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Research Project

Describing the Lived Experiences of Caregivers of Children with Disabilities receiving
Occupational Therapy Services during the COVID-19 Pandemic

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Under the direction of the research advisor:

Jennifer L. Fogo, PhD, OTR

A Research Project Entitled

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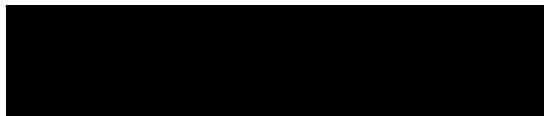
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Abstract

During the pandemic, school-aged children with disabilities abruptly lost access to traditional occupational therapy services (McFayden et al., 2021). Cacioppo et al. (2020) surveyed 1000 participants and reported that only 27% of children continued traditional therapy, and 77% continued therapy services through parents' provision. This occurred when many caregivers were forced to work from home and provide education for their children. Additional role responsibilities, along with other significant changes in routines, can increase demands on parents' mental health. The purpose of our study was to describe the lived experiences of parents of children with disabilities receiving occupational therapy services during the COVID-19 pandemic. We utilized a phenomenological qualitative research approach and interviewed four caregivers of children receiving occupational therapy services prior to and into the pandemic lockdown. Following the analysis procedures described by Saldana (2013) we explored the data for emotion, process, and in-vivo codes. The participants described a process that included (a) Meeting the needs of the child pre-COVID to (b) adjusting to small changes to (c) adapting to fit the new environment to (d) meeting the needs of the child differently. The primary emotion themes that emerged from the data included two broad categories. The first category includes the emotions of feeling *Anxious/worried, Overwhelmed, Guilty, and Frustrated* as they described multiple stressors due to the pandemic. However, regardless of the negative emotions they experienced, they consistently expressed *feelings of gratitude and appreciation* towards occupational therapy services and their occupational therapist.

Describing the Lived Experiences of Caregivers of Children with Disabilities receiving Occupational Therapy Services during the COVID-19 Pandemic

The COVID-19 pandemic has disproportionately impacted children with disabilities and their parents (*Children with disabilities and Covid-19*, 2021). Prior to the pandemic, 7.1 million school-aged children with disabilities within the U.S. engaged in special education services, including physical therapy, occupational therapy, and speech-language pathology through the Individuals with Disabilities Education Act (United States Government Accountability Office, 2020). During the pandemic, school-aged children with disabilities abruptly lost access to therapy services. Cacioppo et al. (2020) analyzed surveys from 1000 participants and discovered only 27% of children with physical disabilities could continue traditional occupational therapy, while 77% continued therapy services through parents' provision. This change became a primary concern of parents with the added roles and responsibilities to provide the services themselves (Cacioppo et al., 2020).

Individuals with disabilities are often marginalized, and the unique needs of parents of children with disabilities are often overlooked or not understood (GPE Secretariat, 2016). Even though professional experts have suggested ways to remedy some of the parents' hardships during the pandemic, researchers have not thoroughly examined the lived experiences of parents with children with disabilities who received occupational therapy services during the pandemic.

We utilized a qualitative research methodology with a transcendental phenomenological approach to provide caregivers of children with disabilities the opportunity to share their experiences during this unprecedented time. Understanding caregivers' experience during this time may provide occupational therapists insight into how caregivers cope and adjust to abrupt change in their child's services. Occupational therapists can then use this information to learn how they might assist caregivers during such change.

Literature Review

Parents' experiences of transitioning occupational therapy services to at-home and online telehealth programs due to the recent COVID-19 pandemic have lacked attention. After reviewing multiple databases, we found a limited number of articles with supporting research on this topic. We appraised the articles to be primarily at level V with most of the articles presenting anecdotal reports from professional experts working in the field and parents of children with disabilities. We found that the main focus, within the minimal research studies we examined, was that researchers focused primarily on access to therapy, parents' perceived effectiveness of services provided (Jeste et al., 2020; White, 2021), and suggestions about ways for parents to maintain mental health and support (Grumi, 2020; Priyadharshini & Chiang, 2020). Experts have also indicated that parents of children with disabilities experienced increased social isolation and excessive mental health demands (Asbury, 2020; Payne, 2020; Masonbrink & Hurley, 2020).

To fully encapsulate the lived experiences of parents, we utilize the occupation-based model, Ecology of Human Performance (EHP), to guide our research. This model emphasizes the importance of contextual factors on one's task performance (Cole and Tufano, 2020). The EHP model is depicted by a diagram where one's context represents a lens of how their environment either facilitates the number of tasks they're involved in, their performance range, or limits them. The performance range is defined as the amount of tasks available to the individual, in relation to their context and their own skills and abilities. Applying the EHP model to our research, we viewed the parent's context as their home and working environments which include their child with a disability. Based on their own skills and abilities, this model helped guide how these environments with their child with a disability influence their performance range or the tasks they have available to them such as daily living activities of cooking, etc.

Access to Therapy Services and Changes in Therapy Delivery

Parents' access to therapy services were greatly impacted when schools and other service providing settings shut down. Jeste et al. (2020) reported that, "Seventy-four percent of parents reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider. Only 56% reported that their child received at least some continued services through tele-education." With this shift to telehealth, therapists were required extra training for this new delivery method as well (Priyadharshini & Chiang, 2020). As the pandemic continued, McFayden et al. (2021) further reported the discontinuation of occupational therapy services. The authors found 65%-83% of students no longer had therapy services at all (counseling, speech, physical and occupational therapy).

Parents Perceived Effectiveness of Services Provided

When services shifted to telehealth, and caregivers were exposed to these services more overtime, there was an increase in family involvement with their child during therapy (Priyadharsini & Chiang, 2020). This demonstrates transactional contextualism through the Ecology of Human Performance (EHP) occupation based model which is a factor that shapes one's occupations based on their extended time in an environment. The EHP model further provides the perspective of intrinsic motivation which can be supported by the research findings that parents are furthering their involvement by being educated and developing skills for their child's services (Priyadharsini & Chiang, 2020). Along with this greater involvement, caregivers reported this delivery method via telehealth as being helpful due to the 1:1 or 2:1 with the OT and child (possibly with parent), which was beneficial to their child and themselves (Jeste et al., 2020).

On the other hand, caregivers of children in preschool reported that their child would lose focus when on the computer, and they believed that some in-person interventions are required to make them effective (White et al., 2021). Allison & Levac (2022) surveyed 402 parents of

children with disabilities and found that over 40% of them accredited these changes in therapy services for their child's declines in their motor, behavior, social, and communication skills.

