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FAMILY ENGAGEMENT AND TELEHEALTH IN PEDIATRIC OCCUPATIONAL THERAPY

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Family engagement is an important part of meaningful and effective pediatric occupational therapy (D'Arrigo et al., 2019). During the COVID-19 pandemic, telehealth emerged as another crucial component of occupational therapy. This article reviews the literature on family engagement and the use of telehealth in pediatric occupational therapy and presents a case example of measuring outcomes of a pediatric occupational therapy practice at the University of Illinois at Chicago Occupational Therapy Faculty Practice: Children, Youth and Families (CYF). Two questions were explored to help discover how family engagement and family-centered occupational therapy models impact occupational therapy services in pediatrics: 1) How is family engagement defined and why is it important in pediatric occupational therapy? and 2) How does the Model of Human Occupation (MOHO) and the Short Child Occupational Profile (SCOPE) help guide family engagement in pediatric occupational therapy? In addition, the advantages and challenges of using telehealth to engage families in pediatric occupational therapy were explored through the following two questions: 1) What is the role of telehealth in occupational therapy? and 2) How can telehealth impact access for under-resourced and rural communities?

FAMILY ENGAGEMENT BACKGROUND

Family engagement is a key component of pediatric occupational therapy practice. Family engagement consists of the involvement in the therapeutic process by all parties and is sometimes an underestimated component of engaging in therapy services (D'Arrigo et al., 2019). Providers should learn all they can from the children and families, and the families should have the opportunity to be involved in their child's growth and development. Family engagement can be described as having three parts: affective (emotional connection), behavioral (collaboration), and cognitive (identifying needs) (D'Arrigo et al., 2016). Each of these factors contributes to the success of occupational therapy for children and families. Pediatric occupational therapy supports participation in occupations such as school readiness, eating, dressing, social participation, and rest and sleep for children with developmental delays or disabilities (Frolek Clark & Kingsley, 2020). Family engagement in pediatric occupational therapy means incorporating families in programs and throughout the occupational therapy process to promote positive child and family outcomes such as school readiness, wellness, respect, and responsibility (Stoffel et al., 2017). The support a child receives through occupational therapy and the knowledge, skills, and responses they and their family learn can benefit their goals and aspirations throughout life. Family engagement can promote positive collaboration and outcomes in pediatric occupational therapy by considering communication, competence, equality, and advocacy (Stoffel et al., 2017). Education is another important aspect of family engagement. Better child outcomes are seen when parents/caregivers understand occupational therapy and educate the occupational therapist or occupational therapy assistant about their family history, personal concerns, family routines, goals, and priorities (Frolek Clark & Kingsley, 2020).

Multiple models of practice and theories guide occupational therapy. One occupation-focused model is the MOHO. The Short Child Occupational Profile (SCOPE) is an assessment tool that is based on the MOHO and is used within the CYF as part of family engagement. The MOHO helps guide family engagement in several ways. The MOHO describes aspects of occupational therapy, including volition (motivation), habituation (patterns and routines), and performance capacity (physical and mental abilities) (Model of Human Occupation Theory and Application, 2021). The MOHO also focuses on the environment and how to enhance one's occupations based on their wellbeing and surroundings. The MOHO supports occupational therapists and occupational therapy assistants in understanding family engagement by first examining the occupations of the child and family, and then addressing barriers to those occupations that the child and/or family may experience. The SCOPE is an occupation-focused assessment that determines how a child's motivation (volition), habits (habituation), skills, and environment support or restrict participation in valued occupations. The SCOPE assesses components of the MOHO while also considering other factors such as diagnosis, age, treatment, and support (Bowyer et al., 2008). The SCOPE uses a rating scale of Facilitates, Allows, Inhibits, or Restricts to support occupational therapists and families in setting meaningful goals and documenting change and progress over time (Bowyer et al., 2008). The SCOPE promotes family engagement because in order to receive all this information, an occupational therapist must consult with the child's family to identify areas of strength and challenge

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for the child. The SCOPE carefully captures these strengths and challenges (according to the child's developmental stage) through observation of child and family activities and interviews with the child and/or parent or caregiver (Bowyer et al., 2008). The SCOPE can help provide an understanding of a child's engagement and gives direction on how to further a child's self-determination. Both the MOHO and the SCOPE help facilitate family engagement, which brings benefit to the child and their family as part of occupational therapy services.

