

**THE EFFECT OF TELEHEALTH OCCUPATIONAL THERAPY SERVICES ON
THE STRESS AND SELF-EFFICACY OF CAREGIVERS OF CHILDREN WITH
SPECIAL NEEDS: A SURVEY STUDY**

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

by

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August 2021

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Certification of Approval

I certify that I have read The Effects of Telehealth Occupational Therapy Self-Efficacy of Caregivers of Children with Special Needs: A Survey Study by Kristy Dai, Amanda Ma, Lorely Sotelo, and Alicia Stearns, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Abstract

The COVID-19 pandemic has impacted the way families of children with special needs receive care. With many clinics closing their doors and limiting face-to-face sessions, patients, healthcare professionals, clients, and caregivers were forced to abruptly shift from an in-person to a telehealth (TH) service delivery model. The purpose of this survey study was to explore the effects of pediatric TH occupational therapy on stress and self-efficacy of caregivers of young children with special needs during the COVID-19 pandemic. Data was collected from 13 caregivers of children with special needs (11 English-speaking; two Spanish-speaking) between April 27 and May 21, 2021, via a 10-question anonymous online survey. The survey was a combination of Likert-scale, multiple-choice, and open-ended questions regarding caregiver primary stressors, stress levels before and after receiving TH, service delivery preference, and the advantages and disadvantages of TH. 10 out of the 13 participants preferred in-person therapy to TH therapy and were equally likely to report the same stress levels to TH before and after TH occupational therapy sessions. Top stressors for caregivers included lack of time, finances, working from or outside the home, and caring for multiple family members. The results suggest that caregiver self-efficacy and stress levels increased as caregivers became more involved in a child's therapy though we hypothesized that caregiver stress would decrease and self-efficacy would increase with TH occupational therapy. Our survey findings indicate a need for greater consideration for family-centered TH treatment that addresses caregiver burden and the creation of standardized caregiver coaching for TH occupational therapists.

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The Effect of Telehealth Occupational Therapy Services on the Stress and Self-Efficacy of Caregivers of Children with Special Needs: A Survey Study

The COVID-19 pandemic has impacted the way families of children with special needs receive care. With many clinics closing their doors and limiting face-to-face sessions, patients, healthcare professionals, clients, and caregivers were forced to abruptly shift from an in-person to a telehealth (TH) service delivery model. A systematic review by Olsen et al. (2018) provides a snapshot into what the TH landscape looked like before COVID-19: inconsistent and unclear regulations for teletherapy, and TH being an underutilized resource to deliver therapy services. Exploring the complexities of TH is important to understanding how healthcare practitioners can better serve and cater to their communities even after the end of the COVID-19 pandemic.

Pediatric occupational therapy's shift onto a TH platform involves both adjusting to technology and also a shift in the roles that occupational therapists and caregivers play in the child's therapy process. Studies have shown that caregivers often feel unprepared and untrained in proper homecare techniques and strategies, which may lead to decreased self-efficacy and negative perceptions about TH therapy (Dhiman et al., 2020; Dahl-Popolizio et al., 2020). TH therapy can be most effective when the occupational therapist becomes a caregiver coach and facilitates the caregiver's implementation of therapeutic strategies. With the increase in caregiver involvement, TH can be utilized as a collaboration between therapists and caregivers, with the aim to increase caregiver carryover of therapeutic strategies into their everyday lives (Gibbs & Toth-Cohen, 2011).

This shift in roles has created a large learning curve for pediatric occupational therapists, who rely on face-to-face interactions and hands-on techniques to guide their

practice. Hines et al. (2019) have noted that there is very limited research and literature that can inform evidence-based practice for TH delivered occupational therapy. While many pilot and case studies provide a rich overview of the TH experience, it is difficult to extrapolate these findings to the general population. Dahl-Popolizio et al. (2020) suggests that TH can be an effective alternative form of therapy, and occupational therapy practitioners across the United States are expressing their support of teletherapy as a permanent option to be used in addition to in-person visits. However, research on the effectiveness of TH services has primarily been from the therapist's professional perspective, and insight on the unique caregiver experience is lacking, especially for families of young children with disabilities (Dahl-Popolizio et al., 2020). There is a growing need for caregiver-centered research to inform occupational therapists on how to implement practices that are the most relevant and effective for an online platform, as in-person techniques do not always translate to the TH therapy setting.

Through this study we wanted to understand the effects that pediatric TH occupational therapy can have on caregiver stress, self-efficacy, and implementation of therapeutic strategies. With therapy services moving online in response to the COVID-19 pandemic lockdown, we hypothesized that: Families of children with special needs 10 years and under who received 4 or more TH occupational therapy sessions between March 2020 and May 2021 would experience less stress, and have higher caregiver self-efficacy, when implementing therapeutic strategies. We hypothesized that caregivers of younger children would have the most significant increase in self-efficacy from TH occupational therapy services because younger children may require more assistance and caregiver involvement in implementing therapeutic strategies. Through a caregiver

questionnaire, we assessed the strengths and challenges of TH occupational therapy from the caregiver's perspective as well as which service delivery model (in-person, online, or a combination) caregivers prefer. We also evaluated the impact that the therapist-caregiver relationship and unique stress factors can have on caregiver self-efficacy and carryover of therapeutic strategies.

Literature Review

Upon review of 24 recent (2015-2020) peer-reviewed articles exploring the viability and effectiveness of TH practice through group discussion, three common themes emerged: common caregiver stress and stressors, the role of community support, and perceived barriers to TH. We also reviewed and utilized articles published during the COVID-19 pandemic, when TH occupational therapy became the new normal, to further inform us on the most current research regarding this service delivery model.

Common Theme 1: Caregiver Stress and Stressors

Caregivers of children with special needs experience unique and chronic stressors that can negatively impact a caregiver's well-being, and these stressors have been exacerbated by the COVID-19 pandemic (Dhiman et al., 2020). Using qualitative interviews and a life satisfaction and psychological well-being measures, Larson (2010) found that caring for a child with special needs can come with stressors that specifically affect positive family relationships, financial security, and balance/order within daily life. Several studies highlight how TH occupational therapy can help to alleviate financial and transportation caregiver stressors in ways that traditional in-person therapy cannot (Clawson et al., 2008; Hines et al., 2019; Kistler et al., 2019; Larson, 2010; Nobakht et al., 2020; Witmans et al., 2008; Wallisch et al., 2019). Larson (2010) found that

caregivers for children with special needs ranked their “ability to manage life’s demands” as the highest indicator of their personal well-being and quality of life. That being said, Hines et al. (2019), Nobakht et al. (2020), and Kistler et al. (2019) concluded that a TH platform, which allows for convenience and flexibility with location, time, and people involved, is not only an effective method of therapy but also an overall better fit into a family’s everyday routines (for example, not having to miss work or school). They found that for families with children who cannot easily tolerate traveling or become anxious in unfamiliar settings, TH was a more suitable option for both the client and the caregiver.

Witmans et al. (2008) and Clawson et al.’s (2008) studies also noted that TH provided families access to specialized and niche care without having to sacrifice their finances or time due to travel expenses. Wallisch et al. (2019) found that TH permitted occupational therapy sessions to be scheduled beyond the typical 8am-5pm time block, allowing caregivers more flexibility in scheduling occupational therapy sessions and leading to fewer missed sessions. The literature suggests that teleconferencing has the potential to minimize caregiver burden when choosing between attending therapy or being practical with limited time and finances. The convenience of organizing TH sessions around a family’s unique schedule and responsibilities is a major reason why this delivery model can potentially help alleviate these caregiver stressors.

Dahl-Popolizio et al. (2020) found that some pediatric occupational therapists reported increased “no shows” while some had fewer, which calls for the consideration of other potential factors that may affect attendance and the frequency of online sessions. These findings point towards the idea that TH may only be convenient for some families and not for others, or that there is a need for larger sample sizes that will accurately

represent this population. Future studies could explore how caregiver stressors, such as socioeconomic status and the ability to fully participate in their child's therapy, can affect caregiver self-efficacy and overall quality of life.

