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The Parents' Perspective: Experiences in Parent-Mediated Pediatric Occupational Therapy for Children with Neurodevelopmental Disorders

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The Parents' Perspective: Experiences in Parent-Mediated Pediatric Occupational Therapy for Children with Neurodevelopmental Disorders

Abstract

Background: Parent-mediated occupational therapy (OT) is a family-centered method of providing care for children and their families. This study aimed to understand and describe the parents' perspectives of whether parent-mediated OT services improve child participation and parent-child social interactions in the home and community.

Method: This study was performed with a qualitative, phenomenological research design using focus groups. Eight participants were included in the study who were parents of children with at least one NDD, such as autism spectrum disorder or attention-deficit/hyperactivity disorder.

Results: Four major themes were developed: It's a Family Affair, Sometimes it Just Takes a Bit of Training, Using [OT Strategies] to the Full Extent, and It's Definitely Better to be in the Session. One-hundred percent of the participants experienced the phenomenon described in two themes and 87.5% of the participants experienced the phenomenon described in two themes.

Conclusion: Parent-mediated OT services may lead to substantial learning among parents, facilitate parents' use of OT strategies in their home and community environments, improve child participation in daily activities, and improve parent-child communication and engagement.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

ADHD, autism, communication, participation, focus groups

Cover Page Footnote

We would like to thank all of the parents who participated in the focus groups used in this research. We would also like to thank Dr. Mary Hildebrand, OTD, OTR/L, for her mentorship and guidance on using qualitative research methods.

Credentials Display

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Neurodevelopmental disorders (NDDs) are a group of conditions characterized by deficits in personal, academic, social, or occupational functioning (American Psychiatric Association [APA], 2013). NDDs include autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), and intellectual disability (APA, 2013). According to the Centers for Disease Control and Prevention (CDC), one in 54 children is diagnosed with ASD, and 9.4% of children have been diagnosed with ADHD (CDC, 2020a, 2020b).

Family-centered care is considered best practice by many in the field of occupational therapy (OT) and occurs when an occupational therapist creates a partnership with parents, identifies family goals, enhances child and family strengths, and educates parents to foster child development (Case-Smith, 2015; Dunn et al., 2012; Miller-Kuhaneck & Watling, 2018). Parent-mediated therapy is one method of providing family-centered OT services. Occupational therapists who practice in a parent-mediated model include parents in the OT session and guide the parent's hands-on interaction with their child, replacing direct therapist-child interaction with parent-child interaction (Jaffe & Cosper, 2015). Occupational therapists who practice in a parent-mediated model empower parents to provide interventions for their children, which is an area of best practice according to the National Professional Development Center on Autism Spectrum Disorder (NPDC, n.d.).

Parents of children with ASD report limited understanding and management of their child's behavior and want to learn more about their child's development and behavior, which can be accomplished through parent-mediated OT services (Hodgson et al., 2018; Miller-Kuhaneck & Watling, 2018). With specific training on how to perform OT strategies, parents may be able to dramatically increase the number of hours per week that a child receives intervention in their natural environment and subsequently improve child outcomes and generalizability (Dai et al., 2018; Dunn et al., 2012; Hassan et al., 2018; Miller-Kuhaneck & Watling, 2018; Siller et al., 2013). Parents may be able to learn how to implement interventions in as few as 8 or between 12–18 hr of training (Miller-Kuhaneck & Watling, 2018). This indicates that parent-mediated OT services may be an effective and financially efficient method of service delivery (Miller-Kuhaneck & Watling, 2018). In addition, research has shown that improvements gained through parent-mediated interventions can be sustained after the conclusion of therapy (Althoff et al., 2019; Leadbitter et al., 2020). Training parents to implement OT strategies in a parent-mediated model is one way occupational therapists can maximize intervention potential and practice in a family-centered model.