TELEHEALTH BACKGROUND

In March 2020, the impacts of COVID-19 required a shift in the provision of healthcare services, including pediatric occupational therapy. Telehealth has been around for many years but has had limited use in clinical professions such as occupational therapy. In 1879, there was an article in the Lancet that first spoke on the subject by describing how a telephone could be used to reduce unnecessary office visits (Institute of Medicine [IOM], 2012). In 1925, the cover of a Science and Invention magazine presented a photo of a doctor diagnosing a patient by radio (IOM, 2012). During that time, they had a vision of technology progressing in the future to one day allowing video examination of a patient (IOM, 2012). With COVID-19 rapidly spreading at the beginning of 2020, many health fields, including occupational therapy, experienced a shift to using telehealth as a service delivery option. The American Occupational Therapy Association (AOTA) describes that, "telecommunication and information technologies have prompted the development of an emerging model of healthcare delivery called telehealth, which encompasses health care services, health information, and health education" (AOTA, 2018, p. 1). Since telehealth first emerged, there has been an array of names for telehealth such as telemedicine, teletherapy, and telerehabilitation. In the field of occupational therapy, AOTA defines telehealth as the "application of evaluative, consultative, preventative, and therapeutic services delivered through information and communication technology" (AOTA, 2018, p. 1).

Before the COVID-19 pandemic, reimbursement for telehealth occupational therapy was not ubiquitous, and therapy sessions were usually not covered (Camden et al., 2019). During the pandemic things changed quite quickly, and telehealth became increasingly relevant as people were told to stay home. In Illinois, Governor Pritzker signed an Executive Order supporting the use of telehealth on March 19th of 2020. This order stated that telehealth services would be "defined to include the provision of health care, psychiatry, mental health treatment, substance use disorder treatment, and related services to a patient, regardless of their location, through electronic or telephonic methods" (Executive Order 2020-09). The Executive Order also, importantly, listed occupational therapists as healthcare professionals who could provide telehealth services. This Executive Order included many common types of technology that patients might have available such as a telephone for a phone call; this could be a cell phone or a landline. A smartphone could also be used with applications such as FaceTime, Facebook Messenger, or Skype. Patients could use electronic, telephonic, or video technologies that support access to the healthcare services they needed (Executive Order 2020-09 2020). The order also stated that health insurance issuers were required to reimburse for in-network services using telehealth at the same rate as in-person services (Executive Order 2020-09 2020). These new procedures and coverage for telehealth, provided for by Governor Pritzker's Executive Order, allowed new opportunities for telehealth usage in many healthcare fields. During the 2021 Illinois spring legislative session, legislators unanimously passed a bill (House Bill 3308) that contains many of the provisions for telehealth that were part of the initial Executive Order, including that patients can receive telehealth from their home and that telehealth coverage and payment is aligned with in-person services (Coalition to Protect Telehealth, 2021). Governor Pritzker signed the bill into law (Public Act 102-0104) on July 22, 2021.

TELEHEALTH ADVANTAGES

Several advantages of telehealth have been identified in the literature including enhanced family engagement, increased flexibility, and expanded availability of service providers. Family engagement may be enhanced through telehealth since parents and caregivers are directly interacting with their child. Families have expressed that, during telehealth sessions, their opinions and perspectives drove interventions for their child (Wallisch et al., 2019) and they felt supported, knowledgeable, and confident with helping their child (Behl et al., 2017). Telehealth promotes family engagement by providing opportunities to partner with families, build family capacity in their natural environments and routines, and support families in being active members of the intervention (Wallisch et al., 2019).

