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Research Article

Occupational Therapy via Telehealth for Families Raising Children with Autism

—Carli Rita

Special focus on family health is emerging in occupational therapy and has potential to create a significant change in the lives of families. Family health is a complex term that captures overall well-being and satisfaction of each individual member, as well as the family unit. Family arguably may be the most critical unit of being in a child's life, and is thus reflective on the overall life satisfaction, development, and well-being of all individuals involved (Newland et al., 2015). Some families may not have thought about nor purposefully developed family health within the challenges of daily life (Stein et al., 2011). The backbone of the occupational therapy profession is supporting participation and engagement in activities or tasks that an individual or group wants or needs to do; therefore, occupational therapy can work with families to facilitate engagement in family life activities. Since much of family life takes place within the home, the telehealth service delivery method is an important platform by which therapy services can take place within a comfortable environment for the client(s).

As an occupational therapy student at the University of New Hampshire (UNH), I did not consider research as part of my academic journey until an honors program meeting during my junior year. I had to choose a mentor in the department and either collaborate on an existing project with them, or develop my own study. When I heard about Assistant Professor Sarah Smith's family health intervention study, I was drawn to it immediately. It caught my attention because of its close ties to family life, an area of my own life that has played a significant role in my personal development. Dr. Smith and I determined that I would be a good fit for the study, and we began diving deeper into its development before starting recruitment and data collection. My research, funded by a 2020 Summer Undergraduate Research Fellowship (SURF) through the Hamel Center for Undergraduate Research, sought to determine the preliminary effectiveness of Dr. Smith's intervention program. We hoped to provide pioneering information to the field of occupational therapy that could shift the way services are administered for children with autism through a more contextualized relevant setting: the family.



Carli Rita

Autism and Familial Associations

Family health may be considerably more difficult for the families with an autistic child to achieve and maintain due to unpredictable behaviors and the tendency for family life to revolve around the child (Smith & McQuade, 2021; Stein et al., 2011). Autism refers to a developmental disability that can cause significant challenges in many areas, including, but not limited to socialization, communication, behaviors, feeding, and self-care (American Psychiatric Association,

2013). These challenges, which in more severe forms may include unpredictable outbursts, physical aggression, self-injury, and self-isolation, may disrupt the balance within a household unit (DeGrace et al., 2014). Participation in desired occupations, or the meaningful everyday activities that individuals desire or need to do, may be affected by the challenges experienced by individuals with autism and their families, and may potentially create an imbalance in family needs (Smith & McQuade, 2021; Stein et al., 2011). For a family raising a child with autism, routines are critical, and a change in routine has the potential to create chaos.

Occupational therapy has been shown to improve family health outcomes for families raising children with autism. However, despite families seeking support for the occupational participation of the family unit, little research examines family health within households of children with autism (Kuhaneck et al., 2015). To address this, Dr. Smith developed the *Healthy Families Flourish Program* (HFFP), a ten-session occupational therapy intervention, to support families raising school-aged children with autism. The telehealth platform this program is built on, and its ability to occur within the client's natural context, the home, has potential to align very well with the client-centered approach of occupational therapy.

Participants

We recruited four New Hampshire families for participation via postings on social media networks and the UNH Healthy Families Research Program website. To be included in the study, families were required to have at least one child aged five to seventeen, with a diagnosis of autism who was living in the home full time as confirmed by a signed parental statement of such, and speak English. My proposed study was reviewed by the UNH Institutional Review Board (UNH IRB) to ensure that it met all guidelines for the protection of study participants.

Family A consisted of a mother, a father, and several young children. The oldest child, who was over age ten, had been diagnosed with autism in the past year. The mother was the only consistent family member to participate in the intervention sessions, and she carried what she learned into her family's everyday life. Family B was a family of four. Both parents were present for the majority of sessions, and both children participated in at least one session for researchers to gather the child perspective. Their oldest child has been diagnosed with autism. Family C was comprised of two family members caring for their teenager with autism. Both parents participated in most sessions, and the teenager was also present for some. Family D was made up of a mother, her partner, and her daughter with autism. Other non-biological children lived in the home but were not participants of the study. The mother and partner both participated in sessions.

Methods for Data Collection

To examine the preliminary effectiveness of the *Healthy Families Flourish Program*, I collected data using a UNH Qualtrics survey that consolidated several self-report tools to assess family satisfaction, family functioning, and personal experience with factors of family health. The survey was completed within two weeks before and after the intervention program. I received a total of seven completed surveys from the four families. Both pre- and post-intervention scores were compared using a nonparametric t-test to analyze statistical significance of the change scores to determine the effectiveness of the intervention program.