Current research suggests that parent-mediated interventions may improve ASD symptoms, cognitive skills, language and communication, social skills, and adaptive behaviors (Koly et al., 2021; Liu et al., 2020; Nevill et al., 2018; Pickles et al., 2016). A systematic review found strong evidence for improvements in child joint engagement during play and moderate evidence for improvements in social communication, social-emotional skills, expressive language, decreased ASD symptoms, and child response to interaction (Althoff et al., 2019). However, mixed reviews were found regarding improvements in child receptive language, initiation, and joint attention (Althoff et al., 2019). There is also emerging evidence that parent-mediated therapy can improve child play skills, daily living skills, functional communication, and independence (Althoff et al., 2019). Parent-mediated interventions may also improve fine and gross motor skills, eye-hand coordination, self-help, dressing, and eating (Koly et al., 2021). A Cochrane review completed by Oono and colleagues (2013) was unable to find statistical significance in improvements in language and communication, child initiation, adaptive behaviors, or parental stress, demonstrating mixed results between studies. While many findings were inconclusive,

strong statistical significance was found regarding positive changes in parent-child interactions, such as shared attention and parent synchrony (Oono et al., 2013).

Parent-mediated therapy not only leads to improvements for the child receiving services but also impacts parents. Parents may experience significant stress and uncertainty when caring for a child with an NDD, which may negatively impact the parent's well-being and quality of life (Hayes & Watson, 2013; Kuhaneck et al., 2015; Nancy et al., 2017). Research suggests that parents who receive training to understand their child's development have greater self-efficacy, which may lead to decreased stress and the ability to maintain positive mental health (Dai et al., 2018; Kuhaneck et al., 2015). Parent-mediated therapy can also improve parent responsiveness to child communication and parent-child interactions (Koly et al., 2021; Oono et al., 2013; Siller et al., 2013). In addition, parents may experience reduced distress, greater acceptance of their child's diagnosis, and improved coping for the entire family (Koly et al., 2021; Leadbitter et al., 2020).

There is a growing body of evidence supporting parent-mediated therapy; however, it is difficult to generalize across all parent-mediated therapy settings because of substantial variability in research methodology, service delivery hours and format, and practitioner specialty (Nevill et al., 2018; Oono et al., 2013). Further research is needed to describe the efficacy and generalizability of interventions provided for children with NDDs in a parent-mediated model in an outpatient pediatric OT setting.

The purpose of this study is to understand better and describe the parents' perspectives of OT services provided for children with NDDs in an outpatient pediatric setting using a parent-mediated model. The research sub-questions are:

1. How do OT services provided in an outpatient setting and using a parent-mediated model improve a child's participation in daily activities in the home and community, as described from the parent's perspective?
2. How do OT services provided in an outpatient setting and using a parent-mediated model improve parent-child social interactions in the home and community, as described from the parent's perspective?

Method

Research Design

This study was performed with a qualitative, phenomenological research design using focus groups. The affiliated UMass Medical School Institutional Review Board approved this study. The study personnel obtained informed consent from all of the participants before they participated in the focus groups. At the time of each focus group, the facilitator reminded all of the participants that they could refuse to answer or withdraw from the study at any time.

Participants

Participants were recruited through a convenience sample of caregivers who had received parent-mediated OT services with Dr. Mary Beth Kadlec at the Center for Autism & Neurodevelopmental Disorders (CANDO), an outpatient clinic in UMass Memorial Health Department of Psychiatry that specializes in diagnostic evaluations and treatment of youth with ASD and NDD presenting with significant behavioral challenges between January 1, 2019, and December 31, 2020. This occupational therapist's practice integrates and applies the Person-Environment-Occupation-Performance (PEOP) and Social Communication Emotional Regulation Transactional Support (SCERTS) models to assess, intervene, and provide education for families with children who have NDDs (Baum et al., 2015; Prizant et al., 2003). Each parent recruited for this study was included in the OT session and received education

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about their child's needs and abilities as well as training on how to use OT strategies and interventions to facilitate child performance in the daily activities outlined in their OT goals. The interventions, strategies, and training addressed the child and parent while considering the social, cultural, and physical environments and necessary supports to enhance social communication and emotional regulation.

