeding interactions can be problematic. Twenty-two percent of the caregivers of children with feeding problems report children vomiting (spitting up) after eating, while 56% report choking during feeding, and 28% describe mealtimes as stressful (Barratt & Ogle, 2010). A feeding problem not only disrupts the child's overall development, but also substantially impacts the caregiver and child interaction. This can cause intense emotional distress for the caregiver (Greer, Gulotta, Masler, & Laud, 2008).

Medically fragile clients who have specific and critical nutritional issues require feeding programs to address these specialized issues (AOTA, 2008). Feeding programs develop because of concerns from families and caregivers about assessing proper expertise and resources in the field of pediatric feeding (Simonsmeier & Rodriguez, 2007). The children involved in clinical feeding programs are often in hospitals repeatedly with medical problems, including respiratory, cardiac, gastrointestinal, metabolic, neurological, or prematurity issues. This may have a substantial impact on their daily lives, as well as the lives of

their caregivers and family members (Franklin & Rodger, 2003; Kedesdy & Budd, 1998). Members of the multidisciplinary team must provide the caregiver and families with resources to ensure the child's success with learning self-feeding skills. It is essential to include the caregivers and families in all aspects of the child's progression in a clinical feeding program.

Purpose, Design, and Methodology

The purpose of this descriptive study was to determine caregivers' perceptions of feeding program services, including their level of satisfaction with the services received in the outpatient feeding clinic of a large hospital for children in the midwest. The research team used survey methodology with a study-specific survey that was developed by the team. The primary investigator and co-primary investigator are experts in the field of feeding problems of young children with more than thirty years of clinical experience combined.

The institutional review board approved the study. The research team recruited participants for the study during a follow-up visit in the outpatient feeding clinic, and provided the participants with an informed consent. Consent was done by a co-investigator. If the caregiver agreed to participate, they were asked to complete the survey. The participants returned the survey as they left the clinic for the day. Therefore, the participants were a convenience sample: those who came to the clinic during the four-month data collection period.

The outpatient feeding team primary physician gave an informational handout to the study team in order to provide an overview of the services offered in the outpatient feeding clinic. The handout described the program as comprised of three developmental pediatricians, a nurse practitioner, an SLP, dieticians, an OT (as needed), a social worker (as needed), and a child psychiatrist (as needed). The section on multidisciplinary team members will discuss the roles of each of these team members.

In order to provide beneficial and medically reasonable services to caregivers with children who have feeding problems, organizations need to assess satisfaction and determine whether the client's needs are met. Client satisfaction and meeting a client's needs are the goal of service providers.

Gathering the perceptions of caregivers involved in feeding programs allows providers to better understand their population's needs and to identify the relevant issues and components. The intent of this study was to have the outpatient feeding program use the information collected to improve services and to assess the value of the professionals providing clinic services. Providing quality feeding services involves clear interventions established using a multidisciplinary approach. Families and caregivers must believe that the status and progression of their child's health and feeding issues are understood, and that they will be able to support the child when at home (Miller et al., 2001). Simply stated, if a child's nutrition and development improve, the families and caregivers

will have fewer occasions to access the health care system, thus using fewer resources and strengthening their community and family systems.

There is limited literature regarding the perceptions of clients receiving feeding services. Improvement in the interactions among health professionals and the families and caregivers of children with disabilities is more likely to occur when health care professionals understand the characteristics of effective approaches as well as the consequences of those approaches at their work setting (Dunst & Trivette, 1996). Implementing a family-centered care approach supports and reinforces the ability of families and caregivers to nurture and encourage the child's behavior and development (1996). Acknowledging the perspective of caregivers is essential to establishing appropriate guidance to give them the confidence and knowledge necessary to manage their child's feeding, eating, and swallowing issues.

The literature suggests feeding intervention is most effective when a team works cohesively toward the goals of the client, family, and caregiver; has implemented evidenced-based interventions; has taken the time to understand the families' routines; and, perhaps most importantly, has the ability to work with the child's caregivers (Caretto et al., 2008.; Franklin & Rodger, 2003; Linscheid, 2006). Because feeding difficulties can be a combination of sensory, medical, oral, and even behavioral characteristics, a multidisciplinary team is critical to provide the best comprehensive evaluation and intervention for the child.