We also used Goal Attainment Scaling (GAS) to collect data. Goal attainment scaling is an evidence-based outcome tool to measure highly individualized and contextualized change on a client's goal outcomes (Harpster et al., 2019; Kiresuk et al., 1994). At the beginning of the intervention, at least two GAS goals were collaboratively developed with each family specifically related to family involvement in daily activities. Progress on these goals was measured upon completion of the intervention. Specific indicators made by the family determined the level of outcome of the goal. For example, if a family had a goal based on mealtimes, specific indicators

might include how many minutes the family sits together at the table, how much the child socialized at the table, and the clean-up participation of the family.

Interventions

The *Healthy Families Flourish Program* was based upon the Family Health Model, a model generated to support strong family health (Smith et al., 2017). Based upon the model, the program dives into the family health areas that include, but are not limited to family communication, adaptation, balance, connection, and flexibility. The program was delivered via Zoom, and families accessed sessions from their homes using smartphones, tablets, or computers. Dr. Smith, a licensed occupational therapist, oversaw each intervention session and supervised me in implementing intervention strategies for families. We worked collaboratively with each family to create goals, interventions, and evaluation methods to support the family's everyday life.

Over the course of ten weeks, we met with each family for one hour each week. Sessions were organized in ways that best fit each family. Typically, the first part of the session was dedicated to reflecting on the past week. Participants would explain what strategies they implemented that week and what worked, versus what did not. Conversations would unfold as to what to continue and what to modify, and then participants and researchers collaboratively worked on modifications. The sessions typically consisted of conversations rather than questions and answers, which allowed Dr. Smith and I to gather a fuller understanding of the participants and their family needs.

Together, Dr. Smith and I designed interventions both during sessions with families and outside of sessions to best meet the participants' goals. Goals ranged from spending more family time together to getting chores done in a timely manner to effective meal preparation, and everything in between. The variety of goals reflected where each family was on their journey to optimal family health. Some families made drastic changes while others just needed help fine tuning previously established systems and protocols. Each family had unique challenges that allowed us to give personalized interventions and strategies to minimize or solve family challenges.

Participants were key members of the intervention process. As researchers, we asked questions to the family members to see what would work best for them in the specific area that we were working on. Family members often had great thoughts on what would work, but needed added support to successfully apply strategies. Often, strategies were simple, but participants had overlooked them as effective methods due to their simplicity. One family struggled with meal planning and preparation, and our solution was providing the family with a two-week sample meal plan that consisted of Crock-Pot, Instant Pot, and one-pot meals along with resources about how to look for simple meals online. The strategy of using online resources to find simple recipes was all that this family needed, as they were unaware of how much time and effort is saved when meals are pre-planned and/or only used one pot.

Another family with two young children, one with autism, often had difficulties managing outbursts due to children not getting their way. One particular toy always seemed to cause chaos, as only one child could use it at a time. The children would take turns, but the child who got to play with it last always seemed to have the upper hand. We suggested a simple visual, such a



The author (right) with her mentor, Sarah Smith. *Photo credit: Sabrina Patterson.*

sticky note, to show how each child gets a certain amount of time with the toy and that they both get the same number of turns before going back inside.

A third family had difficulty spending time together because they were all interested in very different activities and hobbies. We asked the family to gather together and choose one small thing to do as homework that week. All of the family members enjoyed food, so we suggested a meal as a good opportunity for the family to be together. Another suggestion was a walk with the family dog, whom they all adored. Although very simple, these suggestions and strategies to spend time together are often not easy for family members to come up with themselves. Our outside perspective and talking about the family's challenges helped them reflect on their lives and come up with solutions independently. Most of the families overthought the challenges, thinking that they required difficult, life-changing strategies to overcome their obstacles, when they realistically only needed approaches that challenged them just enough and gave them the resources to actively work on reaching their goals.

Results

My preliminary analysis shows that the *Healthy Families Flourish Program* was able to create some change for families. Of the four families that participated in the study, 100 percent of participants noted a positive change in at least one goal created at the beginning of the program. All families made progress in at least one goal, and two families made progress on all of their goals. In addition, families increased their levels of family communication, engagement, and cohesion over the course of the program.

Qualitative feedback from families also allowed us to determine if the program was effective. In the final session with each family, they were asked what they found to be effective about the *Healthy Families Flourish Program*. One mother stated that the program and the outside advice was able to help her create positive change both within herself and within her home. Another family reported that the whole family perspective was important as it brought together the dynamics of each individual member. This family found that the way in which the Goal Attainment Scale framed goals was helpful, as it focused on key areas and different levels of achievement.

Challenges

I encountered some challenges and obstacles throughout the project. The COVID-19 pandemic began months before the project began. By the time the study was conducted in summer of 2020, it quickly became evident that all participants' lives and routines were impacted by COVID-19 in ways that were not applicable when the study was designed. Many families struggled with maintaining routines, managing remote learning, self-care, and designating time with their family members when the majority of time was spent together in the home.