The inclusion criteria were caregivers of children with an NDD or a history of an NDD (i.e. ASD, ADHD, learning disability, or intellectual disability). The term "caregiver" was defined as the child's mother, father, stepmother, stepfather, foster mother, foster father, grandmother, grandfather, or whoever was the legal guardian for the child. OT services may have been provided in the clinic or via telehealth, and the caregiver participating in the study must have participated in at least six parent-mediated OT treatment sessions with their child. Exclusion criteria included adults unable to consent, prisoners, individuals under 18 years of age, and non-English speaking participants. Non-English speaking participants were not included because of funding limitations for interpreter services.

Out of 20 identified possible participants, the sample size for this study was n = 8. All of the participants identified as parents of the child who received OT services at CANDO; therefore, the participants will be referred to as "parents." The participants were the parents of children 7 through 14 years of age who each had at least one NDD, including either ASD, ADHD, or both, as well as co-occurring conditions including anxiety, communication and language disorders, mood disorders, motor skill developmental delays, intellectual delays, sensory processing disorders, aggressive behaviors, seizure disorders, and/or sleep disturbances. The parents' demographic data are described in Table 1. In this small sample, it is notable that parents had different educational backgrounds, and three of the eight parents were of Hispanic or Latinx ethnicity.

Table 1
Participant Demographic Data

Participant	Age	Sex	Ethnicity	Marital Status	Relationship to Child	Primary Language	Highest Level of Education	Service Delivery Setting
Parent 1	35–44	Female	Not Hispanic or Latinx	Partner	Mother	English	Associate Degree	Clinic & Telehealth
Parent 2	35–44	Male	Not Hispanic or Latinx	Partner	Father	English	High School Diploma or GED	Clinic & Telehealth
Parent 3	45–54	Female	Hispanic or Latinx	Single	Mother	Spanish	High School Diploma or GED	Clinic Only
Parent 4	25–34	Female	Hispanic or Latinx	Married	Mother	-[a]	Associate Degree	Clinic & Telehealth
Parent 5	45–54	Female	Not Hispanic or Latinx	Married	Mother	English	Master's Degree	Clinic & Telehealth
Parent 6	45–54	Male	Not Hispanic or Latinx	Married	Father	English	Bachelor's Degree	Clinic & Telehealth
Parent 7	65–74	Male	Not Hispanic or Latinx	Married	Father	English	Doctorate or PhD	Clinic Only
Parent 8	65–74	Female	Hispanic or Latinx	Married	Mother	Spanish	High School Diploma or GED	Clinic Only

[a]Parent 4 omitted Primary Language on the Demographic Questionnaire.

Procedures

Data were collected during two 1.5-hr virtual focus groups, which were recorded. The first author, a Doctor of Occupational Therapy student completing a doctoral research project, facilitated each focus group. The third author, also a Doctor of Occupational Therapy student, was the notetaker for each focus group. The focus group structure was developed using the methodology suggested by Krueger (2002). Focus Group 1 consisted of n = 3 participants, and Focus Group 2 consisted of n = 5 participants. The facilitator followed a semi-structured script for each focus group, including an introduction, a statement of the research aim, an opportunity to refuse to answer or leave at any time, and open-ended questions from a script that required reflection, examples, and group discussion. Questions were asked in a broad to specific format, and the facilitator asked probing questions following the trajectory of the participants' conversations (see Appendix). During each focus group, the facilitator kept a reflective journal, and the notetaker recorded profound quotes and potential themes. After each focus group, the facilitator provided a summary of common themes discussed during the focus group and provided the participants with an opportunity to identify themes that they thought were important during the focus group as well.

Data Analysis

Data analysis began immediately after each focus group, at which time the facilitator and notetaker compared notes and discussed potential themes. Within 2 days of each focus group, the first author began formal analysis of the focus group transcriptions (Krueger, 2002). Focus groups were transcribed verbatim using Zoom transcription software. The first author watched the focus group recordings and reviewed the transcriptions three times each to ensure accurate transcription. If a participant's name was used during the focus group, it was replaced with their assigned participant number.