Multidisciplinary Team Roles

There are various roles in a multidisciplinary feeding team. The role of the developmental pediatrician is to provide a medical history and physical examination, make recommendations, and write orders for diagnostic testing and services. This physical examination typically includes an evaluation and assessment of the body structures and functions involved in the feeding process (gastrointestinal, cardiac, respiratory systems), neurological and sensory evaluations, and the general growth and development of the child. These findings and recommendations are then communicated to the other members of the feeding team (Simonsmeier & Rodriguez, 2007). The role of the RD is to make specific recommendations regarding dietary concerns and objectives. The RD reviews the child's diet record and observes feeding behaviors and growth charts to develop the specific recommendations (2007).

The OT evaluates by observing a feeding session with the caregiver; assessing positioning, sensory responses, and environment; and may need to do an oral examination. Occupational therapy practitioners have always been concerned with the self-care aspects of children and adults (AOTA, 2008; Simonsmeier & Rodriguez, 2007). Interventions within the occupational therapy domain may include recommending and demonstrating the use of assistive devices for positioning; using adaptive equipment for feeding (i.e., specialized utensils); implementing sensory and behavioral interventions to encourage safe

feeding and swallowing; and addressing the psychosocial needs of the family, caregiver, and the child. Families and caregivers need to gain the child's trust for success with a feeding program. Ensuring that the child receives enough nourishment often causes families and caregivers stress. These are complex issues that need to be addressed. Bazyk (2000) discussed these important considerations. Carreto et al. (1999) highlights family and caregiver education when the child's feeding is provided by an OT, as feeding is an activity of daily living, which is an area of occupation (AOTA, 2008).

In the past, the SLP was found primarily in the educational setting, addressing the language and communication (e.g., stuttering and articulation) challenges of students. Their domain extended during the twentieth century into the medical model that not only evaluates communication and language problems but also assesses the oral-motor and respiratory status of the child during the act of eating and swallowing (Harty & Robinson, 1999; Simonsmeier & Rodriguez, 2007).

Methodology

Data was collected in an outpatient feeding pediatric clinic at a large pediatric specialty hospital. The feeding team consisted of neurodevelopment pediatricians, a nurse practitioner, and a dietician. An OT and an SLP were available if requested by one of the team members. The criteria for admittance into the outpatient feeding clinic required that a child be over a year old, have an established feeding

problem, and be referred by a physician. Criteria for inclusion in this study required a family member or a caregiver to sign a consent form, complete the survey created for the study, and function as a caregiver of at least one child receiving services in the outpatient feeding clinic. The study excluded participants who were not seeking services from the feeding clinic, who had an inability to comprehend and complete the survey instrument, or who had impaired cognition.

The research team developed a survey tool to collect data. The survey included a combination of open-ended questions, closed-ended questions, and one three-point Likert scale question. The participants completed the survey tool after consenting.

The questions on the survey included the reason for attending the feeding clinic, what aspects of feeding are difficult for the child, the level of satisfaction with the visit that day, and whether or not the participant felt better prepared to feed their child at home after the clinic visit. Eligible participants were asked to participate in the study after their scheduled feeding clinic visit. Anonymity was maintained. Informed consent was placed in a locked box after being placed in a closed envelope to assure confidentiality. The participants were allowed time to complete the survey.

Results

Out of the 35 questionnaires given to the caregivers of children seen by the outpatient feeding clinic team during a six month time period, 32 questionnaires were returned. Of the 32

questionnaires, results showed 47% indicated it was their first visit to the outpatient feeding clinic. Forty-one percent of the children were male and 59% of the children were female. Ninety-four percent of the caregivers were parents and 6% were grandparents.

When the caregivers were asked whether there are resources (feeding groups, thick-it, OTs, and SLPs with feeding skills and knowledge, etc.) in their communities, 41% stated yes, 9% stated no, and 50% were unsure. Ninety-three percent of the caregivers reported on the survey that they felt better prepared to feed their child at home after the clinic visit and the conversations with the feeding team, while 92% reported that they were better prepared to ask the correct questions of their family physician about community resources.