Common Theme 2: Community Support

Benefits of Caregiver-to-Clinician Relationship

Several studies highlight how the quality of a caregiver-clinician relationship can increase a caregiver's self-efficacy and confidence in carrying over therapeutic strategies learned via TH. Little et al. (2018) explored the effectiveness of virtually delivered caregiver-mediated interventions, such as Occupation Based Coaching, in which caregivers themselves are used to implement strategies to increase a child's developmental skills. With the support and guidance from a therapist, caregivers of children with autism spectrum disorder were able to identify goals, develop individualized strategies, and create a plan to implement these strategies in their everyday routines and specific contexts (Little et al., 2018). Through post-intervention measures, such as the Canadian Occupational Performance Measure—Second Edition and the Caregiving Sense of Competence Scale, researchers found that intervention methods delivered via TH can positively affect caregiver efficacy and children's activity participation by encouraging caregivers to create their own strategies to match their unique strengths and circumstances. Similar to Little et al.'s research, Gibbs and Toth-Cohen (2011) explored the potential for using TH as a tool to provide collaborative occupational therapy in order to improve carryover of home programs for children with autism spectrum disorder. Not only were therapists able to observe the caregiver-child interaction in the home environment and provide meaningful real-time feedback, but

caregivers also gained clarity on specific techniques they were asked to perform with their child, and received additional insight from the occupational therapist on the reasoning behind the home program. Though Gibbs and Toth-Cohen's study did not specifically comment on the factors of caregiver stress or self-efficacy, the study did highlight that being able to ask questions and understand a therapist's clinical reasoning helped caregivers broaden their knowledge base and improve home program continuity.

Furthermore, the findings of studies conducted by Hahn-Markowitz et al. (2018) and Witmans et al. (2008) suggest that continual communication with a child's therapist increases caregiver self-efficacy. Frequent contact and follow-ups via telephone, email, and other mediums allowed caregivers to receive help with recurrent issues or problems arising outside of therapy sessions. Wallish et al. (2019) highlighted the benefits of a strong caregiver to clinician relationship, suggesting that it empowered the caregiver to be in the driver's seat rather than a bystander to their child's therapy. Instead of instructing caregivers on how to best handle their child, clinicians taught caregivers how to problem solve through difficult situations and formulate their own strategies. It is important to note that this collaboration was not one-sided, and involved the therapist's trust and respect for the caregiver's opinions as well.

Studies also show that therapists providing timely responses to a caregivers' questions or concerns contributed to increased caregiver self-efficacy as well as a stronger relationship between the caregiver and therapist (Gibbs & Toth-Cohen, 2011; Witmans et al., 2008). It may be beneficial to study how a therapist's delayed response to a caregiver can affect the level of trust within the clinician to caregiver relationship.

Benefits of Caregiver-to-Caregiver Support Groups

Several studies also touched on the potential benefits of having a strong community support amongst caregivers undergoing TH services together. Both Serwe et al. (2017) and Shaffer et al. (2020) explored the effects of a TH wellness or mindfulness program on caregiver stress by holding six interactive weekly online classes for caregivers caring for children and family members with special needs. While Serwe et al. focused on the delivery of a Powerful Tools for Caregivers program that has been shown to improve self-care and self-efficacy and reduce caregiver stress, Shaffer et al. focused on a mindfulness program in which a group of caregivers were introduced to specific mindfulness-based attitudes, breathing exercises, and guided meditations. Despite the differing program types, participants from both studies valued the shared experience of building relationships among other caregivers through post-survey questionnaires and group discussions. Many caregivers had the opportunity to tell their stories, introduce stress and behavior management strategies, strengthen family relationships through increased communication skills, and promote problem-solving abilities with one another (Shaffer et al., 2020). Through their collective sharing of experiences with TH during post-test discussions, caregivers stated feeling more empowered to prioritize their own self-care and formulate action plans geared towards caregiver self-maintenance (Serwe et al., 2017). Both of these studies suggested that the continued communal support among caregivers promotes a sense of partnership, belonging, and accountability, and helped caregivers feel less alone in their experiences.

Willis et al. (2019) explored how these caregiver group therapy programs created strong friendships between families and allowed the caregivers to continue to meet up

and adhere to their home programs together after the program was over. Edelstein et al. (2017) also found that an email support system helped caregivers stay connected and be able to share relevant information with one another. Both of these articles point towards the need for caregivers to be educated on the importance of surrounding oneself with a tight-knit community, and how connecting with other caregivers can provide additional emotional, mental, and educational support.

Though the literature demonstrates the potential benefits of community support among caregivers undergoing similar experiences, it is unclear how TH has affected the lack of caregiver-to-caregiver relationships that are often formed in the waiting rooms of therapy clinics. Future studies can explore whether it is beneficial to recreate this waiting room experience for an online platform and to determine its potential effect on caregiver well-being.

Common Theme 3: Barriers

Studies have also explored potential obstacles to application of TH that can impact a family caregiver's sense of competence and confidence in their abilities as a caregiver for their child with special needs. The literature suggests that a lack of formal caregiver TH education and training impacts caregiver self-efficacy in the home and makes it difficult for caregivers to successfully implement and carry over home programs. Dhiman et al. (2020) found a high prevalence of depressive symptoms along with moderate anxiety and stress symptoms among caregivers in response to COVID-19's impact on everyday life. Due to the inability to learn proper homecare techniques and strategies from a therapist prior to abrupt stay-at-home orders, caregivers reported that they felt unprepared to transition from in-person to TH services. The study suggests

that a caregiver's knowledge and education on the importance of TH can play a major role in decreasing caregiver strain and caregivers forming a positive perception of TH as a whole.

Although TH is not a new concept, the push for global use of technology in a short time period presents several challenges for users. Reifenberg et al. (2017) and Bearss et al. (2018) found that technological issues, such as glitches, transmission delays, and internet lags, were continued technical barriers to TH. Raval et al. (2017) examined the relationship between a caregiver's prior level of familiarity with technology (technological literacy) before beginning TH services, and found that as long as caregivers received quality training on the use of the service delivery method, it had no significant effect on therapy outcomes. Caregiver programs and interventions, such as Occupation Based Coaching and Powerful Tools for Caregivers, were helpful in providing some form of support through caregiver-mediated strategies and wellness enhancement (Little et al., 2018; Serwe et al., 2017). However, standardized caregiver training to access and navigate TH platforms should be provided as a resource to reduce caregiver stress.

In two studies, caregivers reported that reimbursement and access to appropriate technology are the biggest barriers to them beginning or expanding their use of TH services (Olson et al., 2018; Kistler et al., 2019). Due to the web-based nature of TH, proper education and training on what to expect and how to effectively navigate therapy sessions on a virtual platform would be beneficial for both occupational therapy practitioners and caregivers. Inconsistent local, state, and federal policies and regulations regarding reimbursement for TH services make it difficult for practitioners and caregivers

to provide or access TH services and implement a robust program. For example, insurance providers reimburse for TH services at different rates and there are no standardized state or local policies governing the delivery or quality oversight of TH services.

Theoretical Framework

We chose the Ecology of Human Performance (EHP) as our theoretical framework for this study. The EHP framework is appropriate for our study because it focuses on the importance of one's environment and defines context as a key factor affecting human behavior and occupational performance (Dunn et al., 1994). According to the EHP, people view different tasks through their contextual filter, meaning their experiences and perceptions about the physical, social, and cultural features of their performance setting. For example, a change in a caregiver's context, such as going from in-person therapy to TH, can give rise to additional caregiver stressors, such as shifting home dynamics and decreased social support, which can all play a role in inhibiting a caregiver's occupational performance. The framework also considers how personal variables can inhibit occupational performance, including caregiver perceptions and interpretations of how tasks should be done. Within the EHP, therapeutic interventions focus on establishing new skills and routines, restoring emotional regulation habits, and altering and adapting to new learning environments.

A caregiver's environment, contextual stressors, and resulting performance capabilities are central to our study's exploration of how a virtual environment like TH impacts a caregiver's ability to engage in their child's therapy and manage stress. In the context of the COVID-19 pandemic, TH has, almost overnight, become the new normal.

For many of these caregivers, the home is no longer associated with rest and relaxation, but now functions as a space for work, leisure, school, and therapy. The context of therapy for many caregivers has shifted from the clinic to the home environment, which necessitated increased involvement in their child's therapy. Instead of face-to-face sessions with an occupational therapist at a clinic, hospital, or in-home setting, caregivers are primarily interacting with their child's therapist digitally through video platforms such as Zoom or other electronic communication such as email, text, or video-phone calls (Clawson et al. 2008; Edelstein et al. 2017; Wallish et al. 2019). Because therapists are unable to provide direct tactical cues to direct interventions, caregivers need to be present and engaged with both their child and the therapist during teletherapy sessions. Alongside the many roles that these caregivers assume in their daily lives, they are now expected to be the primary facilitators of their child's therapy directly from home while also managing the child's unique behaviors and temperaments. These additional roles can alter the routines and dynamic of the entire household as well as the impact the well-being and occupational performance of the caregiver.