Once the transcriptions for each focus group were finalized, the first author watched the recorded focus groups a fourth time and created a mind map to begin the code development process. Codes were revised from descriptive codes to in vivo codes and process codes after one round of line-by-line data analysis using NVivo software (released in February 2021) to ensure insightful analysis (Saldaña, 2016). A codebook was then created containing code descriptions, inclusion criteria, exclusion criteria, typical exemplars, atypical exemplars, and "close, but no" exemplars (Saldaña, 2016). The second author, Principal Investigator for this study and the occupational therapist who provided the parent-mediated OT services for the study participants and their children, reviewed the codebook in detail and provided recommendations, revisions, and clarification.

Once a codebook was developed, data analysis occurred in two cycles. During the first cycle, the first author coded each transcript three times. The third author then completed one round of coding to develop intercoder reliability. The initial intercoder agreement ranged from 90.32% to 99.99% for each code. The overall kappa score was 0.65. According to Saldaña (2016), 80%–90% intercoder agreement is considered acceptable, and according to McHugh (2012), a kappa score of 0.60–0.79 is moderate. To improve intercoder reliability, the first and third authors reviewed all disagreements by reviewing the codebook, discussing the codes, and re-coding applicable sections of the transcripts. The second author was available for final code approval if the first and third authors could not agree. Once all disagreements were mitigated, the final intercoder agreement ranged from 98% to 100% for each code, and the final overall kappa score was 1.00 (McHugh, 2012). During the second cycle of coding, the first author combined codes to create categories and develop themes (Saldaña, 2016).

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Trustworthiness

To increase trustworthiness, Dr. Kadlec, the occupational therapist who provided the parent-mediated OT services for the study participants and their children, was not involved in the focus groups. This was done to ensure the participants felt comfortable sharing positive and negative responses about the OT services they received at CANDO during the focus groups. In addition, inclusion criteria required that the OT services had ended before the parents' involvement in this study. Finally, to enhance the validity of the study, the researchers sought consultations from an OT department faculty member with experience conducting qualitative research. The researchers periodically performed check-ins with the consultant to ensure the quality of the research and seek procedural advice for best practices.

Results

Four distinct themes were developed from these focus groups. In this methodology, the development of themes is a bottom-up approach, using the content of the parents' answers to inform the categories that are then classified into themes as outlined in Table 2. According to Saldaña (2016), 75% of the participants should agree on a phenomenon to consider a category or theme for generalizability. In the present study, seven out of eight categories elicited agreement among at least 75% of the participants. In addition, 100% of the participants experienced the phenomenon described in two themes (It's a Family Affair and Sometimes it Just Takes a Bit of Training), and 87.5% of participants experienced the phenomenon described in two themes (Using [OT Strategies] to the Full Extent and It's Definitely Better to be in the Session). These agreement scores indicate sufficient participant agreement to ascertain a commonality among all participants when describing the themes developed through the focus groups (Saldaña, 2016).

Table 2
Development of Codes, Categories, and Themes

Theme	Category
It's a Family Affair	Family-centered care Parents are frustrated and struggling
Sometimes it Just Takes a Bit of Training	OT teaching strategies Parents learn about their child Parents learn about themselves
Using [OT Strategies] to the Full Extent	Parents are able to implement OT strategies at home Parents report transfer of skills for the child
It's Definitely Better to be in the Session	In the session versus in the waiting room

Theme 1: It's a Family Affair

The theme It's a Family Affair is comprised of codes, such as "you're not crazy, this is difficult," "[OT] changed my life and my child's life," and "I didn't know where to start." The parents described being included in the OT session as allowing them to receive support and validation from the occupational therapist when they were feeling alone or frustrated or were struggling to understand and engage with their child. Being included in the OT session also allowed the entire family to benefit from OT and led to greater consistency at home and in the community, as described from the parents' point of view.

Parents described feeling frustrated because of not knowing how to communicate or engage effectively with their children. One parent said, "It's very frustrating, and it feels like you're almost kind of separated from your child because you're just not getting it or you're not getting through to them" (Parent 1). Another parent shared their feelings of frustration and feeling alone. They said, "I was trying my best [and] I just start literally crying because sometimes mom just broke apart. Moms are humans.

Mom, they think they are supermoms . . . it's so so hard" (Parent 4). However, being included in the OT session:

> Helps us know that we're not the only ones. [The occupational therapist] makes you feel like . . . how you react sometimes is not wrong. It's just you need to know a different way to be able to help your child" (Parent 5).