Support for Parents and their Mental Health

Many parents of children with disabilities have expressed concerns about their child's growth and development during the pandemic due to a lack of specialized rehabilitation (Grumi et al., 2020). According to Grumi, it has caused parents to feel stressed, unsupported, and it has impacted their mental health. Parents report they are experiencing more anxiety and depression because they believe that they will not deliver proper services for their child in comparison to a therapist, causing their child to fall behind (Grumi et al., 2020). Provenzi et al. (2021) conducted a quantitative study that consisted of 36 parents who discussed the impact of telehealth programs that aided their children with rehabilitation during COVID-19. With the help of these programs, the "majority reported increased feelings of engagement, self-relevance, perceived support and recognition of their role in child care, with percentages ranging from 86%–95%." (Provenzi et al., 2021).

Many families of children with developmental delays have experienced disparities including limited access to medical care, food, and inadequate housing. Due to these struggles, parents experience an increase in stress and decrease in mental stability (Paulauskaite et al., 2021). When a parent struggles with poor mental health, it can impact how well they provide for their child. In the study conducted by Paulauskaite et al. (2021), 66% of 88 parents reported mental health challenges and indicated that they could not adequately support their family due to their mental health status. After, "juggling the demands of work, virtual schooling, and restless children amidst intense isolation and poor social support do not make for better parenting. They create stress, irritability, and guilt, which can lead to greater mental health problems, chaotic home environments, and the potential for harsh parenting" (Murphy et al., 2021).

To aid in this issue, occupational therapy practitioners in Singapore created telehealth-based occupational therapy sessions, online parent workshops, and online community outreach. These same occupational therapy practitioners collaborated with psychologists to provide emotional support for parents to ensure the child's best at-home care while receiving therapy remotely (Priyadarshini & Chiang, 2020). The results of these implementations were that telehealth and online services could be complementary to other service deliveries. There are a lot of negative perceptions of online services from parents and caregivers that would have to be adjusted moving forward to continue making therapeutic deliveries safe and effective (Priyadarshini & Chiang, 2020).

Conclusion

Based on the literature, the adaptations to services, such as telehealth, have been a guiding tool for occupational therapist practitioners and many other medical professionals throughout this pandemic (Priyadarshini & Chiang, 2020). In turn, it has brought on additional stress and anxiety for parents and caregivers at home who are now taking on a new responsibility for their child's services. Some parents believe telehealth and other virtual treatments cater to children with specific disabilities (White, et al., 2021). Many occupational therapy practitioners have adjusted how they treat their clients to serve the needs of the child best. There is hope for additional strategies to be created by occupational therapy practitioners and other healthcare professionals to support parents/caregivers in the future to aid in these remote occupational therapy services (Grumi et al., 2021). It is still unclear if the adaptations already made by occupational therapy practitioners were beneficial in providing parents with what they needed to support their child. Having a better understanding of the parents' lived experience during the pandemic will help occupational therapy practitioners determine what additional strategies need to be investigated moving forward. White et al. (2021) stated, "Additional research is needed to

develop interventions that can be adapted and delivered remotely to various age groups. Such efforts may have the added benefit of helping to address disparities documented in rural and other underserved communities.” The current research supports the needed improvement to the at-home virtual approach and further development of interventions and resources for this emerging population.

Method

Study Approach/Design

We conducted a transcendental phenomenological research study to determine the lived experiences of caregivers of children with disabilities who received occupational therapy services prior to and into the shutdown caused by the COVID-19 pandemic. The children needed to have been receiving occupational therapy services before March 2020 when the United States Federal Government declared a national emergency due to the COVID-19 pandemic (AJMC, 2021), and they continued to receive occupational therapy for any length of time throughout the time of data collection in the Fall of 2021. We utilized the theoretical framework of Ecology of Human Performance (EHP) designed by Dunn, Brown, and McGuigan (1994) for various practice disciplines, including Occupational Therapy. This theoretical model provided a framework that examined how context (i.e., COVID-19 pandemic) influenced the caregivers’ engagement and performance in daily tasks associated with their child's care and participation in occupational therapy services (Cole & Tulfano, 2020). We examined the data through the EHP lens by exploring the transactional contextualism and the environmental press through the long-term and short-term effects of COVID-19, respectively.

Recruitment Procedures

According to Creswell (2013), phenomenological research typically includes between 5 to 25 participants. We intended to recruit between 5 and 10 caregivers of children with a

disability who received occupational therapy services prior to and into the pandemic caused by COVID-19. At the time of recruitment, the researchers planned to obtain a diverse sample by inviting those who demonstrated varied demographics of either race and ethnicity, employment status, marital status, age, disability of the child, or the setting in which the child received services. However, we were only able to recruit four participants who were caregivers of children with a disability that attended at least five occupational therapy sessions prior to March 2020 and continued occupational therapy services through data collection that occurred in the Fall of 2021. This ensured that all of the caregivers experienced a common phenomenon of having a child with a disability who needed to continue occupational therapy services during the pandemic.

Our objective was to capture a broad perspective of the lived experiences of caregivers who had a child with a disability receiving occupational therapy during the pandemic. Therefore, we used purposive sampling to obtain participants with maximum variation based on race and ethnicity, employment status, marital status, child's age or disability, or the children's setting receiving occupational therapy services before the onset of the pandemic. We also used a convenient sampling technique by virtually distributing informational flyers through local occupational therapists, therapy organizations, Community Patient Resource Group of the University of Indianapolis. We also emailed caregivers who met the inclusion criteria and posted information about our study on social media sites, such as Facebook. We used the snowball sampling technique and asked the participants to pass the information on to other caregivers who met the criteria and might be interested in participating in the study. Even though we used multiple recruitment procedures, we were only able to secure four caregivers who met the inclusion criteria. This limited our ability to obtain a diverse sample. When individuals contacted the primary investigator indicating they were interested in participating, the primary

investigator reviewed details of the study over the phone and answered questions. If the caregiver was still interested in participating in the study, the primary investigator collected demographic information (Appendix A) from the participants and set up a convenient date and time for participants to be interviewed virtually using Zoom (Zoom Video Communications Inc., 2016).

