

# Parent Perspectives on Telehealth Education for Pediatric Rehabilitation

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## Abstract

This research study aimed to address the current knowledge gap by qualitatively assessing what parents need for telehealth education programming to be accessible, useful, and beneficial for their families. Interviews and online surveys were utilized to acquire qualitative data over the course of one year. Three themes emerged: current resource utilization, desired resources, and educational supports and barriers. Parents used various online resources primarily to connect with other caregivers and to enhance their child's skill sets. The subjects desired easy-to-use resources, session notes with visuals, and online forums for support. Consistent communication and resources from pediatric rehabilitation therapists were greatly valued. Future research should evaluate the efficacy of educational programming developed based on the recommendations provided.

**Keywords:** Children, family-centered care, rehabilitation, qualitative

## Introduction

Telehealth education and service delivery are emerging areas of practice within rehabilitation.<sup>1-3</sup> Telehealth services have been found to promote greater participation due to convenience, specifically elimination of travel time and scheduling flexibility.<sup>4-8</sup> For pediatric rehabilitation, telehealth offerings have been found to be effective for meeting therapeutic goals.<sup>9-12</sup> Rehabilitation therapists have also reported success with 77% of therapists approving of telehealth programming and 78% supporting its permanent use.<sup>13</sup>

Telehealth education and service delivery may be an appropriate option for use in rehabilitation,

particularly in addressing common challenges in the pediatric setting.<sup>14-15</sup> Family-centered practice, which is most supported through home-based services, can be fostered through telehealth services.<sup>16</sup> Additionally, telehealth education has been shown to improve therapeutic outcomes and carryover of recommendations at home.<sup>6,17</sup>

When considering the appropriateness of telehealth offerings, benefits must be weighed against their limitations. It is known that virtual services cannot replace evaluation or treatment techniques that require a hands-on approach from a trained practitioner.<sup>15</sup> Telehealth utilization also requires parents and practitioners to be proficient in technology.<sup>14</sup> Technology is becoming increasingly

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ubiquitous, eliminating skill and availability as barriers; however, some experts caution that technology is already being used excessively and should be used more judiciously.<sup>18</sup>

Currently, many telehealth offerings are left to the discretion of individual practitioners, guided solely by their own expertise and self-taught technical skills.<sup>19</sup> As such, there is a great disparity in the availability and quality of resources.<sup>18</sup>

This study aimed to address the current gap in knowledge by qualitatively assessing what parents need for virtual education programming to be accessible, useful, and advantageous for their families. This research study aimed to answer the question, "What do parents need from virtual education services?" The results from this study add to the understanding of how virtual education can be developed and utilized by rehabilitative professionals to benefit families and promote the carryover of therapeutic strategies at home.

## Methods

After receiving Institutional Review Board approvals, this research study first employed semi-structured interviews to collect data from parents of children who received pediatric occupational therapy (OT) services. Parents were recruited via virtual flyers on social media platforms and physical flyers dispersed in pediatric outpatient clinics in Florida. Interviews were conducted both virtually and in-person, recorded, and transcribed by the primary investigators.

After the initial round of interviews, it was noted that early intervention was not represented. A second round of interviews were conducted to address this disparity. Due to difficulty with recruitment, the interview questions were adapted to an open-response Google Form format.

The interviews and Google Form survey consisted of nine open-ended questions as illustrated in Figure 1. Questions underwent expert review by four Doctors of OT to diminish potential bias before administration. The interviews lasted approximately 10 to 20 minutes and were conducted via Microsoft

Teams, with no identifying information shared to ensure confidentiality was maintained. All interviews, both virtual and in-person, were audio-recorded and transcribed verbatim and analyzed along with the Google Form survey responses.

### Figure 1

#### *Nine Open-Ended Questions*

1. How do you use online resources (websites, apps, blogs, Facebook groups, etc.) to help your child?
2. What online resources (websites, apps, blogs, Facebook groups, etc.) do you use to help your child?
3. Why do you use those online resources (websites, apps, blogs, Facebook groups, etc.) to help your child?
4. If an online website was made to support you as the caregiver of your child what would it look like?
5. If an online website was made to support you as the caregiver of your child what would it include?
6. What other resources do you use to help your child?
7. Where do you find those resources?
8. What helps you carryover what was done in therapy at home?
9. What does not help you carryover what was done in therapy at home?

The inclusion criteria for participating was being the parent of a child younger than 18 years of age who receives OT services at a rate of at least one weekly session and has access to a technological device (i.e., computer, phone, or tablet). Participants were excluded from participating in this study if they had experience working as an occupational therapist or a certified occupational therapy assistant (COTA) or if the child had been receiving OT services for less than one month.