Telehealth can also provide an option for improving needed access to therapy services for rural and under-resourced communities (Behl et al., 2017; Cole et al., 2019; Little et al., 2018). Telehealth has been found to be acceptable to families and can result in cost savings (Little et al., 2018). Decreased travel

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time for in-person visits may lead to providers being able to use telehealth to provide increased therapy services for more children and families (Behl et al., 2017; Cole et al., 2019). Behl and colleagues (2017) documented travel time of EI providers for in-person home visits versus the time spent troubleshooting technology challenges during telehealth. The average time to drive for providers to serve families was about 61 minutes or 39 miles per visit, while the average time spent on troubleshooting technology was 11 minutes (Behl et al., 2017). Even with added time to troubleshoot technology challenges, there was an average of 50 minutes saved per visit. If technology is working properly, the time saved from not needing to travel could then possibly be used to provide services to more children. Additionally, time spent navigating technology challenges often will decrease with repeated telehealth visits as providers and families become more familiar with how to use the video platforms.

Telehealth could provide increased opportunities for an occupational therapist or occupational therapy assistant to observe a child and family in their home environment. Telehealth can increase flexibility by being able to observe children and families during daily activities or routines, such as dinnertime, that might otherwise be difficult for a provider to observe in-person (Cole et al., 2019). Wallisch et al., 2019 found that families reported that telehealth "was highly convenient and compatible with their family's daily life" (p. 19). Telehealth might also decrease missed or cancelled sessions if it can be used as a service delivery option in cases where families or providers would have otherwise cancelled due to illness or weather. For example, an EI service coordinator in the Cole et al., 2019 study stated that families could still receive services (via telehealth) and therefore did not have to cancel the appointment.

Telehealth became the new norm for many healthcare providers in 2020-2021, and the literature supports several advantages. Increased use of telehealth occurred due to the COVID-19 pandemic, but telehealth could also become an option for healthcare in the future as it is further researched and as policy changes allow for continued use beyond the public health emergency during the COVID-19 pandemic.

TELEHEALTH CHALLENGES

Although there are many advantages to telehealth described in the literature, it is important to explore potential challenges as well. Hersch et al., 2015 indicated that occupational therapy practitioners reported feeling that telehealth has potential, but that they did not feel adequately trained or skilled to provide occupational therapy services via telehealth technology. It can take time for healthcare professionals to understand how to use technology effectively and appropriately for telehealth (Cole et al., 2019). Due to the COVID-19 pandemic, telehealth usage rapidly increased, and healthcare professionals had to adapt and learn new skills in a short timeframe. As the technology industry grows and telehealth policy and implementation allow for continued use, additional education and training may be needed to support best practice use.

Another challenge is that some families and providers may be limited with internet connection and access, and/or may struggle with technology. Even before the COVID-19 pandemic, sufficient and stable internet connections was identified as a challenge for telehealth use (Cole et al., 2019). If providers are using a combination of telehealth and in-person services, they also need a place to provide the telehealth services. Cole et al., 2019 found that EI providers who did not have an office struggled to figure out where to go to provide a telehealth session if the telehealth session was scheduled in between in-person sessions and the therapist was in the car.

Telehealth needs to continue to be studied over various communities. There may be advantages and challenges that we still do not know about. As more literature becomes available in the coming years, the use of telehealth in healthcare and occupational therapy will likely continue to grow.

CASE EXAMPLE

The CYF is a clinical practice through the UIC Department of Occupational Therapy. The CYF applies the UIC Department of Occupational Therapy's community-engaged Scholarship of Practice Model (Hammel et al., 2015), which emphasizes the meaningful relationships between community partnerships, research evidence and occupational therapy practice, in its evaluation, intervention and consultation services. This case example is presented to demonstrate outcomes of a pediatric occupational therapy practice related to family engagement and telehealth. Results from a family satisfaction survey, goal attainment data, and SCOPE results are presented. As part of their UIC Honors Capstone projects, the first and second authors assisted the CYF in collecting and analyzing these outcomes.