Data Collection Procedures

Three researchers were present virtually during the interview. One researcher facilitated the interview with a semi-structured interview guide. The other researcher recorded field notes to capture participants' non-verbal responses and noted potential follow-up questions to clarify the participants' responses when needed. The third researcher documented a summary of the responses and verified the content with each participant immediately after the interview. This provided the participants the opportunity to clarify or refute their responses to the questions. Each interview lasted between 30 and 60 minutes. Before initiating the interview, the interviewer verbally reviewed the informed consent document, answered questions, and obtained verbal consent from the participant. This consent process was recorded with Zoom (Zoom Video Communications Inc., 2016). Each participant was assigned a participant code to eliminate the use of participant names and maintain confidentiality.

The researchers developed the semi-structured interview guide using grand tour and mini-tour questions described by Spradley (1979). Spradley (1979) suggested that an interview begins with grand tour or mini-grand tour questions that are broad and open-ended, allowing participants to describe their experiences fully. The grand tour questions were followed by more open-ended questions, per Spradley's (1979) recommendation, which helped participants narrow the focus to describe the details of their experiences. After the interview guide was developed, we completed a practice interview with a colleague who was a caregiver of a child who was

receiving occupational therapy services during the pandemic. This allowed us to adapt the interview procedures using Zoom and revise the interview guide as appropriate based on feedback from the practice interview. Using the adapted semi-structured interview guide allowed us to ask further questions about the information shared by the participants, yet ensured that the researcher asked all participants similar questions.

All interviews were recorded through Zoom, which included audio, video, and automated transcripts. The recorded interviews were saved in a password-protected laptop and in a Google drive folder that was only accessed by the researchers. There were technical difficulties in the first interview with participant 1, which caused the automatic transcript not to save. Therefore, three research members transcribed the interview by hand, typing the interview into a Google document. Each team member reviewed the interview and the hand-typed transcription for accuracy. Automated transcripts were correctly saved for participants 2,3, and 4.

Data Analysis

After we completed each virtual interview, we downloaded the Zoom recordings using automated transcripts. Two researchers who were not involved in the interview process reviewed each transcript and compared it to the recorded interview to ensure the verbatim accuracy of the transcripts. Starting with the first participant, the researchers independently re-read and pre-coded the transcript. Saldana (2013) describes pre-coding as "circling, highlighting, bolding, underlining, or coloring rich or significant participant quotes or passages." Then each researcher independently added memos to their copies of the transcript to identify relevant details about the participant (Saldana, 2013). To analyze the data, the researchers followed a process of first and second-cycle coding described by Saldana (2013). The team of researchers met and worked together to generate the first cycle process, emotion, and in-vivo codes for participant number 1. Process codes were identified to capture the actions of the participants in response to the

COVID-19 pandemic. Process codes can help discern actions and interactions used to identify solutions to resolve problems brought on by external conditions (Wood et al., 2010). We wanted to describe *what the participants did* in response to the pandemic. The onset of the pandemic brought about many unknown factors which heightened peoples' reactions and emotions. Therefore we believed it was important also to capture *how the participants felt* during the pandemic by identifying emotion codes. Also, during the first cycle coding, it was essential to use the participant's own words to ensure we were describing their experiences. To complete the first cycle coding, we created a table with a column for each type of code. As a group, we went through the first transcript line by line to extract process, emotion, and in-vivo codes and entered them into the table along with the line number in the transcript. This allowed us to establish consistency with coding among the research team members. We then continued working as a team of researchers and combined similar first-level codes into broader categories to establish second cycle process, emotion, and in-vivo codes.

During the second coding process, our research team completed and reviewed the coding of the transcript of Participant 1 as a group. We then divided into smaller groups of three researchers to complete the first and second-cycle coding of the transcripts of participants 2 and 3, and 4. The final second cycle codes were further reviewed by three other research team members and all final codes were reviewed by the primary researcher, matching the codes to the initial transcript. This process ensured consistency among all the researchers during code development and ensured that the codes accurately reflected the participants' data.

Next, researchers conducted a cross-case analysis by combining and regrouping the secondary codes from all the transcripts to develop overall process and emotion themes describing the lived experiences of caregivers of children with disabilities who received occupational therapy services during the pandemic. We used the preliminary in-vivo codes to

strengthen the process and emotion codes by using the words of the participants to describe the themes. We used Google Docs to create the code tables. The code tables were saved as an audit trail capturing the changes we made throughout the analysis process. Prior to and throughout the analysis process, each researcher maintained a reflexivity journal, documenting personal experiences of working with children with disabilities and their families, as well as other personal experiences during the shutdown caused by the COVID-19 pandemic. This was used to help reduce researcher bias during data collection and analysis.

Findings

The purpose of our study was to explore the experiences of caregivers who had children with a disability receiving occupational therapy services prior to and into the pandemic. We interviewed four female participants, three participants were mothers, and one participant was a grandmother caring for a child with a disability. See table 1 for a full description of each participant. The children were between the ages of 7 and 13 years old and had received occupational therapy services for a lengthy period of time prior to the onset of the pandemic (See table 2 for a description of the children receiving care from the participating caregivers.) Each caregiver's life circumstances prior to the onset of the pandemic played a substantial role in their experiences of caring for a child who received occupational therapy during the pandemic. We have provided a brief description of these life circumstances in table 1.