Figure 1 depicts the discrete averages of the difficult aspects of feeding reported by the caregivers. The aspects of feeding were divided into the following three categories: Sensory and behavioral issues; feeding, swallowing, eating, and digestive issues; and other. The category other includes: "Gaining weight," "losing weight," "none," "picky eater," "not eating," "everything," and "trying new textures of foods." Some caregivers chose more than one category as a response. Nineteen percent reported sensory and behavior issues, 63% reported feeding, swallowing, eating, and digestive issues, and 41% reported other.

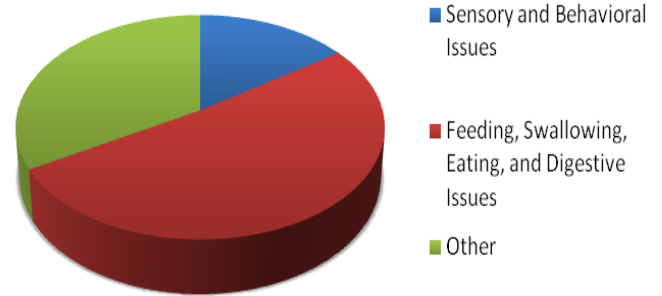


Figure 1. Discrete percentages of the difficult aspects of feeding.

Figure 2 depicts the discrete averages of the caregiver's reasons for the clinic visit. The reasons for attending were divided into the following four categories: Weight problems, evaluation/recommendations, developmental delay, and feeding/digestive problems. Some caregivers chose more than one category as a response. Therefore, discrete percentages were calculated. For discrete percentages, 25% reported weight problems, 59% reported evaluation/recommendations, 3% reported developmental delay, and 25% reported feeding/digestive problems.

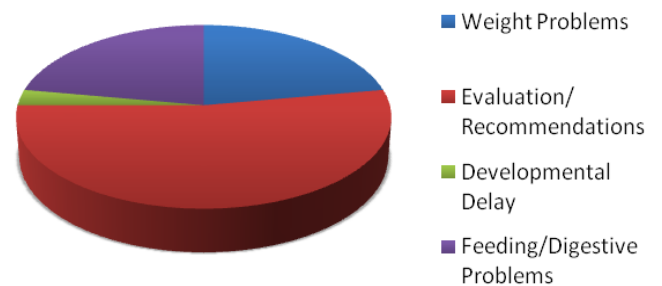


Figure 2. Weighted percentages of reasons for attending the clinic.

Figure 3 depicts the caregiver's responses regarding what specifically would help them follow the home program recommended by the feeding team. Six percent of the caregivers stated accessibility, 25% stated continuity, 22% stated further information was needed, and 47% stated other. The category accessibility includes the responses "receiving supplies at home" and "the right products." The category continuity includes the following responses: "Our perseverance," "time management," "go by a schedule," "dedication to the schedule," "structure," "continue the same plans that we started," "my own strength to follow recommendations," and "more precise daily schedule." The category further information includes the following responses: "Home health," "telling how to eat," "written instruction," "the advise the doctor and dietician gave us," "the instructions are written down clear and detailed," "having a follow up appointment," and "being informed and educated." The category other includes the responses "nothing," "nothing right now," "don't know yet," "all helps," and "they are great."

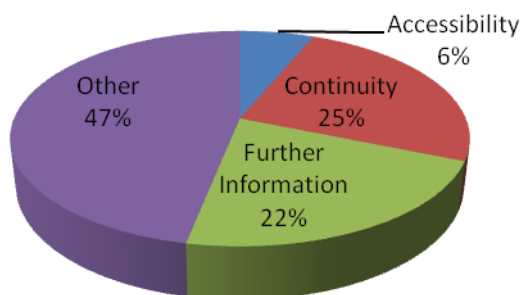


Figure 3. What will help you follow the home program that was recommended by the feeding team.

Nine out of 32 caregivers provided additional comments at the end of the questionnaire. The responses were as follows: "Thanks for the help," "everything was fine today, wish that they had these clinics more than one day a week," "I believe that everyone at Riley is very nice, and care about your concerns," "I am so pleased and excited about this now that we have met; so many questions were answered and issues I feel resolved."