The parents shared that being included in the OT session provided an opportunity for them to receive emotional support and validation for their parenting from the occupational therapist. One parent said,

> [The occupational therapist] helped me [learn] how I am capable to do some stuff. Because sometimes, like mom [thinks] "oh, I'm not capable to do this, I don't have the stronger [*sic*] to do this." [The occupational therapist said] "You are you able to do this. You're doing an awesome job." And she makes the whole difference in my life. (Parent 4)

In regard to being included in the OT session, Parent 1 said,

> That was kind of a key component with her, is just like, you know, it's not just bringing her there, our daughter to [the occupational therapist], and having [the occupational therapist] do all the work, like it's a family affair and it's something that we all need to kind of be involved in together.

Parents shared that they needed to be included in the OT session to learn what to do at home to help their child participate in their daily occupations.

Theme 2: Sometimes it Just Takes a Bit of Training

Codes in the theme Sometimes it Just Takes a Bit of Training included "the hands-on experience . . . was very helpful," "I learned . . . to understand my own child," and "we all have needs that need to be met." The parents described learning a substaintial amount through observing the occupational therapist model, the OT strategies, the interventions, and the hands-on practice during the OT sessions; discussions with the OT; and by being included in the OT session. The parents learned about themselves, their child's needs and abilities, and how to communicate more effectively with their child. One parent said, "I think the biggest learning was more from my standpoint, not so much for [my child]" (Parent 6).

Parents described that being included in the OT session allowed them to reflect and learn about their own sensory needs and preferences. One parent shared,

> The interconnectedness of a family unit and the sensory issues and recognizing, like, my own sensory needs too was very, very helpful. And just seeing, like, "oh, wow I am getting escalated." That was something that was really pivotal that, you know, we did discuss about how to present ourselves, but also like kind of meeting our own sensory needs. (Parent 1)

The parents also learned ways they are different from their child, which allowed them to reflect on how to best interact with their child. For example, Parent 1 said,

> Our kids are just working, their brains, their bodies are just a little bit different from ours. We were brought up a certain way, we were taught a certain way, [but] that doesn't mean they're going to be able to learn the same way that we did. And that doesn't mean we're going to be able to figure

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> out as easily how to teach them because we're stuck in our own ways. So, having to relearn all that stuff is so important and how we can translate it to our children the best that we can.

The parents also shared that through learning how to understand and communicate more effectively with their children, the parent-child relationships have improved. Parent 4 shared OT strategies that they use to communicate with their child. They said,

> Just give him a minute, give him a pencil, give him a paper, and give him some pictures, what is going on, what do you want, what do you need, that type of thing, that she gave me change how I understand more of my child. (Parent 4)

This parent also said that before being included in the OT session,

> I would not, like, take my time and sit down and wait for him to finish the conversation on what he was saying or show me something that he wanted to show me, and me, like, take the time to pay attention to that. So that's how it changed, and now I do that. So, to have a better conversation together and, like the relationship has grown a lot. (Parent 4)

Finally, the parents reflected on the various ways that they learned from the occupational therapist during the OT sessions. One parent shared an example of shared-decision making and hands-on practice implementing an OT strategy to prevent the child from kicking and scratching the parent's legs while they sleep in the same bed at night:

> [The occupational therapist] showed me how to wrap [my child] from the waist down so he wouldn't be able to move his feet and scratch on my thighs all night. So, we did like an example. So, we both went onto the mat, and we did it together and we make believe he was falling asleep. We came up with the idea of finding a blanket that he likes, in a pizza style because he likes pizza. So, we went and picked that up, and that's how we figured out that he was able to sleep next to me and not [scratch my thighs]. (Parent 3)

Theme 3: Using [OT Strategies] to the Full Extent

The theme Using [OT Strategies] to the Full Extent included codes such as "just a little step is so huge" and "I could actually engage and feel like I was connecting with my child." The parents described how they were able to use the strategies that they learned in OT sessions in their home and community to facilitate the transfer of skills and generalizability from OT to other environments. This led to greater improvements in the child's abilities as well as the ability for the parents to engage and connect with their children. One parent described how being included in the OT session was helpful for coming up with ideas for sensory-based activities during the COVID-19 pandemic when they were not able to use their local playground. They said:

> Even bringing it into the home, like, for example, the transition with COVID. We were like, "how do we reproduce the gym?" We ended up taking the cushions off of our couch, you know, bunching them up into a pile, letting her jump off the couch and just throw her body down on it. We took a fitted sheet, wrapped her up in it, and like rocked her back and forth to simulate the swing and the compression swing from the gym. Just coming up with like these crazy ideas. (Parent 1)

The parents provided examples of how they use OT strategies, such as visual supports, in their home environments to facilitate their child's participation in daily activities. For example, Parent 4 said,

> My oldest son, he helps me [with] cooking. And I just put the picture, and the picture has some numbers, "what is the first thing that you need to do? The second?" And he just went by his own. I don't need to tell him what to do, I just put a picture and he just go on alone.

Parent 1 shared an example of how they use OT strategies to take turns during play, which led to a stronger connection between the parent and the child. They said,

> I could actually engage with her and feel like I was connecting with my child, where before she would just kind of be kind of standoffish, which I thought was just her. But it was like learning those little things of how to connect with her and how to teach her not only that am I connecting with her, but how to connect me as well. (Parent 1)

When reflecting on how the parents used OT strategies to improve the child's participation in daily occupations from the parent's point of view, one parent became emotional.

> I just literally start crying because you never know at that moment how capable your child [is] to make some stuff. Because you never was like expecting that part of the child because you never was trained how to, how do you teach your child. Because you never had experience to be with your child in OT sessions. (Parent 4)

Theme 4: It's Definitely Better to be in the Session

The theme It's Definitely Better to be in the Session is comprised of codes including "they had me in the waiting room the whole time" and "I was almost kind of intimidated." The parents reported that being included in the OT session led to greater benefits for their child and their family compared to being in the waiting room. In past experiences, some of the parents did not understand the benefit of OT or how to use OT strategies at home because they were not included in the session. One parent shared an example:

> It's better to go in there with [the occupational therapist] because [in past experiences, the other occupational therapist] would take [our child] in the room. And I would get upset because all they did in the room was play or color, and she wasn't, you know, doing anything constructive or showing us what to do.

The parent went on to describe how being included in the OT session was "a lot better." Regarding sitting in the waiting room while the child received OT services, the parent wondered, "So how was [the occupational therapist] helping her or how [was the occupational therapist] helping us? She wasn't doing neither" (Parent 8). Other parents agreed with this example, sharing that they have

> Talked to some people who've done OT where they did wait outside for their child, and they would get, like, this little kind of print out paper of what was worked on and what strategies they were using. But most parents, we're like, "okay, what does that mean?" And not being able to translate it into the home or being able to do it themselves to model it for their children. (Parent 1)

Another parent shared that it is "much better for us as parents to be in the session because it's not just [our child] getting OT, but it's us learning how to give [our child] OT in everything we do with her in her life"

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(Parent 7). Parent 1 also reflected that "If we hadn't been involved in [the OT session,] we wouldn't have been thinking outside the box and thinking of her sensory needs differently and how we can, you know, present them to her as parents."

However, some of the parents can see drawbacks to being in the OT session or were intimidated to be in the session at first. Parent 1 shared that parents may want a "break" while their child has OT and are "hoping that, you know, they could just kind of sit outside and just take that moment to, like, collect themselves and let their child like do what they need to do." This parent went on to describe that "navigating having a child with autism is a very difficult process" (Parent 1). They shared,

> When I first started, I was afraid it was going to be like that similar situation of people [such as other health care professionals] judging you. Like they want to see how you're interacting with your kid, "oh, you're doing this wrong, you're doing that wrong." So, I did have that feeling of being scared, and I was almost kind of intimidated, and I think that's true of a lot of parents. So that could also be why they want to sit out to the side. They don't want to be involved in that because it's a scary thing, and they're constantly being told, "well, your child has autism. Did you try this? Did you do this? And did you do that?"