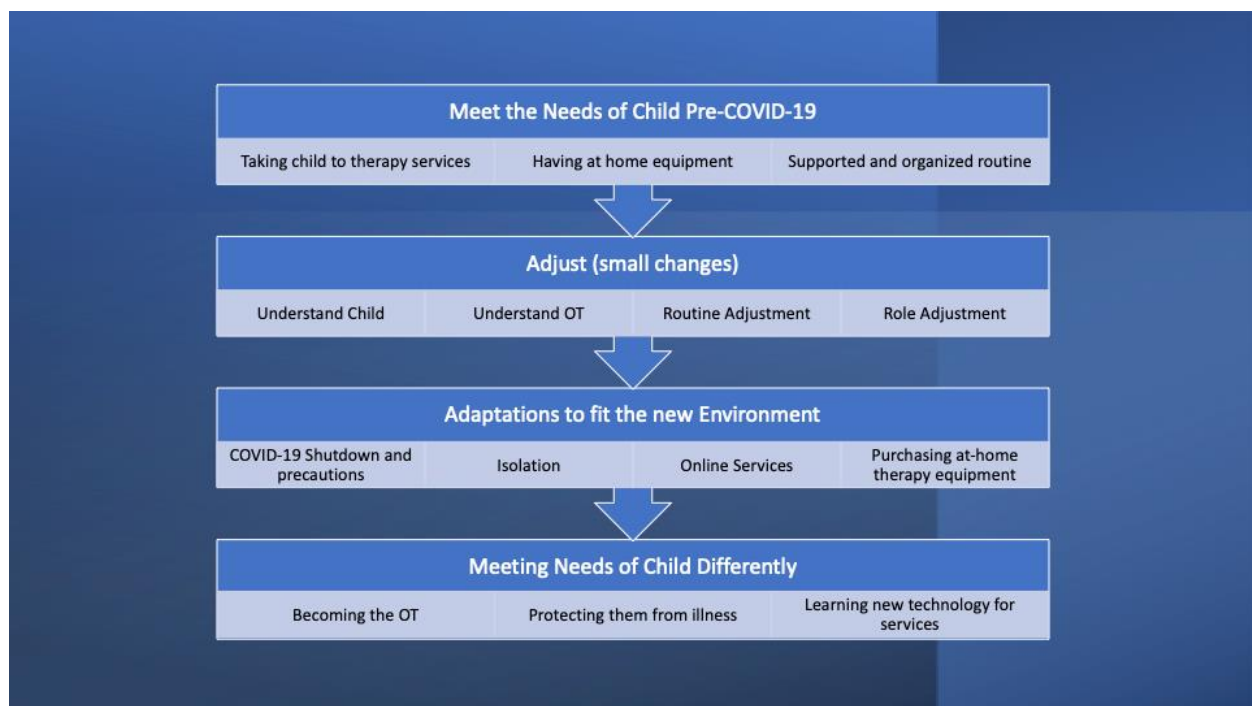
Process Themes: What they did

The participants described their daily routines and life experiences prior to the pandemic, during the lockdown in March of 2020, and their daily routines at the time of data collection, which was in the Fall of 2021. This was approximately 18 months after the initial shutdown. We used this data to inform the processes the participants went through during this time. The process

themes that emerged depicted four clear stages of change for the participants, which included: (a) *Meeting the needs of the child pre-COVID*, (b) *Adjusting (small changes)*, (c) *Adapting to fit the new environment*, and (d) *Meeting the needs of their child differently*. The participants also described several consistent and specific activities they engaged in during each stage in the overall process. (See figure 1).

Figure 1

Process Themes



Meeting the Needs of their Child Pre-COVID

The caregivers described well-established daily and weekly household activities prior to the lockdown caused by the COVID-19 pandemic that ensured they were supporting the therapeutic needs of their child. They described three primary ways they met the needs of their child pre-COVID-19, which included regularly taking their child to therapy services, having therapy equipment at home to use with their child to reinforce therapy services when the child was at home, and having a supported and organized routine.

Each participant clearly described a weekly routine that included regularly scheduled occupational therapy services for their child. All of the children began receiving occupational therapy through early intervention services with two of the caregivers indicating their child started receiving occupational therapy “at birth”. The participants described having a busy schedule balancing occupational therapy services with other family and child activities such as school, physical therapy, speech-language pathology, and the caregiver(s) work schedule. Several of the participants also reported that they chose to receive outpatient OT services beyond the occupational therapy that their child was receiving within the school system, indicating they did not believe all of their child’s occupational therapy needs were being met through the school system.. Even though the schedules were busy, the caregivers did what they needed to do to make sure their children received the services they needed. For example, participant 2 scheduled all of their child’s therapy services one day a week during the school day: “She would get [therapy on] Thursdays and we had called it “Therapy Thursday.” We had PT and OT back to back, came home, ate lunch, and then we went to speech therapy ... she loved it.” Participant 3 also took their child to therapy one day a week after school: “then, when he comes home, you know he'll have a snack he loves looking at uh playing games on his tablet. He goes once a week... to occupational and physical therapy.”

Participant 1 reinforced the importance of having therapy-based equipment at home: “I’m mildly obsessed with having stuff and activities that he can do... We have right here theraputty, these things... I ordered a bunch of stuff... beads and stuff...” While participant 2 remained involved in various local programs to engage the child in various formats: “We were ... connected with Down Syndrome Indiana, we do a learning program so always kind of just reinforcing skills, whether it's school, social, OT, PT, speech, whatever through play and

activities and connection.” The participants understood how to reinforce their children’s therapeutic goals and created ways to make that happen at home.

Each caregiver described an established daily and weekly routine to support their child’s needs. Participant 4 described their routine before COVID as: “Prior I mean everything was going like a well oiled machine, you know they were working on things.” Participant 1 explained a thorough morning routine

We’re close to the school. I leave the house to take him to school at 8:30 we’re always there a little early. It’s just easier to leave at that time... dad gets him up... He’ll feed him breakfast. They’ll do a puzzle during breakfast, and he loves magazines so he likes to look at it and flip through those. And then brush his teeth and medicine and dressed and out the door.

Participant 3 described their morning routine, reporting that, “my husband does most of getting him ready for school and you know he eats breakfast and then he goes to school he loves school.”

Adjust (small changes)

During the next phase of the process, at the onset of COVID-19, the participants began to adjust to a new lifestyle. They described having to gain a deeper understanding of their child and their occupational therapy goals. They also shared how they made adjustments and adaptations to their prior routines and roles. Due to the shut down caused by the pandemic, the participants reported that they now spent the majority of their time at home. Participant 2 reported

life went from this routine that I told you about of what we did, every day, and everybody went to their place, and then we came back as a family and just all sorts of stuff, and then suddenly it was pretty much [the child] and me 24 hours a day.

Additionally, participant 2 shared how they created a new routine at home

I actually made an activity schedule for us every day... And you know she could check it off, and she can kind of dictate what we did, but that way, we had some kind of routine or schedule versus just 'uhhh... we're bored at the house, What are we gonna do?

Several of the caregivers also reported that because they were “forced” to be with their child most of the time, they discovered new activities, different food, and more interests that their child enjoyed. For example, participant 4 explained that she discovered her child loved eggs and tomatoes and she also figured out a way to integrate his occupational therapy goals through cooking this new-found meal, she said “it was just trying to find new inventive ways to try to get therapy in without him knowing we were doing therapy.” They reported that they had to understand their child’s occupational therapy goals and have a better understanding of how occupational therapy was meeting their child’s goals. Participant 3 stated, “I feel like I learned as much as [the child] does as far as you know, like it was her idea that he learned to fold laundry.” Even with services shifting online, participant 2 affirmed this by stating, “There's not any replacement value for being in person with an OT with their hands and their brain and their care and their connection, but I think it actually translates fairly well to an online platform.” Along with this appreciation of OT came more involvement with the services and additional roles that participants began to take on. Participant 1 indicated “we did everything. I became his... all of those therapy sessions I was telling you about? He kept them all, but I did them.” hours a day” and “So yeah, I was wearing all of the hats.”