Methodology

Study Design

The survey was conducted on Survey Planet in English and Spanish. We chose this website because it is cost-effective and easy to use. This website also provided an organized and comprehensive method of compiling the data through pie charts and summaries of individual and collective participant data. The survey targeted caregivers of special needs children who were 10 years of age or younger and was shared through social media platforms, such as Facebook and Instagram, personal contacts, and in

pediatric clinic waiting rooms. At the time of flyer distribution, lockdown restrictions were partially lifted, allowing some families to receive in-clinic occupational therapy services as well as TH. Although the demographics that we reached through local clinics and personal contacts were primarily from California, we hoped to reach caregivers from multiple states and in multiple languages through social media platforms. The survey was live for three weeks, from June 30th, 2021 to May 21st, 2021.

We identified diagnosis-specific caregiver Facebook groups such as “Raising children with cerebral palsy!” and other generalized special needs caregiver support groups to reach caregivers of children who received occupational therapy services between March 2020 and May 2021. We created a caregiver-friendly flyer—one without medical jargon, and included cartoon images—that promoted the survey on online platforms and in in-person clinics (see Appendix C). This was to ensure our survey was accessible to caregivers with lower health literacy.

To prevent skewed data (a particular group of caregivers representative of only one diagnosis), we posted to caregiver groups of children with different diagnoses. We also asked occupational therapists on Instagram to share our English and Spanish survey links with caregivers or clinics they knew either on their 24-hour story or as a post.

Our survey contained 10 questions that were a combination of multiple choice, Likert-scale scoring, and semi-structured and open-ended questions (see Appendix A). These questions were modeled after a combination of quantitative and qualitative caregiver needs assessment measures cited in our literature review (caregiver interviews and COPM-2). We adapted all 10 questions to ensure we were not excluding participants of a lower literacy level by using clear, direct, and simplified questions to reduce

ambiguity. We prioritized questions we thought would further inform our study on the caregiver experience. Our dependent variables were self-efficacy, caregiver stressors, and level of involvement in therapy and our independent variables included TH occupational therapy. Demographic information, the child's age range, number of TH occupational therapy sessions completed, and the type of setting, were collected utilizing multiple-choice questions.

To measure caregiver stressors, a combination of multiple choice and Likert scale questions was utilized. Caregivers were asked to identify their top 3 stressors (multiple choice) and their level of perceived stress level before and after receiving TH occupational therapy services (Likert scale 0-4). The scale ratings were determined as follows: 0 = no stress, 1 = some stress, 2 = moderate stress, 3 = a lot of stress, and 4 = extreme stress. To measure caregiver comfort with and confidence in receiving TH occupational therapy services, we asked participants to use a rating scale of 1 to 5. The statements were as follows "I participate more in my child's therapy process," "I feel supported by my child's occupational therapist," "I feel more confident doing the therapeutic activities described by my child's occupational therapist," and "I received enough technology training before using TH services." The scoring for each of the statements were as follows: 1 = strongly disagree, 2 = slightly disagree, 3 = neutral, 4 = slightly agree, and 5 = strongly agree.

Caregivers were also asked which occupational therapy delivery model they preferred and why. The final open-ended questions invited the caregivers to share positive and/or negative aspects they experienced with TH occupational therapy and

included an optional section for participants to share any additional thoughts about their overall experience with the TH occupational therapy platform.

Data Collection

Data was collected through Survey Planet and two separate hyperlinks (English and Spanish) were created to be shared through social media. Both surveys remained active for 3 weeks until May 21, 2021. A positive aspect of our data distribution and collection was that it included a no-contact approach (due to the ongoing threat of COVID-19), and it was shareable to other potential participants.

Data Storage

A benefit to using Survey Planet was that the results were automatically analyzed and collected as responses came in. Data was anonymous as we did not ask for personal identifying information. Survey data was not stored on personal devices. We had exclusive access to the survey data via one password protected email account (created and owned by the Stanbridge University: pedstelehealthproject@my.stanbridge.edu). Survey responses were anonymous and no personal identifying information was requested. For example, participants were identified in the results and analysis only as “Participant 1 (P1).”

The survey results in both Spanish and English were downloaded as a PDF and stored into our shared thesis group email pedstelehealthproject@my.stanbridge.edu with entry access only granted to our group and thesis advisor. To ensure the analysis was appropriate, a statistician at Stanbridge assisted with analyzing the Likert-scale data. We aggregated the caregiver responses from the open-ended questions into a spreadsheet and identified common themes from the data.

Analysis

Individual analysis was completed for each question of the online survey. Likert scale questions were assigned ratings, averaged, and presented as a graph. Essay responses were coded to identify patterns and common themes. Only data collected between April 27 and May 21, 2021 was analyzed. From analysis of the survey results, we were able to identify trends within our sample size as to whether caregiver self-efficacy improved after TH occupational therapy.

Results

To examine if the study's sample is representative of the full population as it pertains to "self-efficacy of caregivers of children with special needs up to 10 years implementing therapeutic strategies after 4 or more sessions of TH occupational therapy sessions" (see Figure 10), a chi-square goodness of fit test was employed. The study's sample is not representative of the full population and failed to yield statistically significant results.

Quantitative Results

Demographic Results

Our study had a total of 13 participants who completed the survey. As presented in Table 1, most of our participants were English speakers ($n = 11$; 85%) compared to those who utilized the Spanish survey ($n = 2$; 15%). The caregivers who participated in this study mostly had children within the 0–3 age range ($n = 6$; 46%), followed by the 7–10 age range ($n = 4$, 31%), and then the 3–6 age range ($n = 3$, 23%). The amount of TH occupational therapy services received by the participants since March 2020, were spread out between the three options (4–8, 9–12, 13+). 5 caregivers (38%) reported they had

received 13+, 4 caregivers (31%) reported 9-12 sessions, and 4 caregivers (31%) reported between 4–8 sessions. Most of our participants ($n = 7$) classified their therapy history prior to receiving TH as early intervention/in-home. Three caregivers had reported primarily school-based, two caregivers reported “other,” one caregiver reported outpatient clinic, and no participants had received only TH prior to March 2020.

Table 1*Participant Demographics*

| | Frequency | % |
|---|-----------|----|
| Language | | |
| English | 11 | 85 |
| Spanish | 2 | 15 |
| Child's Age Range | | |
| 0-3 | 6 | 46 |
| 3-6 | 3 | 23 |
| 7-10 | 4 | 31 |
| # of TH sessions received since March 2020 | | |
| 13+ | 5 | 38 |
| 4-8 | 4 | 31 |
| 9-12 | 4 | 31 |
| Services received BEFORE TH | | |
| Early intervention in-home, outpatient clinic, school-based | 1 | 8 |
| Early Intervention/In-Home | 7 | 54 |
| Early intervention/in-home, outpatient clinic | 1 | 8 |
| Outpatient Clinic | 1 | 8 |
| School-Based | 3 | 23 |

To examine the relationship between services received before TH occupational therapy and delivery preference, a chi-square test of independence was employed which yielded a statistically significant relationship between these two variables, [$\chi^2(6, N = 11) = 13.06, p = .042$]. First, this finding indicates caregivers were significantly more likely

to prefer in-person delivery if they received early intervention/in-home (36.4%) and school-based (27.3%) services before TH (see Table 2). This finding also indicates caregivers were significantly more likely to select they prefer TH delivery if they had received outpatient (9.1%) services before TH (see Table 2). Lastly, this finding indicates caregivers were significantly more likely to prefer a combination of in-person and TH delivery if they received early intervention/in-home (9.1%) and other (9.1%) services before TH (see Table 2).