Discussion

Parent involvement in OT sessions rather than waiting in the waiting room is one way occupational therapists can engage in family-centered care, which is an integral part of pediatric OT practice (Miller-Kuhaneck & Watling, 2018). In seeking to understand and describe the parents' perspectives of parent-mediated pediatric OT services for children with NDDs in an outpatient setting, four major themes were developed: It's a Family Affair, Sometimes it Just Takes a Bit of Training, Using [OT Strategies] to the Full Extent, and It's Definitely Better to be in the Session. These themes describe the parents' perspectives not only of the benefit of parent-mediated OT services but also of how this service delivery model facilitated the parents' use of OT strategies in their home and community environments and subsequently led to improvements in the child's participation in daily activities and parent-child social interactions.

The results of the present study indicate that parents perceive they are better able to understand and communicate with their child after participating in parent-mediated OT services. By being included in parent-mediated OT services, parents may use OT strategies in their home and community, yielding improvements in the child's participation in daily occupations. These improvements include ADLs (dressing, toileting), IADLs (cooking), play (play schemas, turn-taking, following rules), social participation (initiating requests, engaging in a conversation), and sleep and rest, as described by the parents' perspective. These findings are in line with prior research, which found that parent training may be an effective service delivery model in OT, lead to greater parent and child outcomes, foster greater parental understanding of the child's needs and abilities, and improve parent-child interactions (Dunn et al., 2012; Koly et al., 2021; Leadbitter et al., 2020; Miller-Kuhaneck & Watling, 2018).

In a qualitative research study using focus groups to assess a parent training program, parents and caregivers reported making changes to their own behavior to support their child's performance (Hodgson et al., 2018). These researchers also found that parents could transfer skills from the training sessions to other activities in their home and community environments (Hodgson et al., 2018). These findings support the parents' perspectives that parent-mediated OT services provided strategies that parents used in a variety of activities and environments, leading to greater generalizability of skills.

In the present study, the parents reported that learning occurred through observing the occupational therapist model how to interact with their child, hands-on practice and collaboration, and verbal explanations and instructions provided by the occupational therapist. Not only did the parents report substantial learning on their part and improved participation for their children, but they also reported a preference for being included in the OT session rather than being in the waiting room while their child received OT services. Being included in the OT session provided learning opportunities for the parents, which was important to them, as evidenced by their report that they did not know how to best help their children before receiving parent-mediated OT services. This is supported by prior research that found that a majority of parents of children who have ASD are interested in learning about and receiving training on their child's needs (Hodgson et al., 2018). Parents in the present study also shared feelings of intimidation or not having their needs met by other health care providers, which has been evidenced in prior studies as well (Raspa et al., 2015). These findings highlight the importance for occupational therapists and other health care providers to maintain a welcoming environment and practice open listening to foster trust and collaboration between the provider and the parent, which are major tenets of family-centered care and are vital if parents have not had positive prior experiences with health care providers (Case-Smith, 2015).

Previous studies found that parents of children with NDDs exhibit high levels of stress and poor quality of life compared to parents of typically developing children (Hayes & Watson, 2013; Nancy et al., 2017). This supports the findings from the present study, where parents reported feelings of frustration, feeling alone, or at times becoming emotional because they did now know how to best understand, communicate, or connect with their child. By being included in the OT sessions, parents shared that they learned that they were capable of helping their child and managing their behaviors, indicating improved self-efficacy and confidence. Prior research has also shown that including parents in therapy sessions may improve parental mental health and self-efficacy (Hodgson et al., 2018; Koly et al., 2021; Kuhaneck et al., 2015; Leadbitter et al., 2020). These findings highlight the importance for health care practitioners to provide validation and emotional support for parents of children with NDDs. In the present study, the parents described that being included in the OT session allowed parents to learn about their own needs, receive emotional support and validation from the OT, and have their needs met in addition to their child's needs. Overall, the parents in the present study reported a preference for being included in the OT session rather than waiting in the waiting room.

Participation in the study was voluntary and drew from the caseload of the second author, which is described in the limitations of this study. The broader implications for this sample are that the clinic is one of a few in the area that offers OT for children with NDDs from diverse backgrounds ethnically and economically and accepts public health care insurance policies. The parent-mediated process provided the structure to develop trust between the clinician and parents that supported shared engagement in the therapy sessions. A larger sample size with a broader range of ethnic and economic backgrounds is warranted to make any other inferences about the findings in this study.