Adaptations to Fit the New Environment

These small adjustments soon became adaptations to better suit participants' new situations. We identified four main adaptations within this phase of the process, the overall COVID-19 shutdown and precautions that came along with it, isolation at home and from others, services shifting online, and purchasing at-home therapy equipment. Participant 4 said

it was the second week and the third week and on, that became worse because.

Not only that, he wasn't allowed to go into restaurants or anything like that, we still do some drive through, but he was sit and cry he was a good boy he cried "I good boy I good boy." And I'd be like "it's not you bubby it's the restaurants are sick. They described their isolation from other family members by stating,

she herself was medically fragile And stuff and we didn't see her for Thanksgiving, we saw her for Wigilia, which is a Polish Christmas on Christmas Eve, that was the first time I've seen my sister since um since October And stuff.

Participant 1 also commented about feeling isolated and alone "A lot of it was hard. Because now we went to having a team of people and giving us a break to now being full-time with everything." Several participants isolated themselves due to medical precautions caused by the risks associated with COVID-19 and they had to shift therapy services to online. Some participants enjoyed this change and adapted to this conversion. Participant 2 stated, "[the child] did well with it and it worked fine for her, and I think it was a good thing for her to be able to be connected, even just visually, to somebody besides me." On the other hand, Participant 4 did not see the benefit of online services stating

virtual OT were offered, however. They I mean they wouldn't have done any good.

Because like I said the attention span and for him to sit and have someone especially a

therapist to sit there and try to tell us how to do something and to work with him on certain things. I mean you could try but it's not going to work out the way you want it to.

As these services shifted online, some of the participants adjusted to these new conditions through buying new therapy equipment to provide therapeutic intervention in a new virtual environment. Participant 1 commented

we took a room in our basement and we found online and purchased a therapy swing, like the one that looks like a hammock. Because we were doing the sessions and it so hard to keep him interested and for me to feel like I was doing a good job. Umm...We also got one of those big bolsters.

Participant 4 also supported this adjustment by stating

We ordered a peanut for him to bounce on and do some activities. we also ordered a two pound weighted ball. To help him with tossing and like Bowling and stuff like that, for more accuracy and build up that upper body strength and, of course, climbing his bounce house which had a slide and we had work on that because he does not have the upper body strength. I bought a great big whiteboard for him to use for writing and stuff like that.

The participants adjusted to their new environment after the shut down as therapy services shifted to online by buying therapy equipment to help their child as best they could because they were the only ones who were available to help.

Meeting the Needs of their Child Differently

As COVID-19 continued with constant unknowns of what the future would look like, families had to change their roles from being only caregivers to providing occupational therapy

services for their child. Caregivers had to adjust their routines and adapt to their environments, but also strive to meet the specific and unique needs of their child. This included becoming the at-home occupational therapist, protecting their child from the COVID-19 illness, and learning new technology for services via telehealth. Due to this huge learning curve, caregivers admitted to struggling to take on so many roles and responsibilities.

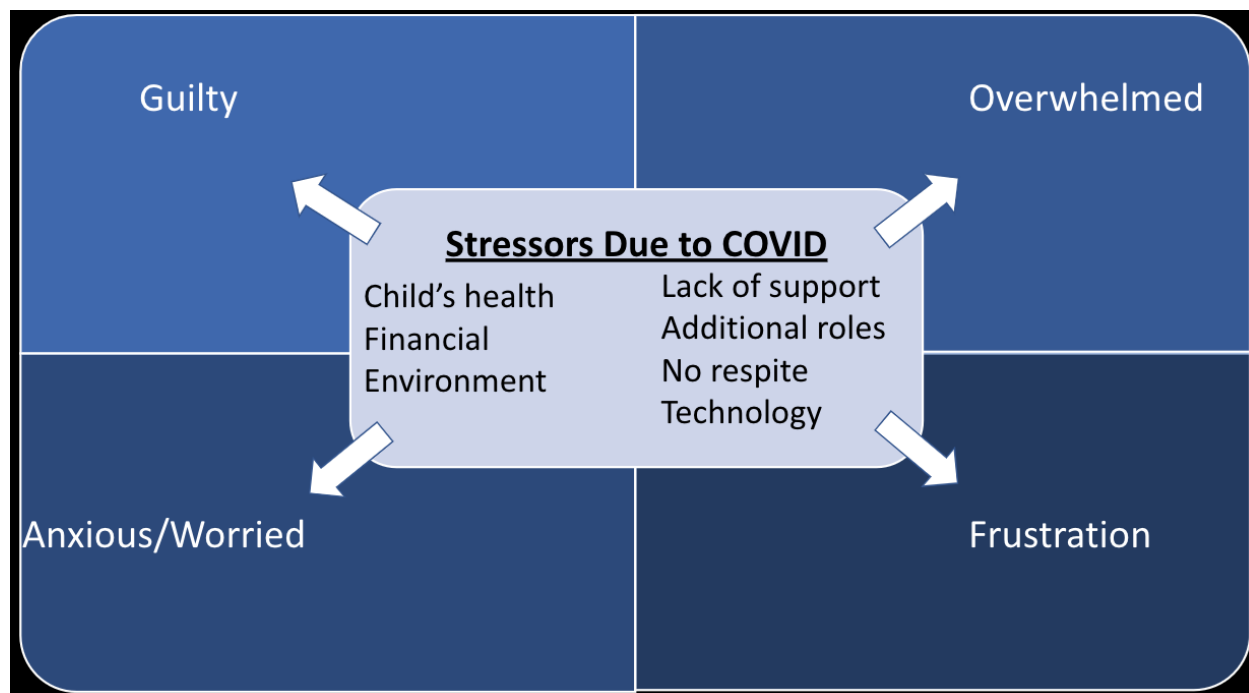
Struggles varied from participant to participant. Participant 1 expressed, “Struggling to make sure the ipad caught the exercise. So we had to buy a tripod to put it on.” Participant 2 struggled with “just being able to keep the child safe” due to the fear of their child contracting COVID-19. Struggles and challenges were exacerbated when resources were limited and there was limited support available due to the pandemic. Participant one explained they had to take on additional responsibilities due to having limited respite care hours. Eventually, they decided to pay out of pocket for their respite care worker because they were desperate for some relief from being alone with their child 24/7. For others, paying out of pocket for additional help or therapy items and equipment was not an option.