Table 2

Services Received Before TH and Delivery Preference

| Service Type | In-person | | | Tele health | | | Combo | | | χ^2 | df | p |
|-----------------------------|-----------|------|------|-------------|------|-----|-------|------|-----|----------|----|------|
| | O | E | % | O | E | % | O | E | % | | | |
| Early Intervention /In-Home | 4 | 3.64 | 36.4 | 0 | 0.45 | 0.0 | 1 | 0.91 | 9.1 | 13.06 | 6 | .042 |
| Outpatient Clinic | 0 | 0.73 | 0.0 | 1 | 0.09 | 9.1 | 0 | 0.18 | 0.0 | | | |
| School-Based | 3 | 2.18 | 27.3 | 0 | 0.27 | 0.0 | 0 | 0.55 | 0.0 | | | |
| Other | 1 | 1.45 | 9.1 | 0 | 0.18 | 0.0 | 1 | 0.36 | 9.1 | | | |

O = observed count. E = expected count. Df = degrees of freedom. χ^2 = chi-square. P = p-value

Stress Levels

Participants were asked to identify their top three stressors when it came to caring for a child with a disability or medical condition. Participants were unable to rank their choices by the level of importance, but they could select up to three stressors. A total of 8 major stress areas were identified: financial needs, transportation, time, caring for multiple family members, lack of additional support, working from or outside the home, and access to technology. Most caregivers of children with special needs up to 10 years of age reported “time” (n = 9; 69%), “financial” concerns (n = 7; 53%), “working from or

outside the home” (n = 8; 62%), and “caring for multiple family members” (n = 7; 53%) as their top stressors.

Using a Likert scale (0 = no stress to 4 = extreme stress), participants were asked to rate their stress levels before and after receiving TH occupational therapy sessions. Six participants reported “moderate” stress and another six participants reported “a lot of stress” before TH. Only one participant reported “extreme stress” prior to TH. Five participants reported “moderate” stress, six participants listed “a lot of stress,” and two participants reported “extreme stress” after receiving occupational therapy services.

To examine the relationship between stress level before and after TH occupational therapy sessions, a chi-square test of independence was employed but failed to yield a statistically significant relationship between these two variables, [$\chi^2(4, N = 13) = 0.42, p = .809$]. This finding indicates caregivers were equally likely to report the same stress levels before and after TH occupational therapy sessions, as shown in Table 3.

Table 3

Stress Level Before and After TH OT

| Stress Level | Before | | | After | | | χ^2 | df | p |
|-------------------|--------|------|----|-------|------|----|----------|----|------|
| | O | E | % | O | E | % | | | |
| 0 no stress | 0 | 0.00 | 0 | 0 | 0.00 | 0 | 0.42 | 4 | .809 |
| 1 some stress | 0 | 0.00 | 0 | 0 | 0.00 | 0 | | | |
| 2 moderate stress | 6 | 5.50 | 46 | 5 | 5.50 | 39 | | | |
| 3 a lot of stress | 6 | 6.00 | 46 | 6 | 6.00 | 46 | | | |
| 4 extreme stress | 1 | 1.50 | 8 | 2 | 1.50 | 15 | | | |

Note. O=observed count. E=expected count. df=degrees of freedom. χ^2 =chi-square. p=p-value.

Self-Efficacy Levels

To understand caregiver self-efficacy, caregivers were asked to rate statements regarding their experience with TH occupational therapy on a Likert scale of 1 to 5 (1 =

strongly disagree to 5 = strongly agree). Participants were asked to rate how strongly they agree or disagree with four statements.

Statement 1: “I participate more in my child’s therapy process.” As shown in Figure 1, a large percentage of caregivers of children with special needs up to 10 years of age endorsed the statement “I participate more in my child’s therapy process” with a “strongly agree” (n = 7; 54%).

Figure 1

Caregivers Who Participate More in Their Child’s Therapy Process



Statement 2: “I feel supported by my child’s occupational therapist.” Figure 2 shows that within our study, most caregivers (n = 6; 46%) of children with special needs up to 10 years of age endorsed the statement “I feel supported by my child’s occupational therapist” with “strongly agree.”

Figure 2

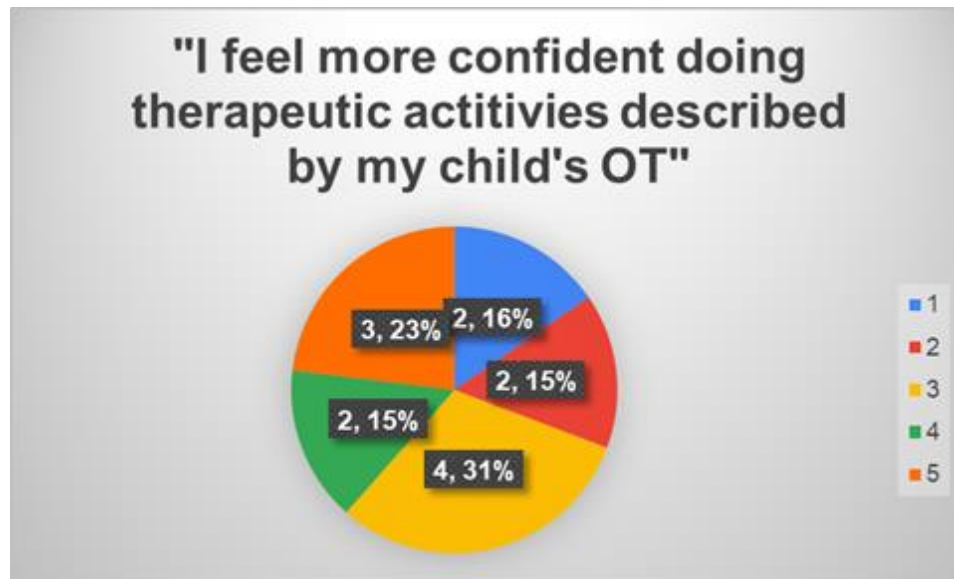
Caregivers Who Feel Supported by Their Child's Occupational Therapist



Statement 3: "I feel more confident doing therapeutic activities described by my child's OT (occupational therapist)." The results in Figure 3 indicate that within our study, most caregivers ($n = 4$; 31%) of children with special needs up to 10 years of age endorsed the statement "I feel more confident doing therapeutic activities described by my child's OT (occupational therapist)" by choosing "neutral" on the Likert scale.

Figure 3

How Caregivers Feel About Doing Therapeutic Activities Described by Their Child's OT

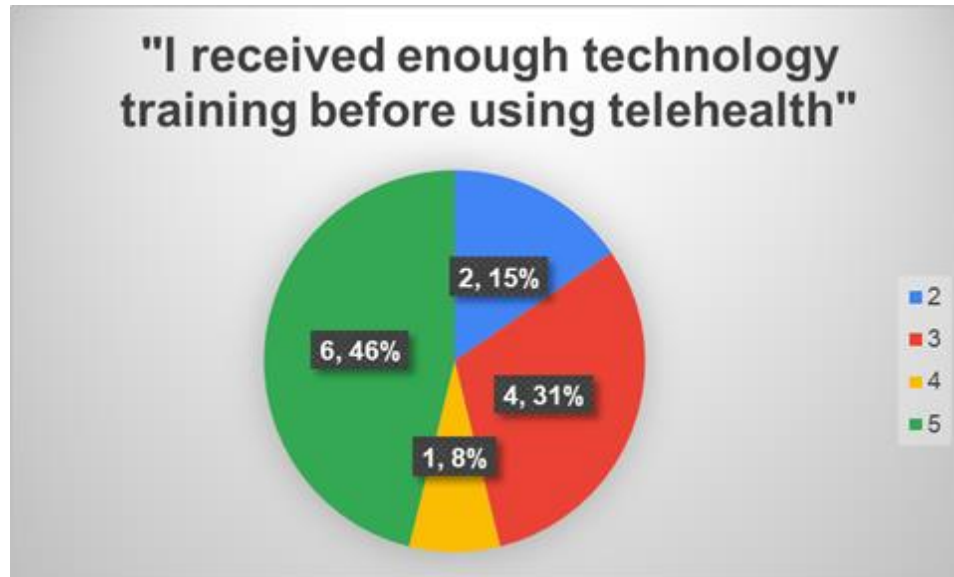


Statement 4: "I received enough technology training before using telehealth."

Figure 4 demonstrates that with our study, most caregivers of children with special needs up to 10 years of age endorsed the statement "I received enough technology training before using telehealth" with "strongly agree" (n = 6; 46%).