A CYF Family Satisfaction Survey was developed and included questions specific to family engagement concepts as well as questions about telehealth usage. CYF families were included in the development and review of initial iterations of the CYF Family Satisfaction Survey in order to ensure that the questions were relevant, accessible, and meaningful to the intend-

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ed audience (i.e., CYF families). The CYF began using telehealth as a service delivery option in March 2020 due to the COVID-19 pandemic; therefore, questions related to telehealth satisfaction were also included. An online survey platform, UIC Qualtrics, was used to administer the survey and collect responses. CYF families previously provided input on the best method for obtaining their feedback, and they overwhelmingly preferred an online method.

Table 1: Family Engagement and Telehealth Results from the CYF Family Satisfaction Survey

RESULTS	CYF FAMILY SATISFACTION ITEM(S)
100% of surveyed families were **"Very Satisfied"** with:	• being included in their child's occupational therapy • being informed about their child's occupational therapy • the child and family being treated respectfully • being involved in their child's occupational therapy telehealth sessions
100% of surveyed families were **"Very Satisfied"** or **"Satisfied"** with:	• collaborating with their child's occupational therapist to develop goals that address their concerns and priorities
83% of surveyed families were **"Very Satisfied"** or **"Satisfied"** with:	• their child's telehealth therapy versus in-person therapy

The final CYF Family Satisfaction Survey consisted of 14 questions with four questions specifically related to family engagement and three questions related to telehealth including one open-ended question. The survey was available in English and Spanish due to the CYF serving families with those primary languages. From November 2020 to January 2021 the survey link was sent to families via email by the CYF occupational therapists. Families completed the survey anonymously, and all questions were optional. During the time the survey link was active, 80% of currently served families completed part of the survey with 60% of currently served families completing all questions (except the open-ended response questions). Results from the family engagement and telehealth questions of the CYF Family Satisfaction Survey are summarized in Table 1. Results indicate that overall, CYF families are highly satisfied with many aspects of family engagement, including being included and informed, feeling respected, and collaborating with their child's occupational therapist. CYF families also reported high satisfaction with their telehealth services, although fewer families were as satisfied with telehealth as compared to in-person services.

Goal attainment was analyzed for children who received occupational therapy through the CYF from March 2018 to October 2020 and who were not part of Early Intervention. Goals and outcomes for children receiving Early Intervention are written and collected in accordance with Early Intervention procedures (i.e., not able to be analyzed as "Met" or "Partially Met") and were thus excluded from the CYF goal attainment results for this project. Goal attainment results revealed that 100% of Short Term Goals (STGs) and Long Term Goals (LTGs) were Met or Partially Met, with 67% of STGs Fully Met and 58% of LTGs Fully Met. Partially met goals meant the child had made some progress but had not fully met the goal at the time of outcome measurement. Some children had goals that were partially met due to length of service being shorter than expected, such as because the family moved out of state. Overall, children receiving occupational therapy through the CYF demonstrated positive goal attainment. Seeing that all goals were met or partially met demonstrates the value and positive impact family engagement has had on these families and children. SCOPE results from children who were currently receiving occupational therapy or who had previously received occupational therapy through the CYF were also reviewed and summarized. Each SCOPE subtest was scored on a scale of 1-4, with higher scores indicating enhanced or higher participation in that area. The mean of each subtest was calculated from the SCOPE results of children seen for occupational therapy through the CYF from March 2018 to October 2020. Figure 1 provides information about the SCOPE assessment results which revealed that, on average, children receiving occupational therapy through the CYF improved in all subtests of the SCOPE from their initial evaluations to an outcome measurement point (progress report or discharge).