Several of the participants shared that they altered their routines to limit their exposure to others who might pass along COVID to their child. They established protective barriers and practiced safe social distancing. Participant 4 stated, “we missed a lot of his appointments” and participant 1 was fearful of their respite provider being safe from COVID-19. Caregivers had to balance and prioritize the importance of therapy, the health of their child, and how to continue to support their child with disabilities during quarantine. When asked if they could go back in time and provide themselves with advice, one participant stated to have more patience: patience with their child, with the process of taking on more roles as their caregiver and occupational therapist, and patience with understanding the impact of COVID-19 because so much was unknown about the disease at this time.

Once accepting the roles and changes they were faced with, the participants began to feel more comfortable and confident in their ability to be their child's at-home caregiver and provide some level of occupational therapy intervention with the online resources provided by their registered occupational therapists. They reported that their occupational therapists provided ideas and resources that helped them provide treatment at home. Participant 2 stated her occupational therapist "always gave me a list of "here's what I work on" this allowed her to feel more confident that she was working on their child's therapeutic goals at home.

Figure 2.

Emotion Themes



Emotion Themes

The participants expressed many emotions when they described the process changes they experienced when the lockdown occurred and as the pandemic continued. Two primary categories of emotion themes emerged from the data. The first category included the negative emotions of feeling *Anxious/worried*, *Overwhelmed*, *Guilty*, and *Frustrated*. The second

category of emotion included positive emotions of gratitude and appreciation. The participants discussed the heightened negative emotions as they shared about specific events or stressors brought about by the pandemic. These stressors included: (a) worrying about their child's health, (b) financial stress due to job insecurity and uncertainty, (c) stress related to uncertainty about what was happening around the world (d) experiencing a lack of support from others outside the immediate family, (e) the addition of new roles and responsibilities, (f) not having a break from their child, (g) and the stress of trying to learn new technology. We will discuss the negative emotions participants experienced during the reported events and stressors as well as the positive emotions of gratefulness and appreciation for the services received despite having those negative emotions.

The participants consistently described feeling anxious and worried at the onset of the shutdown and throughout the pandemic. For example, participant 4 experienced anxiety when she encountered a medical emergency with her son during the onset of the pandemic. The caregiver did not want to take her child, who was immunocompromised, to a hospital where there was an influx of COVID patients. She was worried because her son's injury required immediate care, and she had to make the difficult decision to take her son to the hospital for treatment and risk getting COVID: "I was just like freaking out taking him in." Due to the pressing situation, the participant felt forced to make the decision when there was no safe choice between the risk of contracting COVID and compromising her son's health. Likewise, participant 1 felt anxiety because her child was no longer receiving therapy services. The uncertainty of the duration of the pandemic caused significant worry about further delay in her son's development. She stated she was "so terrified this was going to be even worse." Hence, the uncertainty of exposure to the virus and the duration of the pandemic caused anxiety for caregivers of children with disabilities because their children were immunocompromised prior to

the pandemic and they were already developmentally delayed with the potential to become more delayed due to lack of services.

The participants also shared negative feelings of being overwhelmed during the pandemic. Participant 4 reported feeling the burden of providing consistent care for her child and described the feeling of being overwhelmed when she stated

I felt like I didn't get a break as a mom. Ya know, because I constantly had him you know. It's like don't get me wrong, I love my kid, do anything for my kid, wanted him for forever, but need a break once in a while.

Similarly, the participants also attributed feelings of being overwhelmed with new caregiver challenges caused by the pandemic, such as learning how to use technology, and figuring out how to provide their child education and therapy services without external support. Participant 2 stated, "I think just the weight of being a parent of a child who has special needs, just like exponentially grew in the pandemic". Participant 1 describes how the lack of support during the pandemic made caregiving responsibilities more challenging, "If you have a strong support system, you can make it through. Umm... And so when that went away, it just kinda, it put a lot of stress on us." Without occupational therapy services, caregivers felt burdened by the additional responsibility to provide services to their child. Participant 4 stated, "Just trying to find ways to continue with therapy was very stressful you know, without him having to go to therapy." Furthermore, participant 4 shared how the pandemic caused considerable shifts in social norms and ultimately felt powerlessness as a result of being overwhelmed when stating, "So it was a lot, it was a lot to deal with... because it becomes emotionally draining, not just for the child, but for the parent too. Because how do you make things right?" Also, the pandemic took a toll on caregivers' decision making as some catastrophized and had to consider how to

protect and provide for their children during the pandemic. Participant 4 recalled that “It’s really hard when she has other respiratory stuff so then it’s like that all blew up and just trying to all the other things that every other parent was scrambling to figure out...how are we going to provide care for our kids.” Although the caregivers had different life experiences, they all expressed feeling overwhelmed with the multiple stressors brought on by the COVID-19 pandemic.

The third negative emotion expressed by the caregivers was guilt. Participant 1 stated “I’m not able to execute it the way I’m supposed to” when discussing their newly found role as a therapist. She felt that although she was well versed in all of the therapies, she was not able to execute them, because their child would not participate with her as the parent the same as they did with their actual therapist. Participant 3 had difficulty connecting with therapy due to the change in her grandson's guardianship and feels “if they could have gotten ahold of me, then I could have arranged something for him.” However, she admits she feels guilty for not scheduling therapy services for several months during the pandemic, “I just feel bad for him that we lost that you know, six months in there that we could have been doing something um, but we did nothing...I feel like we lost ground”. Participant 3 feels responsible for her grandson’s regression due to the cessation of therapy services and the lack of action taken to resume therapy. Each participant had other stressors in their personal life as well as the stressor of having to care solely for a special needs child during a pandemic, evoking a sense of caregiver guilt.

Participants also experienced negative feelings of frustration during the pandemic because they expressed that they were misunderstood due to their nontraditional caregiver role of children with special needs. Participant 4 wished that “people who have typical kids would have more grace because they don't understand the pressures that, you know a special needs mother is under.” This participant also felt strongly about receiving services in a timely manner to prevent further setbacks in the child’s progress. Additionally, participants felt frustration when they did

not fully understand how to utilize new technology in order to accommodate their child in a virtual learning environment. Participant 3 described the struggle with their technological challenges: “That was tough, um because my husband [...] is the most computer person, [and] we have [...] virtual learning with [the child].” These technological barriers presented a challenge with school services, and was also a factor that impeded this family from participating in virtual therapy services. Participant 1 experienced frustration with the loss of respite hours early into the pandemic

I don’t know if we really handled it, I mean that, it was just one of the, umm...we didn’t have any option. Um The one person that we had for respite, she was very careful going into quarantine because she knew that she wanted to watch [the child]. She watched him some, but we couldn’t...We couldn't even use.. I mean we used a lot of her hours in April, May, and June... So we felt like we had the support because we had our respite, and we had someone who could watch him very regularly. Umm... Then we ran out of respite hours.