Figure 4

How Caregivers Feel About the Technology Training They Received Before Using Telehealth

***Service Delivery Preference***

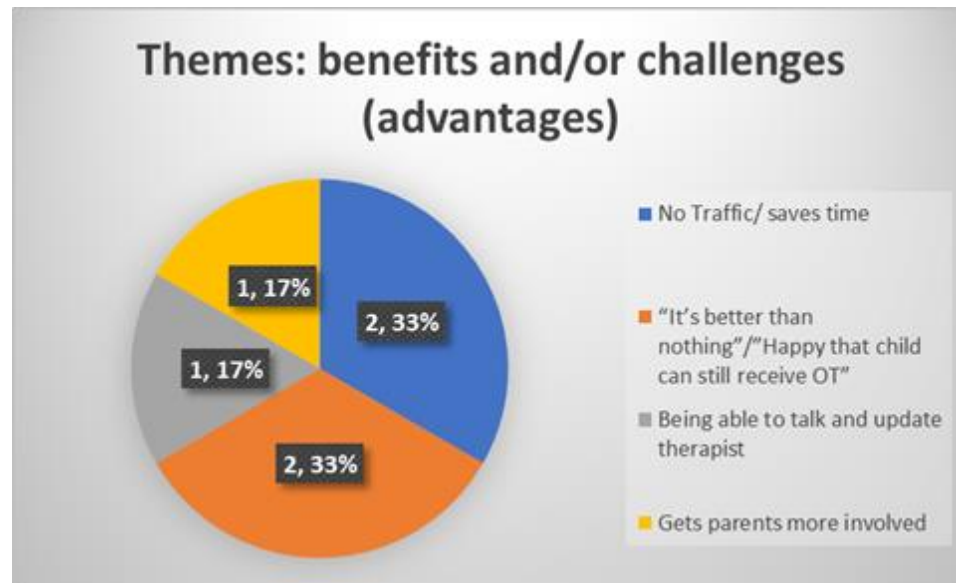
When caregivers were asked which service delivery format they would prefer, the majority of the respondents replied with “only in-person” (n = 10, 76%). Two participants (15%) preferred a combination of in-person and TH. One participant chose the “only telehealth” option stating that she preferred TH until COVID-19 was under control and her children were vaccinated.

Qualitative Results

Through an open-ended question, caregivers were asked to identify any benefits or challenges they experienced utilizing TH occupational therapy services. Figure 5 lists common caregiver themes that are perceived as advantages of TH is “no traffic/saves time” (n = 2; 33%) and “it’s better than nothing/happy that child can still receive OT (occupational therapy)” (n = 2; 33%).

Figure 5

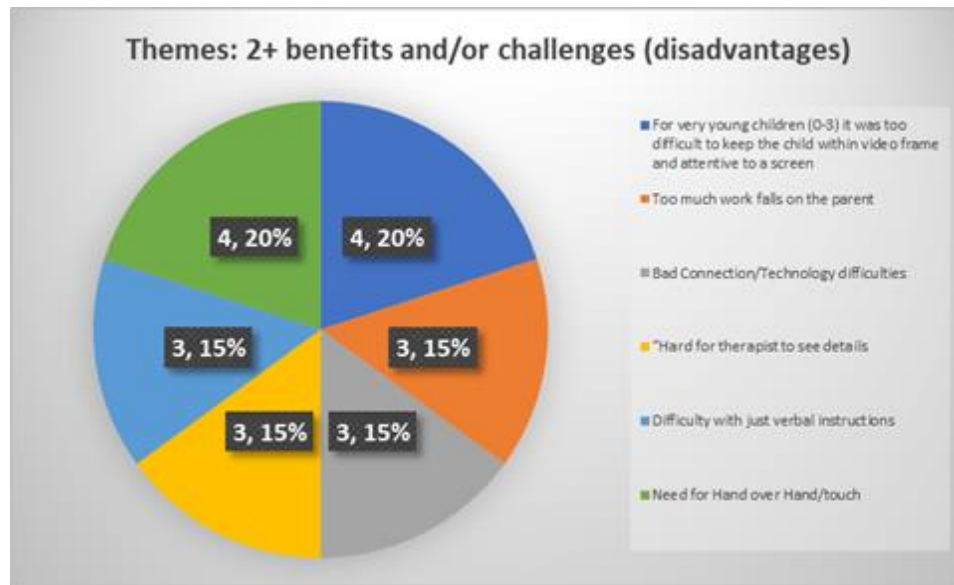
Themes: Benefits/Challenges (Advantages) According to Caregivers



The perceived common disadvantages of TH reported are presented in Figure 6, and these were: “For very young children (0–3) it was too difficult to keep the child within video frame and attentive to a screen” (n = 4; 20%) and “Need for Hand over Hand/touch” (n = 4; 20%). Caregivers who mentioned a need for hand over hand or touch within therapy sessions are referring to the advantages of having a therapist be able to physically direct their child versus just verbally when using a TH platform.

Figure 6

Themes: Benefits/Challenges (Disadvantages) According to Caregivers



To examine the relationship between services received before TH (see Table 1) and perceived benefits (see Figure 5), a chi-square test of independence was employed but failed to yield a statistically significant relationship between these two variables, ($\chi^2[9, n = 6] = 4.55, p = .872$; see Table 4).

Table 4

Services Received Before TH and Advantages

| Service Type | Comment 1 | | | Comment 2 | | | Comment 3 | | | Comment 4 | | | χ^2 | df | p |
|-----------------------------|-----------|------|----|-----------|------|----|-----------|------|----|-----------|------|----|----------|----|------|
| | O | E | % | O | E | % | O | E | % | O | E | % | | | |
| Early Intervention /In-Home | 1 | 0.67 | 17 | 1 | 1.33 | 17 | 1 | 1.33 | 17 | 1 | 0.67 | 17 | 4.55 | 9 | .872 |
| Outpatient Clinic | 0 | 0.17 | 0 | 0 | 0.33 | 0 | 1 | 0.33 | 17 | 0 | 0.17 | 0 | | | |
| School-Based | 0 | 0.00 | 0 | 0 | 0.00 | 0 | 0 | 0.00 | 0 | 0 | 0.00 | 0 | | | |
| Other | 0 | 0.17 | 0 | 1 | 0.33 | 17 | 0 | 0.33 | 0 | 0 | 0.17 | 0 | | | |

Note. O=observed count. E=expected count. df=degrees of freedom. χ^2 =chi-square. p=p-value. Comments: 1. Being able to talk and update therapist; 2. No Traffic/ saves time; 3. "It's better than nothing"/ Happy that child can still receive OT"; 4. Gets parents more involved.

To examine the relationship between services received before TH (see Table 1) and perceived challenges (see Figure 6), a chi-square test of independence was employed but failed to yield a statistically significant relationship between these two variables, [$\chi^2(15, N = 21) = 12.82, p = .616$ (see Table 5). These findings indicate caregivers were equally likely to report the same benefits and/or challenges regardless of services received before TH (see Table 4 and Table 5)

Table 5

Services Received Before TH and Disadvantages

| Comment | Early Intervention/In-Home | | | Outpatient Clinic | | | School-Based | | | Other | | | χ^2 | df | p |
|---------|----------------------------|------|-------|-------------------|------|------|--------------|------|-------|-------|------|------|----------|----|------|
| | O | E | % | O | E | % | O | E | % | O | E | % | | | |
| 1 | 0 | 1.71 | 0.00 | 1 | 0.57 | 5.00 | 2 | 1.14 | 10.00 | 1 | 0.57 | 5.00 | 12.82 | 15 | .616 |
| 2 | 2 | 1.29 | 9.52 | 0 | 0.43 | 0.00 | 1 | 0.86 | 5.00 | 0 | 0.43 | 0.00 | | | |
| 3 | 1 | 1.71 | 4.76 | 0 | 0.57 | 0.00 | 2 | 1.14 | 10.00 | 1 | 0.57 | 5.00 | | | |
| 4 | 2 | 1.29 | 10.00 | 0 | 0.43 | 0.00 | 1 | 0.86 | 5.00 | 0 | 0.43 | 0.00 | | | |
| 5 | 3 | 1.71 | 14.29 | 1 | 0.57 | 5.00 | 0 | 1.14 | 0.00 | 0 | 0.57 | 0.00 | | | |
| 6 | 1 | 1.29 | 5.00 | 1 | 0.43 | 5.00 | 0 | 0.86 | 0.00 | 1 | 0.43 | 5.00 | | | |

Note. O=observed count. E=expected count. df=degrees of freedom. χ^2 =chi-square. p=p-value. Comments: 1. Bad Connection/Technology difficulties; 2. Too much work falls on the parent; 3. Need for Hand over Hand/touch; 4. Difficulty with just verbal instructions; 5. "For very young children (0-3) it was too difficult to keep the child within video frame and attentive to a screen"; 6. "Hard for therapist to see details".