The initial purpose of the study was not to focus on life during a pandemic, but because that was life at the time this study took place, the impact of COVID-19 on our participants' lives became a common topic. We could not just push the pandemic away, and it was nearly impossible to ignore the implications of being home. Instead of trying to look to the past and ask families what challenges existed pre-COVID-19, we embraced the opportunity to optimize family health as we saw it, regardless of a pandemic looming in the background.

Conclusion

Occupational therapy has the potential to make a meaningful difference in the lives of families. This project brought about numerous triumphs, both for the participating families and for me personally. While further research in this area is necessary to develop evidence-based practice, participant testimonials have suggested that programs such as the *Healthy Families Flourish*

Program have potential to create change in family health and participation in daily life. Participant families made progress each week toward the goals that they had developed with our support. Even when only little progress was made from week to week, it was incredible to see and hear about the difference that the program was making in the lives of participants. The family members that we spoke to may have felt defeated in the past when something did not work, but during the program, they felt supported and were excited and empowered to continue implementing new strategies as they pushed toward reaching their goals.

In the final session with each family, we reflected on where the families were at the beginning of the ten-week program, and recognized and celebrated the progress that had been made. One participant stated that the program was life changing. She explained that the way she viewed herself had changed. She would often use negative self-talk and humor, and over the program we worked on eliminating negative language so that she could become a more positive person. She was able to reflect on how her awareness of her situation had changed, and how her journey in life had a more positive trajectory after participating in this program. These testimonials are indications that programs such as these can make a difference in the lives of families.

Going forward, after graduating with my bachelor's degree in May 2021, I will be returning to UNH in the fall of 2021 as a graduate student, and plan to complete my master's degree in occupational therapy in December 2022. As I near the professional years of my studies and career, I have set goals for myself to become more knowledgeable in my discipline, voice my ideas confidently, ask more questions, and begin to truly think like an occupational therapist. Looking back on this experience, I am proud to say that I have made significant progress in meeting these personal goals. I am grateful that this research opportunity has allowed me to be a central part of real occupational therapy interventions. The experience has opened my eyes to a family-centered approach in occupational therapy rather than a focus on a single client. Family health is just as important as individual health, and this project has allowed me to look into families' lives, both the good and the bad, giving me a unique perspective not often seen. My biggest takeaway from this experience is that no family is the same, and that all families deserve access to services that allow the entire family unit to be just as successful and fulfilled as each individual member.

I would like to thank several people, for without them my participation in this study would not have been possible. First, to my mentor, Dr. Sarah Smith, thank you for sharing so much of your time, dedication, and wisdom with me and challenging me to grow as a student and future therapist. Thank you to the Hamel Center for Undergraduate Research and the SURF Program for funding my research, and especially to Dr. Elizabeth Blesedell Crepeau, Dr. Lou Ann Griswold, the UNH Parents Association Undergraduate Research Fund, and the Occupational Therapy 50th Anniversary Endowment for Undergraduate Research for your generous support. Thank you to all of my family and friends for the never-ending love and support throughout all of my personal and academic endeavors. Lastly, a special thank-you to my parents for instilling within me a passion for scholarship, a love for helping others, and a work ethic that continuously pushes me to strive for more.

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Author and Mentor Bios

Carli M. Rita, from Mattapoisett, Massachusetts, is a member of the University Honors Program. She completed her research through a Summer Undergraduate Research Fellowship and as part of her honors thesis. Her passion for working with children and families led her to her mentor, Dr. Sarah Smith, who got Carli involved in the Healthy Families Research Program at the University of New Hampshire (UNH). Carli says that having an opportunity to work on this project has given her a much deeper understanding of the research process than she previously had, and elevated her perspective in clinical reasoning and intervention strategies. She agreed to submit to *Inquiry* after being contacted by the journal's staff, and she's glad that she took advantage of the opportunity. After graduating with her bachelor of science in occupational therapy this spring, Carli plans to continue her studies at UNH as she purses a master's degree in occupational therapy. In the future, she plans to become an occupational therapist and hopes to form strong connections with her patients to make a difference in their lives.

Sarah Smith, DSc, OTR/L, is an assistant professor in the Department of Occupational Therapy. She began working at the University of New Hampshire (UNH) in 2017, with research and teaching focused on occupational therapy for children with special health care needs and their families. She is passionate about undergraduate research because it allows students to learn in a way that the typical classroom setting can't provide. She enjoys mentoring students because their curiosity and dedication are energizing. Carli became Dr. Smith's research mentee when she came to Dr. Smith with an interest in UNH's Healthy Families Research Program, and together they decided to launch a study on telehealth to support families of children with autism. Although this project was not originally designed to alleviate family stresses specifically caused by the COVID-19 pandemic, the parent-coaching approach was a perfect match for helping families readjust their everyday activities to the constraints of the pandemic. Carli is the first of Dr. Smith's research mentees to write for *Inquiry*. Dr. Smith notes that writing for a broad audience, like *Inquiry's*, helps students improve their knowledge translation skills, which are imperative for any occupational therapy professional.