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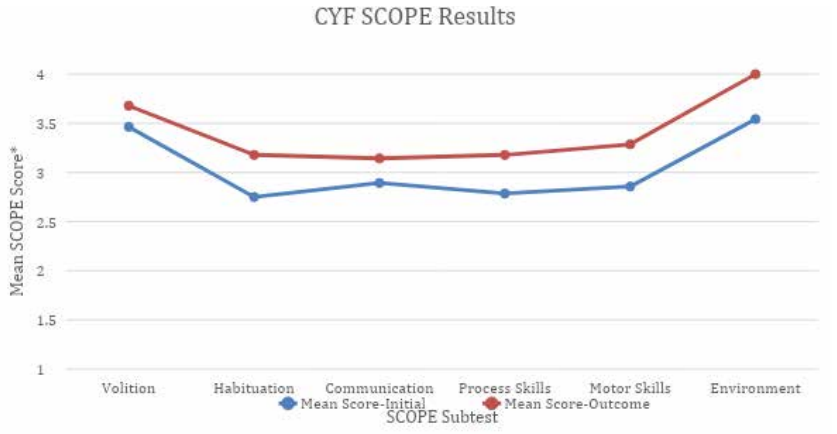

Higher SCOPE Scores indicate enhanced participation

Figure 1: CYF SCOPE Outcomes (March 2018-October 2020)

IMPLICATIONS FOR OCCUPATIONAL THERAPY

Family engagement is a beneficial aspect of pediatric occupational therapy. For the child to get the most out of their occupational therapy services, it is important that families, providers, and the child collaborate on goals, priorities, concerns, and ideas they may have. Intentional collaboration helps the provider better understand the child and their environment, and families may feel more included and respected. An occupation-focused assessment like the SCOPE provides an opportunity to incorporate the family and child voice as part of family engagement. The SCOPE can also be used to write goals and measure outcomes that are important to the child and family. Providing opportunities for feedback from families to be heard by providers, such as through a family satisfaction survey, can be an important way to enhance family engagement.

Advantages of family engagement include supporting families in learning about occupational therapy and strategies they can incorporate for their child in daily life. Occupational therapists and occupational therapy assistants who incorporate family engagement also learn about the family's values and beliefs, as well as priorities and concerns. Pediatric occupational therapists and occupational therapy assistants who promote family engagement by working to provide inclusive care with the child and their family may see more positive goal outcomes, while the family may also experience enhanced participation in services and in daily life. The presented case example indicates that families report feeling included, informed, and respected when family engagement is incorporated into occupational therapy practice.

During the COVID-19 pandemic, telehealth became an important service delivery option for providing occupational therapy services. Telehealth supports family engagement by providing opportunities for families to be active participants in sessions. Literature indicates that there are advantages to telehealth such as improved time management, ability to observe children in their natural settings, involvement of families, and access for rural and under-resourced communities. Challenges with telehealth have also been reported in the literature and include providers having adequate space and a location for telehealth sessions and limited or lack of internet and data access. In order for telehealth to be a viable service delivery option in the future, policy and reimbursement, as well as internet/data access issues, will have to be addressed. Continuing education opportunities for providers around best practice use of telehealth as well as education to occupational therapy clients about the benefits of telehealth will also be needed for telehealth to successfully continue as a service delivery option post pandemic.

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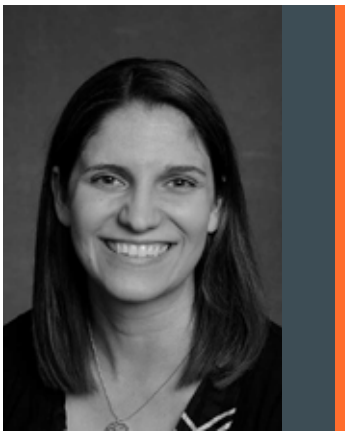

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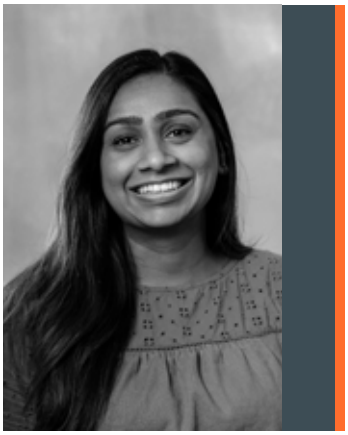

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