Discussion

Utilizing an open-ended short answer question, participants were asked what advantages and disadvantages they perceived in TH occupational therapy services (results are presented in Figure 5 and Figure 6). Based on their answers, we inferred caregivers could conceptualize the benefits of TH, despite not personally experiencing those benefits themselves. One participant stated that in theory “[TH] saves time . . . [but] took more time for me” while another shared that though they did not benefit from TH occupational therapy, they recognized that “the therapist did their best.” Others felt that TH had a place, but not for caregivers of “small children in . . . feeding therapy or physical therapy” or caregivers of children who are “intellectually disabled, [physically] disabled,

nonverbal, [have] vision issues, and cannot follow any [commands] or participate without full assistance.” Statements, such as “at least it was better than nothing,” indicated that TH, despite being the primary delivery model for occupational therapy services during the COVID-19 pandemic, has a long way to go until it is accepted as a preferred service.

Before the COVID-19 pandemic, occupational therapy was primarily delivered in person. We hypothesized that caregivers would prefer a TH delivery service model because an online platform would encourage increased interaction between child and caregiver and, therefore, increase caregiver self-efficacy. This hypothesis was supported by several caregiver responses. One of the Spanish-speaking participants reported that “[TH occupational therapy services] were good . . . when [children] are under 1” because “[they teach] the mom how to help her baby and how to get closer to them.” However, an English-speaking participant reported a different perspective, stating that “after 3 months . . . we canceled the TH sessions and went to a special in-person option” because “[TH occupational therapy was] more of a hassle . . . for a 1-year-old who needs a lot of help and is very demanding.” Clearly, caregiver opinions on the benefits of TH occupational therapy for infants vary and are dependent on the unique needs of both the caregiver and the child.

Despite our literature review indicating that caregiver stress is negatively correlated with caregiver self-efficacy, our results showed that they were positively correlated. Our participants noted that as their involvement and self-efficacy increased, so did their stress. Perhaps because caregivers were living with overall increased stress conditions due to COVID-19, such as caring for multiple family members and working

from home, our survey did not distinguish the effects of caregiver stress from other sources and TH occupational therapy services.

Limitations

At the time of our survey development, local COVID-19 restrictions were beginning to lift as a portion of clinics began to resume pre-COVID-19 operations in-person. However, during our distribution period, COVID-19 restrictions increased in response to a surge in cases. This may have increased overall caregiver stress and influenced survey responses. Our survey questions were not adequately nuanced or able to adapt to the changing COVID-19 conditions to distinguish between caregiver stress caused by other COVID-19-related lifestyle changes and TH occupational therapy services for their child.

Due to COVID-19 safety precautions, we were only able to distribute 25 English and 25 Spanish copies of our flyers between two in-person pediatric clinics, which restricted our reach to participants who may come across our study while taking their children to therapy. We were aware that word of mouth would have been more effective to disperse the flyers and attract participants, but local COVID-19 restrictions limited movement and communication. Due to these restrictions, we primarily advertised our survey on online sites, such as private Facebook groups for caregivers of children with disabilities. Due to the posting rules set in place by administration, we were limited to only one post per group.

We initially expected 30 caregiver responses, but only received 13 in total—11 responses in English and 2 responses in Spanish. The survey was live for three weeks, which limited our time to recruit the number of participants we were hoping for.

Ethical and Legal Considerations

The principle of beneficence states that occupational therapy personnel shall demonstrate a concern for the well-being and safety of persons (American Occupational Therapy Association, 2020). Due to the safety concerns around COVID-19, we wanted to find the safest method of data gathering for families of young children. Conducting an online survey ensured that participants could contribute to the study without potentially jeopardizing their health or well-being from in-person interviews with researchers. The principle of autonomy states that occupational therapy personnel shall respect the right of the person to self-determination, privacy, confidentiality, and consent. We conducted an anonymous survey where no identifying information about the individual was recorded. A welcome page was included at the beginning of the survey to inform participants about the nature of the study and ask participants for their informed consent. Participants were given the choice to participate or not participate in the study and were also asked to acknowledge that they met all eligibility requirements before proceeding. Once participants gave their informed consent, they were then directed to the survey questions. Finally, the principle of justice states that occupational therapy personnel shall promote equity, inclusion, and objectivity in the provision of occupational therapy services. Most of our research regarding caregiver experience was collected in English. To ensure that our survey results were more representative of the population, and included bilingual or low-income families, we made the survey accessible to both English and Spanish-speaking caregivers. By translating the survey into two languages, we were able to expand our range of eligible participants and ensure that our study results could include the perspective of occupational therapy consumers who spoke a language other than

English. One of the student researchers, who is fluent in Spanish, translated the English survey questions and social media captions accordingly.

Clinical Significance

According to the literature, caregivers of children with special needs benefit the most from TH occupational therapy services when they are holistic, client-centered, and involve the entire family (Wade et al., 2014). According to Dahl-Popolizio et al (2020), occupational therapy practitioners found that occupational therapy services delivered during the COVID-19 pandemic were most effective when therapists acted as caregiver coaches. The coaching model can be easily adapted by practicing therapists and applied quickly to TH sessions to improve caregiver self-efficacy and reduce caregiver stress. This idea was also supported by Raval et al. (2017) findings that higher clinician engagement in TH sessions increased client involvement and led to decreased caregiver stress. Evidence from both studies suggests that TH can be a powerful tool for occupational therapists because it allows providers to communicate and work with patients and caregivers in natural environments. Receiving real-time feedback and guidance from a therapist can empower and inform caregivers on how to integrate therapy interventions in their own homes and daily lives.

Therapists may also have to anticipate potential new challenges for caregivers, such as utilizing technology as an integrated delivery model as well as considering a family's unique social and environmental contexts. Therapists are now expected to familiarize caregivers with the technology to receive occupational therapy services, help families navigate technical difficulties such as poor internet connection, and prioritize digital forms of communication. Studies have shown that caregivers are satisfied and

willing to participate in future TH sessions because they report increased flexibility in scheduling as well as fewer demands for transportation and taking time off work, which can ultimately lower costs for accessing services (Clawson et al., 2008; Hines et al., 2019; Kistler et al., 2019; Larson, 2010; Nobakht, 2020; Witmans et al., 2008; Wallisch et al., 2019). Insurance companies can also benefit from reimbursing for TH occupational therapy services because providing services via technology decreases the necessity of overhead administrative costs (Benson et al., 2018; Wallisch et al., 2019). Providers would no longer be required to maintain a physical facility to offer therapy services when utilizing TH. Future research about the cost-effectiveness of TH might provide evidence and support for insurance companies to include coverage for this therapy delivery model.

Based on prior research and our current study results, we recommend that therapists and caregivers discuss clear role expectations before conducting TH sessions. The TH platform requires caregivers of young children to be highly involved during therapeutic interventions, but many caregivers felt this expectation was overwhelming. Dhiman et al. (2020) discussed how working from home during the COVID-19 lockdown and living with extended family members were factors associated with poorer psychological health and greater stress for caregivers. This home dynamic could be a great opportunity for therapists to consider including siblings and other family members in the implementation of home therapy programs to reduce caregiver burden. Occupational therapists can continue to gain increased awareness on the added challenges for caregivers when occupational therapy is given through a TH platform.

Conclusion

With great consideration for caregiver needs and preferences, TH can be an effective vehicle for intervention and help to alleviate the daily stress that caregivers experience. Studies exploring caregiver stress suggest that having a community of individuals, whether it be family, friends, or other caregivers, can be therapeutic for caregivers and empower them to prioritize self-care, increase communication and problem-solving skills, and hold each other accountable in home program continuation (Serwe et al., 2017; Shaffer et al., 2020). Studies have also suggested that TH encourages caregivers to be a more active and engaged participant in their child's therapy journey, highlighting how a respectful and collaborative therapist-caregiver relationship can increase a caregiver's confidence and self-efficacy in the home (Gibbs & Toth-Cohen, 2011; Hahn-Markowitz et al., 2018; Stredler-Brown, 2017; Witmans et al., 2008). It is clear that even when in-person therapy sessions can safely resume, TH may be an effective supplement—rather than an alternative option—to the in-person only therapy model. As this new landscape of therapy emerges, there may be a greater need for family-centered treatment, such as addressing caregiver burden and stress, creating formal caregiver training for TH occupational therapists, and fostering avenues for greater emotional support for caregivers. Future studies can explore the nuances and complexities of TH, including areas such as caregiver stress, coregulation skills, and social factors (e.g., language barriers and socioeconomic status). The development of a standardized caregiver self-efficacy assessment tool could also be an effective way to ensure both providers and caregivers of children with special needs get the support they need.