This study revealed that 19% of the participants indicated they were receiving occupational therapy services in their local communities to address sensory and behavioral issues related to feeding. It is relevant to note that addressing the sensory and behavioral aspects of feeding is within the scope of practice of occupational therapy (AOTA, 2008). Specifically, OTs may address arousal, sensation, environmental factors, and behaviors that may interfere with successful feeding (AOTA, 2008). However, for this study, caregivers were not asked about the frequency, duration, or intensity of the occupational therapy services received.

In addition, 16 pediatric feeding clinics across the United States were contacted via phone by a co-investigator. Eleven clinics specializing in addressing pediatric feeding issues in 11 different states responded. Ten of the 11 pediatric feeding clinics, including three of the top ranked children's hospitals per U.S. News & World Report (2011), responded that they had one or more OTs on their feeding team.

Discussion

The findings from this study indicate a need to explore further the experiences of the caregivers and children who receive services in an outpatient pediatric feeding clinic. The intent of this study was to identify potential areas of improvement in services provided in the outpatient pediatric feeding clinic. The investigators aimed to determine if occupational therapy services may be a needed service during the clinic visit, instead of only when one of the primary team members requests an OT to see the client. Survey research allows researchers to explore the perceptions of individuals. In this study, the caregivers who are involved in this clinical feeding program were to share their level of satisfaction regarding the services they and their child have received. In addition, they were asked to share their perceived ability to transfer strategies learned from a clinical setting to their home environment. Most were unable to articulate or discuss this with any ease.

Findings suggest that the caregivers perceived the services provided by an outpatient pediatric feeding clinic as helping them to better understand their child's feeding issues. Although 94% of the caregivers surveyed provided statements related to feeling better prepared to feed their child at home, 53% of the caregivers did not identify what specifically would help them follow through with recommendations from the feeding team.

The themes that emerged in this subset were: (a) providing caregivers with identified products, (b) scheduling, and (c) providing written

information as possible resources that would help the caregivers to remain consistent with feeding team interventions at home.

An OT could be a resource in this clinic to address specific feeding schedules, and mealtime routines and processes for clients who have feeding issues. AOTA stipulates that occupational therapy practitioners have the specialized skill set to modify and recommend appropriate positioning equipment to facilitate more successful feeding (2008). This too could be a resource for caregivers regarding ordering the appropriate products for their child's success with feeding at home. Regarding the caregiver responses of requesting more written information, a suggestion to this clinic may be to provide home programs to the caregivers of children receiving services in this clinic. This may improve the recollection of both recommendations made by the staff and possible product vendors or product information, such as what to purchase and where to purchase the products.

This study did have limitations, including a small sample size and the use of a new survey instrument developed for the study (no reliability or validity data available). Due to the scheduling of this outpatient clinic, researchers approached the caregivers after they were seen by all disciplines of the feeding team. At times, this may have caused some of the caregivers to have inadequate time to complete the survey, secondary to their schedule. The investigators made the assumption that the caregiver attending the clinic was the most reliable source of the feeding information. The caregivers

may not have provided all of the information to the specific questions, or may not have provided in-depth responses, due to a desire to go home after being at the clinic for four hours.

This study identified aspects of feeding that fall within the scope of occupational therapy, specifically sensory issues and caregiver education, as a reason for receiving services from an outpatient feeding clinic.

Conclusion

Quality, efficient services can improve health outcomes for clients, decrease stress for the families and caregivers of clients, and reduce costs. It is vital that services provided within and outside of the profession of occupational therapy meet the physical, environmental, and emotional needs of the consumers of these services. For the caregivers in this study, satisfaction with services was directly related to feeling efficacious in continuing the recommendations from the feeding team

professionals when they returned home.

Recognizing the experiences of caregivers with children who have feeding difficulties can help professionals to be more attuned to client-centered interventions. This study has demonstrated the importance of assisting caregivers to locate the necessary resources to help them to ensure their child's feeding success. The findings from this study about caregivers cannot be generalized because the participants do not represent the entire population of caregivers of children with feeding problems. However, this study does add to the body of knowledge regarding feeding for at-risk children. It also shares what types of service may assist in serving both the child and the caregiver holistically, when it comes to eating, feeding, and swallowing. The study also provides insight into possible perspectives and the need for occupational therapy within feeding programs.

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