The second broad categorical theme included the positive emotions of feeling grateful and appreciative. Their appreciation reflected their feelings toward the OT profession, their child’s OT, and the new information they learned regarding OT and their child. Although many mentioned having limited support from respite and family/friends, they were thankful for the support that they did receive. Even though they experienced anxiety, worry, feeling guilty, and feeling overwhelmed during this process of change, several of the participants were appreciative of the unexpected, forced family time as many of them were experiencing hardships prior to the pandemic and it provided them time to cope that they would not have had otherwise.

According to Participant 3, “there's not any replacement value for being in person with an OT with their hands and their brain and their care and their connection, but I think it actually translates fairly well to an online platform.” Participant 2 stated that “occupational therapy, in particular, is really well equipped to help people because you have the mental health, the cognitive perspective, the LIFE skill, the occupation, which is not your job.” In addition, Participant 2 also described how it is

...hugely commendable, because every healthcare professional also have their own stresses and their own issues to be dealing with yet they're also trying to support families and kids who have special needs in order to be okay ... not only supporting [the child] but supporting me, so I could support [the child].

The participants' appreciation for occupational therapy recognizes not only the value of therapy services received but the compassion that the profession provides to their families.

Discussion

We asked caregivers who had children receiving occupational therapy services to share their experiences before the pandemic, during the shutdown caused by the pandemic in March 2020, and approximately a year and a half after the shutdown in October 2021.

Before the pandemic, the caregivers maintained well-established weekly and daily routines to complete personal, household, and work tasks while meeting the needs of their children. According to the Occupational Therapy Practice Framework (OTPF-4), routines are “patterns of behavior that are observable, regular, and repetitive and that provide structure for daily life” (American Occupational Therapy Association, 2020). These routines provided structure which allowed caregivers to help their children prepare for and participate in their daily activities with decreased effort and stress. O’Nions et al. (2018) reported that when parents

created and established routines to meet the unique needs of their child with a disability, their child exhibited a decrease in problem behaviors, which helped to reduce caregiver stress.

As the world shut down due to the spread of COVID-19, the established routines of caregivers of children with disabilities were quickly disrupted, causing uncertainty about what was happening and how they would continue to meet the needs of their children. They had to adapt by creating new routines (Rogers et al., 2021) integrating the added responsibilities of creating their child's social, academic, and therapeutic environments in the isolation of their home (Fitzpatrick, 2021; Garbe, 2020). The shutdown also forced caregivers to fulfill new roles, such as being their child's teacher and therapist while maintaining their traditional roles of being a caregiver, spouse, friend, sibling, and worker at a time when work also had to take place in the home (Garbe, 2020). As caregivers established new routines and adapted to the roles of teacher and therapist, they maintained the primary goal of meeting their child's needs. To do this, they had to understand their child's therapy and education goals and figure out therapeutic and educational methods that worked best for their child to be successful. They had to purchase new supplies and equipment and learn new technology for their child to engage in online learning and participate in telehealth therapy. These added stressors and the dramatic change in routines caused caregivers to be overwhelmed and frustrated, which intensified because the caregivers felt isolated, with no respite time away from their child. Asbury et al. (2021) also attributed feelings of being overwhelmed to caregivers having total or conflicting responsibilities for their children, being unprepared, and having no support or respite while struggling with the challenges of handling their children and their behaviors.

Additional stressors that caused caregivers to be worried and anxious included the uncertainty of the global and economic impact of COVID-19 and the unknown duration and severity of the pandemic. Businesses were shutting down, causing them to worry about how

they would meet their personal financial needs. They were also getting mixed messages from the media about how to best protect themselves and their child from getting COVID-19. Garbe et al. (2020) also explained that caregivers of children with disabilities were anxious about their child's return to social normalcy. As things started to open back up, caregivers were also faced with difficult decisions, such as deciding if leaving the house to get groceries or going to work was worth the risk of their medically fragile child becoming severely ill if they caught COVID. Rogers et al. (2021) reported that caregivers were overwhelmed by the uncertainty and fear of the unknown implications of the pandemic. Through all of this, the caregivers' primary goal was to continue meeting the needs of their child and providing assistance to help their child continue to make progress or not become more delayed. That being said, the caregivers' feelings of being anxious and worried, frustrated, and overwhelmed were layered with feelings of guilt because they felt they did not have the skills to adequately help their child or prevent their child from regressing developmentally or educationally. These feelings were enhanced because they now had limited to no social support. Under the pressure of new responsibilities, caregivers expressed having difficulty tolerating extensive time at home with their child, which led to higher levels of feeling overwhelmed and anxious (Garbe et al., 2020).

All of the caregivers in our study were either mothers or grandmothers. Mothers in general, have a higher level of anxiety and guilt compared to their counterparts (Minarikova et al., 2022), especially if they value traditional gender roles (Batram-Zanvoort et al., 2021). When mothers feel like they can not adequately meet the needs of their child, they feel like they are not being a good mother adding to their sense of guilt (Batram-Zanvoort et al., 2021).

Even when caregivers experienced negative emotions of frustration, guilt, being overwhelmed, and anxious, they expressed high levels of gratitude and appreciation. They were appreciative and grateful for occupational therapy services, occupational therapy practitioners,

and the newfound understanding of their child. Being isolated and having “forced” time with their child helped caregivers discover new ways to integrate therapy into their daily lives because they learned new things about their children. For example, some caregivers described learning about new foods their child would eat. Some discovered their child was more engaged in activities if the child determined the activities of the day. Some caregivers also learned that their child liked to help with household tasks such as cooking and gardening and realized that their child’s participation in these activities was meeting therapy goals. Ludgate et al.(2022) also found that spending increased family time during the lockdown provided caregivers with opportunities to gain skills to creatively and efficiently provide therapy intervention with a newfound understanding of their child’s interests and abilities.