References

- American Occupational Therapy Association. (2020). AOTA 2020 occupational therapy code of ethics. *American Journal of Occupational Therapy*, 74(3), Article e7413410005. <https://doi.org/10.5014/ajot.2020.74S3006>
- Bearss, K., Burrell, T. L., Challa, S. A., Postorino, V., Gillespie, S. E., Crooks, C., & Scahill, L. (2018). Feasibility of caregiver training via telehealth for children with autism spectrum disorder and disruptive behavior: A demonstration pilot. *Journal of Autism and Developmental Disorders*, 48(4), 1020–1030. <https://doi.org/10.1007/s10803-017-3363-2>
- Benson, S. S., Dimian, A. F., Elmquist, M., Simacek, J., McComas, J. J., & Symons, F. J. (2018). Coaching caregivers to assess and treat self-injurious behavior via telehealth. *Journal of Intellectual Disability Research: JIDR*, 62(12), 1114–1123. <https://doi.org/10.1111/jir.12456>
- Clawson, B., Selden, M., Lacks, M., Deaton, A. V., Hall, B., & Bach, R. (2008). Complex pediatric feeding disorders: Using teleconferencing technology to improve access to a treatment program. *Pediatric Nursing*, 34(3), 213–216. <https://pubmed.ncbi.nlm.nih.gov/18649810/>
- Dahl-Popolizio, S., Carpenter, H., Coronado, M., Popolizio, N., & Swanson, C. (2020). Telehealth for the provision of occupational therapy: Reflections on experiences during the COVID-19 pandemic. *International Journal of Telerehabilitation*, 12(2), 77-92. <https://doi.org/10.5195/ijt.2020.6328>
- Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among

- caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, Article e103790. <https://doi.org/10.1016/j.ridd.2020.103790>
- Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, 48, 595–607. <https://doi.org/10.5014/ajot.48.7.595>
- Edelstein, H., Schippke, J., Sheffe, S., & Kingsnorth, S. (2017). Children with medical complexity: A scoping review of interventions to support caregiver stress. *Child: Care, Health & Development*, 43(3), 323–333. <https://doi.org/10.1111/cch.12430>
- Gibbs, V. & Toth-Cohen, S. (2011). Family-centered occupational therapy and telerehabilitation for children with autism spectrum disorders. *Occupational Therapy in Health Care*, 25(4), 298–314. <https://doi.org/10.3109/07380577.2011.606460>
- Hahn-Markowitz, J., Berger, I., Manor, I., & Maeir, A. (2018). Cognitive-functional (cog-fun) dyadic intervention for children with ADHD and their caregivers: Impact on parenting self-efficacy. *Physical & Occupational Therapy in Pediatrics*, 38(4), 444–456. <https://doi.org/10.1080/01942638.2018.1441939>
- Hines, M., Bulkeley, K., Dudley, S., Cameron, S., & Lincoln, M. (2019). Delivering quality allied health services to children with complex disability via telepractice: Lessons learned from four case studies. *Journal of Developmental & Physical Disabilities*, 31(5), 593–609. <https://doi.org/10.1007/s10882-019-09662-8>
- Kistler, J., Cristaldi, K. K., Queenan, C., Garber, K., Wells, E., & McElligott, J. T. (2019). Caregiver perceptions of telehealth school-based health centers. *Health Behavior Policy Review*. 6(4), 344–352. <https://doi.org/10.14485/HBPR.6.4.3>

Larson, E. (2010). Identifying indicators of well-being for caregivers of children with disabilities. *Occupational Therapy International*, 17(1), 29–39.

<https://doi.org/10.1002/oti.284>

Little, L. M., Pope, E., Wallisch, A., & Dunn, W. (2018). Occupation-based coaching by means of telehealth for families of young children with autism spectrum disorder. *American Journal of Occupational Therapy*, 72, Article e7202205020.

<https://doi.org/10.5014/ajot.2018.024786>

Nobakht, Z., Rassafiani, M., Hosseini, S. A., & Hosseinzadeh, S. (2020). A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial. *Research in Developmental Disabilities*, 105, Article e103731.

<https://doi.org/10.1016/j.ridd.2020.103731>

Olson, C. A., McSwain, S. D., Curfman, A. L., & Chuo, J. (2018). The current pediatric telehealth landscape. *Pediatrics*, 141(3), Article e20172334.

<https://doi.org/10.1542/peds.2017-2334> .

Raval, M. V., Taylor, N., Piper, K., Thakore, M., Hoff, K., Owens, S., & Durham, M. M. (2017). Pediatric patient and caregiver preferences in the development of a mobile health application for management of surgical colorectal conditions. *Journal of Medical Systems*, 41, Article 105.

<https://doi.org/10.1007/s10916-017-0750-3>

Reifenberg, G., Gabrosek, G., Tanner, K., Harpster, K., Proffitt, R., & Persch, A (2017).

Feasibility of pediatric game-based neurorehabilitation using telehealth

technologies: A case report. *American Journal of Occupational Therapy*, 71(3),

1–8. <https://doi.org/10.5014/ajot.2017.024976>

- Serwe, K. M., Hersch, G. I., Pickens, N. D., & Pancheri, K. (2017). Brief report - Caregiver perceptions of a telehealth wellness program. *American Journal of Occupational Therapy, 71*, Article e7104350010.
<https://doi.org/10.5014/ajot.2017.025619>
- Shaffer, E. J., Lape, J. E., & Salls, J. (2020) Decreasing stress for caregivers of special needs children through a web-based mindfulness program: A pilot study. *The Internet Journal of Allied Health Sciences and Practice, 18*(4), Article 16.
<https://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1887&context=ijahsp>
- Stredler-Brown, A. (2017). Examination of coaching behaviors used by providers when delivering early intervention via telehealth to families of children who are deaf or hard of hearing. *Perspectives of the ASHA Special Interest Groups, 2*(9), 25–42.
<https://doi.org/10.1044/persp2.SIG9.25>
- Wade, S. L., Karver, C. L., Taylor, H. G., Cassedy, A., Stancin, T., Kirkwood, M. W., & Brown, T. M. (2014). Counselor-assisted problem solving improves caregiver efficacy following adolescent brain injury. *Rehabilitation Psychology, 59*(1), 1–9.
<https://doi.org/10.1037/a0034911>
- Wallisch, A., Little, L., Pope, E., & Dunn, W. (2019). Caregiver perspectives of an occupational therapy telehealth intervention. *International Journal of Telerehabilitation, 11* (1), 15–22. <https://doi.org/10.5195/ijt.2019.6274>
- Willis, C. E., Reid, S., Elliott, C., Nyquist, A., Jahnsen, R., Rosenberg, M., & Girdler, S. (2019). “It’s important that we learn too”: Empowering caregivers to facilitate participation in physical activity for children and youth with disabilities.

Scandinavian Journal of Occupational Therapy, 26(2), 135–148.

<https://doi.org/10.1080/11038128.2017.1378367>

Witmans, M., Good, J., Schoepp, G., Dosman, J., Hawkins, M., Young, R., & Witol, A.

(2008). Delivery of pediatric sleep services via telehealth: The Alberta experience and lessons learned. *Behavioral Sleep Medicine*, 6, 207–219.

<https://doi.org/10.1080/15402000802371312>

Appendices Table

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| IRB Approval | Appendix E |

Appendix A

Survey (English)

Welcome page:

This anonymous 5-10 minute online questionnaire will help Stanbridge University occupational therapy students learn more about caregiver stress, self-confidence, and the telehealth experience. Compensation will not be provided, and the survey will be open from April 23, 2021 to May 21, 2021.

By continuing, I acknowledge that:

I am the primary caregiver of a child with special needs 10 years or younger.

I am at least 18 years old.

My child has received at least 4 OT TH services from March 2020 - present.