The results of this study describe the benefits of parent-mediated OT services from the parents' perspective. Occupational therapists should consider using a parent-mediated OT service delivery model when working with families of children with NDDs in an outpatient pediatric setting. However, when considering the feasibility of including parents or caregivers in the OT session, occupational therapists may experience barriers, such as room or gym capacity limits, discomfort with parents or caregivers joining in the session, or pushback from management or administration regarding changing the service delivery model. If occupational therapists are unable to remove these or other barriers, they should

consider other ways of ensuring that parents or caregivers fully understand the strategies that the occupational therapist recommends and how to transfer them to the home environment. For example, consider using a parent-mediated model at least one time before discharge or add additional time for discussion with parents or caregivers at the end of the session. It is recommended that, if possible, this is done in a private setting to allow for the parents or caregivers to feel safe with receiving information, asking questions, and brainstorming strategies specific to them and their child. These strategies may increase the parents' or caregivers' understanding of the occupational therapist's recommendations and can provide the opportunity for increased generalizability to the home environment.

Limitations and Future Research

There are a few limitations to consider when interpreting the results of this research. First, this study was completed with parents of children who received outpatient pediatric parent-mediated OT services at one clinic with one occupational therapist. This should be taken into account when applying these results to other parent-mediated OT services, as the intervention methods, practitioner style, and clinic environments may differ. In addition, given the small sample size of this study, Saldaña's benchmark of 25% participant agreement about a phenomenon to consider a code for analysis is less meaningful (2016). Twenty-five percent agreement was attained with just the agreement of two participants in this study, which may not accurately reflect the feelings of parents when applied to a much larger audience. For these reasons, caution should be used when applying the findings of this research broadly to all parent-mediated OT services.

Another limitation of this study is the reliance on parent perceptions of parent-mediated OT services. This may have caused errors in reporting because of the length of time since the conclusion of OT services, lapses in memory, or the skills being addressed by multiple providers.

Future research should address the parents' perceptions of parent-mediated OT services of a larger sample size across multiple occupational therapists. In addition, future researchers may consider using a mixed methods research model to include a quantitative component to measure performance.

Conclusion

The findings of this research describe the parents' perspectives on parent-mediated OT services provided in an outpatient pediatric setting. The findings suggest that parents of children with NDDs want to be included in OT sessions, learn how to best interact with and understand their child, and appreciate when health care providers address the entire family's needs. The findings also suggest that parents are able to transfer OT strategies they learn in OT sessions to their home and community environments, which may lead to greater generalizability of skills for children with NDDs. Pediatric occupational therapists should strongly consider including parents of children with NDDs in their OT sessions to provide education and training to enhance parent and child OT outcomes.

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Appendix

Focus Group Questions

1. What is your relationship to the child?
2. About how much time do you spend with the child every day? Do you spend the most time with your child?
3. Did your child have occupational therapy in-person or through telehealth?
4. Has your child ever had occupational therapy before?
5. Have you ever been in an occupational therapy session with your child before, other than at CANDO?
6. What was it like being in the occupational therapy session with your child?
7. Did the occupational therapist do anything differently than you usually do at home?
8. What did you learn most from the occupational therapist?
9. Describe how you changed your voice (tone, speed, volume) when you talk to your child because of occupational therapy.
10. Describe how you changed how you set up games or activities for your child now (e.g., visuals like pictures, brightness of the room, volume of noise, how much time you give them to do something).
11. Would you have known to do this if you hadn't been in the occupational therapy session with your child?
12. After receiving occupational therapy services, was your child able to do more by themselves? Give examples of what they can do now.
13. What changed the most because of occupational therapy at CANDO?
14. Is there anything that you would have changed about occupational therapy at CANDO?
15. Is there anything from occupational therapy at CANDO that was not helpful?
16. What do you all have in common about the occupational therapy services you participated in with your child?

Probing Questions

1. Tell me more about… ?
2. Can you provide an example of… ?