The caregivers also expressed having a new appreciation for occupational therapy and their occupational therapy practitioner. During the pandemic, the caregivers had to implement occupational therapy on their own. They were grateful for the continued support and availability of the occupational therapists who provided ideas about alternative ways to integrate therapy with the supplies and equipment they had in the home. They developed a deeper appreciation of how occupational therapy intervention was specifically designed to help their child reach their occupational therapy goals. Some of the caregivers also discussed appreciating occupational therapy being delivered through telehealth because it reduced the necessary travel for outpatient occupational therapy. After the caregivers learned how to use the technology for telehealth, some caregivers were able to see that the occupational therapist was able to help their child meet some of their therapeutic goals through telehealth services. The caregivers were grateful for the opportunities to integrate a new understanding of their child’s likes and dislikes and new creative therapeutic strategies into their newly established routines to help them meet the needs of their child in a different way.

Conclusion

Our findings suggest that when caregivers of children receiving occupational therapy services are faced with major obstacles causing their child's services to be dissolved, they quickly begin a process towards making sure their child's needs continue to be met. Caregivers adjust by creating new routines, learning more about their child, and developing a better understanding of their child's occupational therapy goals and services. They may purchase the necessary equipment and supplies to take on new challenges, such as learning new skills for alternate service delivery methods (learning technology for telehealth and online education). At the same time, they adapt to larger environmental changes if needed, in this case, they adapted to feeling isolated, having no respite or time away from their child, and they adapted to the precautions caused by COVID-19. Even if the process causes negative feelings of being anxious and worried, frustrated, overwhelmed, and feeling guilty, they will do what it takes to make sure their child is successful, and their needs are being met. During this time, they are also grateful and appreciative of any assistance they can get to make sure their children's needs are being met.

Beyond the shutdown caused by the COVID-19 pandemic, abrupt changes in service delivery for children who are receiving occupational therapy services are inevitable, such as when families move or experience a death or loss in the family. Occupational therapy service providers should understand a caregiver's drive to ensure their children's therapeutic needs continue to be met. They can provide vital assistance to support caregivers during this time. Occupational therapy service providers should help caregivers quickly create new routines and learn new skills if needed. Occupational therapy service providers are also equipped with the skills to address the psychological stress of caregivers. They should work with caregivers and help them find new support networks so they do not feel isolated and alone during these changes, which will ultimately help the child for whom they are providing services.

Limitations

Due to the qualitative methodology of our study, the findings can not be generalized to all caregivers who had a child with a disability receiving occupational therapy prior to and into the pandemic. However, our results are transferable to similar participants experiencing the same phenomenon. Our intent was to recruit participants with a maximum variation of socioeconomic status, gender, race, and child's disability. However, we were not able to obtain such a sample. Future research should be done with participants who represent caregivers with varied demographics because it has been shown that many of these differences can affect the lived experience during this unprecedented time (Neece et al., 2020). This will allow for greater transferability of the results that may be more representative of all caregivers who have a child with a disability receiving occupational therapy during the pandemic. Researchers should also examine the long-term impact of COVID-19 on caregivers with children receiving occupational therapy. Based on our results, some of the caregivers liked using telehealth as an option for implementing occupational therapy. This will help occupational therapy practitioners provide more client-centered services while providing optimal support for families to produce better outcomes for their children.

As COVID-19 continues to impact the world, researchers should continue to explore how this affects caregivers of children with disabilities and the services they receive. Follow-up studies can be done to see if caregivers' processes or emotions have changed since the initial data collection. Researchers should also identify how caregivers were best supported during this major life-changing event so occupational therapists will know how to provide the support needed for caregivers to continue to meet the needs of their children during other life-changing experiences.

Findings

Table 1. Caregiver Demographics

Participant	Age	Relationship to the child	Occupation	Marital Status	Education level	Life Circumstances
1	44	Mother	Real Estate and runs a Non-Profit	Married	Masters degree	Parents are married, father transitioned to working from home. Parents had established a non for profit organization to support families with children with disabilities prior to the pandemic.
2	46	Mother	Physical Therapist	Divorced/single	Graduate degree	Month prior to and into the shut down family was all sick. Mom took FMLA so she could stay home with her daughter. Her daughter's physicians were concerned about her daughter's compromised respiratory status and they did not want mom to be exposed to COVID and possibly bring it home to her daughter. Husband/child's dad was recovering from addictions and relapsed. Parents divorced during the lockdown and mom and daughter moved to a new city approximately 2 ½ hours away to live with the child's grandparents.
3	65	Grandmother	Paralegal/ Retired	Married	Paralegal degree, associates degree	Lost daughter a few months before the pandemic started and became "full-time" caregiver of grandchild due to limited involvement of the child's father. Child lives with his father, grandparents do all of the child's care.

4	52	Mother	Homemaker	Single	Junior year in college	Lost father at beginning of the pandemic. Lost her father's brother (uncle) 5 months later. Lost cousin who lived across the street 6 weeks later. Her partner/child's father lives across the street because he was taking care of his mother before she passed away in the summer of 2021.
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Table 2. Child Demographics

Participant	Child Age	Child Diagnosis	Duration of OT services before March 2020	Duration of OT services after March 2020
1	9	Hydrocephalus	Since child's birth	All in-person therapy stopped. They began virtual therapy services/created an at home therapy gym. Received school OT/PT services once schools opened. Continued x1/week outpatient.
2	7	Down Syndrome	Since child was 6 mo; began Theraplay at 2017	Moved to virtual therapy services in April 2020. Continued therapy Thursdays in Indianapolis. Dropped PT due to a child being involved in gymnastics.
3	13	Cerebral Palsy	?	OT and PT ended with the shut down caused by the pandemic. They did not do virtual OT, they resumed OT in August 2020. Grandma reported that dad received an email asking about virtual OT, but dad did not use computers regularly, therefore he did not get the email. She regretted not having done anything for three months.

4	8	Down Syndrome	Since child's birth Outpatient OT and speech 3x/wk at KidsAbility School OT, PT, and speech	Around mid June 2020
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Appendix

Introductory Questions to be completed during the initial phone call.

Tell me more about your family and children.

- a. How many children do you have?
- b. How old is your child with a disability?
- c. What is your child's diagnosis?
- d. Where did your child receive occupational therapy services prior to the pandemic?
- e. How long did your child receive occupational therapy services prior to the onset of the pandemic in March of 2020?
- f. How long did your child receive occupational therapy after the onset of the pandemic?

Tell me about yourself.

- g. How old are you?
- h. Do you currently work, if so where?
- i. What is your marital status?
- j. What is your highest level of education?
- k. What are some of your Interests and hobbies?