We appreciate your participation! For more information, please contact

pedstelehealthproject@my.stanbridge.edu

Demographic Information:

1. **Multiple Choice:** What is your child's age range? (choose one)
 - a. 0-3 years
 - b. 4-6 years
 - c. 7-10 years
2. **Multiple Choice:** How many OT telehealth sessions have you and your child received from March 2020 - Present.
 - a. 4 - 8 sessions
 - b. 9 - 12 sessions
 - c. 13+ sessions
3. **Multiple Choice:** My child received _____ occupational therapy services **BEFORE** starting telehealth OT services.
 - a. Early Intervention/In-Home
 - b. Outpatient Clinic
 - c. School-Based
 - d. Only TH
 - e. Other: _____

Caregiver Stress:

4. **Multiple Choice + Ranked:** What are your primary stressors of caring for a child with special needs? Please select your top 3 choices.
 - a. Financial
 - b. Transportation
 - c. Time
 - d. Caring for multiple family members
 - e. Lack of additional support
 - f. Working from home/working outside the home

g. Access to adequate technology

h. Other: _____

5. Based on your top 3 stressors, how would you rate your stress in these areas

BEFORE your child received OT telehealth services?

a. 0 = No stress, 1 = Some stress, 2 = Moderate stress, 3 = A lot of stress, 4 = Extreme stress

6. Based on your top 3 stressors, how would you rate your stress in these areas

AFTER your child received at least 4 OT telehealth services?

a. 0 = No stress, 1 = Some stress, 2 = Moderate stress, 3 = A lot of stress, 4 = Extreme stress

TH Impact:

7. **Likert Scale:** On scale of 1-5, how much do you agree with each of the following statements regarding your experience with occupational therapy (OT) telehealth services:

1 = strongly disagree, 2 = slightly disagree, 3 = neutral, 4 = slightly agree, 5 = strongly agree

a. "I participate more in my child's therapy process."

b. "I feel supported by my child's occupational therapist."

c. "I feel more confident implementing the therapeutic activities described by my child's occupational therapist."

d. "I received adequate technology training prior to utilizing TH services."

TH Preferences:

1. **Short Answer:** If given the option, how would you prefer OT services be delivered? (Select one)

a. In-person exclusively

b. telehealth exclusively

c. Hybrid of both

i. **Comment:** Please state which you prefer, and briefly explain why you chose this option in the comment section below.

TH Experience:

2. **Open Ended Question:** What are some benefits and/or challenges you have experienced while utilizing occupational therapy telehealth services?

3. **[OPTIONAL] Open Ended Question:** Is there anything else you would like to share in regards to your overall experience with telehealth services?

Appendix B**Survey (Spanish)**

Reconozco y afirmo que:

Yo confirmo que soy el padre/madre o guardián de un hijo/a con necesidades especiales (edad 10 años o menos) y que tengo por lo menos 18 años o más.

Mi hijo/hija ha recibido por lo menos 4 sesiones de terapia ocupacional (por medio de telesalud) entre Marzo 2020 - Presente.

Demografía:

1. **Opción Múltiple:** Identifica la edad de su hijo/a
 - a. 0-3 years
 - b. 4-6 years
 - c. 7-10 years
2. **Opción Múltiple:** ¿Desde Marzo 2020, al momento actual, cuántas sesiones de terapia ocupacional (por medio de telesalud) ha recibido su hijo/a?
 - a. 4 - 8 sesiones
 - b. 9 - 12 sesiones
 - c. 13+ sesiones
3. **Opción Múltiple:** Mi hijo/a estuvo recibiendo ____ tipo de sesiones de terapia ocupacional **ANTES** de empezar sus sesiones sobre telesalud.
 - a. Intervención Temprana/Terapia Domiciliaria
 - b. Clinica Externa
 - c. Terapia en la escuela
 - d. Solo Terapia sobre Telesalud
 - e. Otro: _____

Estrés del cuidador:

4. **Opción Múltiple y Clasificar en Orden:** Cuales de estos factores provocan el mayor estrés en el cuidado sobre su hijo/a con discapacidad. Favor de elegir los 3 más importantes.
 - a. Financiero
 - b. Transporte
 - c. El Tiempo
 - d. Cuidar a varios miembros de la familia
 - e. Falta de apoyo adicional o recursos
 - f. Trabajar desde casa/trabajar fuera de casa
 - g. Acceso a la tecnología adecuada
 - h. Otro: _____
5. En base a sus 3 elecciones más importantes, ¿cómo consideraría su estrés en estas áreas **ANTES** de que su hijo/a recibiera los servicios sobre telesalud de la terapia ocupacional?

- a. 0 = Sin estrés, 1 = Un poco de estrés, 2 = Estrés intermedio, 3 = Mucho estrés, 4 = Estrés extremo
- 6. En base a sus 3 elecciones más importantes, ¿cómo consideraría su estrés en estas áreas **DESPUÉS DE** de que su hijo/a recibiera los servicios sobre telesalud de la terapia ocupacional?
 - a. 0 = Sin estrés, 1 = Un poco de estrés, 2 = Estrés intermedio, 3 = Mucho estrés, 4 = Estrés extremo

Impacto de la Telesalud:

- 7. **Escala Likert:** En una escala del 1 al 5, ¿en qué proporción está usted de acuerdo con cada una de las siguientes declaraciones sobre su experiencia con los servicios de telesalud de terapia ocupacional?

1 = totalmente en desacuerdo, 2 = poco en desacuerdo, 3 = neutral, 4 = un poco de acuerdo, 5 = totalmente de acuerdo

- a. "Ahora participo más en el proceso terapéutico de mi hijo".
- b. "Me siento apoyado/a por el/la terapeuta ocupacional de mi hijo/a".
- c. "Me siento más seguro/a implementando las actividades terapéuticas presentadas por el/la terapeuta ocupacional de mi hijo/a".
- d. "He recibido suficiente preparación tecnológica antes de empezar a usar los servicios de telesalud".

Preferencias de Telesalud:

- 8. **Respuesta corta:** Si se le diera la opción, ¿cómo le gustaría que se ofrecieran los servicios de terapia ocupacional? (Seleccione uno)
 - a. En persona exclusivamente
 - b. Exclusivamente telesalud
 - c. Una combinación de los dos tipos de servicios
 - i. **Comentario:** Por favor, diga cuál prefiere, y explique brevemente por qué eligió esta opción.

Experiencia de Telesalud:

- 9. **Pregunta abierta:** ¿Cuáles son algunos de los beneficios y/o retos que ha experimentado al utilizar los servicios de telesalud de terapia ocupacional?
- 10. **[OPCIONAL] Pregunta abierta:** ¿Hay algo más que le gustaría compartir sobre su experiencia general con los servicios de telesalud?

Appendix C

Flyer (English)

Participants Needed for OT Telehealth Survey



Study Description

You are invited to participate in a Stanbridge University research study about the caregiver telehealth experience. Participants will be asked to complete a 5-10 minute anonymous online survey by **May 21, 2021**. Participation in this study is completely voluntary and compensation will not be provided.

Participant Eligibility

- 18 years or older
- Primary caregiver of a child with special needs 10 years or under
- Fluent in English or Spanish
- Have participated in at least 4 occupational therapy (OT) telehealth sessions since March 2020

Survey

English- <https://s.surveypplanet.com/ym9pp6MDe>

Spanish - <https://s.surveypplanet.com/aRLzqPLVF>



For more information, please contact
pedstelehealthproject@my.stanbridge.edu

Appendix D

Flyer (Spanish)

Se buscan participantes para una encuesta sobre telesalud terapia ocupacional



Descripción del estudio

Se le invita a participar en un estudio de investigación departe de la Universidad de Stanbridge. El estudio sera sobre su experiencia como cuidador de niños con discapacidades. La encuesta tomara entre 5-10 minutos para completar, es anónima y estara disponible hasta el **21 de Mayo de 2021**. La participación en este esteestudio es completamente voluntaria y no se proporcionará ninguna compensación.

Elegibilidad del participante

- Tener 18 años o más
- Ser el cuidador principal de un niño con necesidades especiales de 10 años o menos
- Tener dominio del inglés o del español
- Haber participado en al menos 4 sesiones de terapia ocupacional a través de telesalud desde Marzo de 2020

Encuesta

En Inglés - <https://s.surveymonkey.com/ym9pp6MDe>

En Español - <https://s.surveymonkey.com/aRLzqPLVF>



Para más información, favor de contactarnos por medio de
pedstelehealthproject@my.stanbridge.edu

Appendix E

Institutional Review Board Approval

04/09/2021

Re: IRB Application Number MSOT10-03

Dear Dr. Emas and Research Team,

The Stanbridge University Institutional Review Board has completed a review of your application entitled, "Measuring the Effect of Occupational Therapy Telehealth Services on Stress and Self-efficacy of Caregivers of Children with Special Needs: A Survey Study." Your research protocol MSOT10-03 is fully approved and categorized as exempt.

Should you wish to modify this approved protocol, please submit a modification request.

Sincerely,

Dominique N. Wascher

Dominique N. Wascher, Ph.D.

IRB Chair