Following the collection of data, two researchers reviewed the audio recording, transcripts, and

field notes independently to hand code. Thematic analysis method was utilized to analyze the data.<sup>20</sup> The researchers independently identified recurring terms, general topics, and feelings to determine themes from the interviews and surveys.<sup>21</sup> After independently reviewing the data, the investigators discussed the themes that emerged from the wording and perception of parents' responses to reach a consensus.<sup>22</sup>

## Results

Thirty-four individuals expressed interest in participating; however, only 18 met the inclusion criteria. A total of 18 interviews and online surveys were completed to acquire qualitative data over the course of one year. The majority of participants were female (83%). Of the participants, nine reported their child received services in an outpatient setting, eight reported their child received services in the natural environment (e.g., home), and one reported their child received services at school. The participants had children between the ages of 0 to 11 years old receiving services at the time of the interviews and surveys. Three themes emerged from the data: current resource utilization, desired resources, and carryover supports and barriers.

### Current Resource Utilization

Subjects articulated the educational resources they used, described how they utilized those resources, and provided rationale for why they chose those resources. Subjects utilized resources such as search engines (e.g., Google), social media (e.g., Facebook groups), educational programming (e.g., ABC Mouse), and YouTube. When asked how resources were found, Participant #7 stated, "I search online for all." Other participants agreed, and Participant #5 said that they specifically used YouTube to conduct searches. Participants also reported therapists, family members, and doctors to be their main sources of how resources were found (#1, #3, #5). Participants #6 and #8 were outliers, reporting that they used "mostly books" recommended by their child's therapist and pediatrician.

Participants described how they utilized their resources. Participant #10 explained that when trying to find resources to help their child, "I usually just do a, you know, generic Google search and see where the information leads me from there." Participant #4 elaborated, "Whenever I go and look these things up, half the time I do get the right answer."

When asked why they use online resources, parents expressed their desire to help their children succeed. Participant #5 stated they were motivated by the "zeal to help" their child. Participant #1 said, "I have a lot of motivation to help my son be successful." Participants also reported seeking a sense of camaraderie when faced with similar situations. For instance, Participant #5 responded that they utilize resources "to help and learn from others' experiences on how they care for their child." They stated that their decision was made due to the overwhelming nature of therapeutic recommendations. Participant #6 elaborated, "I just focus on what the therapist says."

### Desired Resources

Subjects described specific features and content that would be beneficial. Desired features included "user friendly" and "interactive" components (#2, #5, #10). Participant #4 reported wanting a "search bar or somewhere where you can put in like your kid's, maybe like, a diagnosis...or typing my kid is hyper, out of focus, or sensory needs and it pulls up, you know, things that you could do for the hyper, the focus, and sensory stuff." Having easy-to-utilize resources was also important because "We're given a lot of information, and it's all helpful but a lot to remember" (Participant #4). Participants #6 and #9 desired a resource that provides video and written materials to appeal to parents' unique learning styles (e.g., auditory, visual).

Fifty percent of participants responded requesting a "forum" or parent blog and believed it would be beneficial. Participant #5 elaborated, wanting access to "reviews of other parents with descriptions of what their child has been going through, for how long, and what improvements have been made/shown by using the education provided." Participants detailed

the importance of having help from professionals for a forum. Participants stated that "having constant aid from a professional" in a forum would be beneficial for all users (Participant #5).

Subjects described the content they would like to include in a virtual education resource. Responses included step-by-step guides for skill development, explanations of developmental milestones, descriptions of therapeutic techniques in non-specialist terms, and creative ideas for activities parents can do at home with their children. Participant #4 reported wanting "something that gives you the definition for the words that you need to know, an explanation that anyone can understand." Specific skills that were requested included reflex integration, coordination, and visual memory activities (#1), potty training guides (#2), diagnosis and prognosis (#10), and "what is going on in therapy" (#5, #6, and #9). Ninety percent of participants reported that they would like content to be organized by skill rather than age. Participant #8 disagreed with the majority, stating "I want to refer to the age groups ahead of where my child is to see what they are working towards."

Subjects also suggested that receiving session notes with visuals and easy-to-understand videos would assist in the home implementation of therapy practices. Participant #1 stated that having videos of therapy techniques would be beneficial because "it is information overload at times... then you go home and you forget". Only three participants reported that they "don't know" or were "not sure" what they would like a new parent education resource to resemble or include.

### Supports and Barriers

Subjects described the supports and barriers they encountered when utilizing educational resources. Regarding supports, parents reported success with demonstration, handouts, and follow-up. One participant noted the therapist's demonstration of certain skills/techniques, such as "brushing and compressions" to have supported her ability to carryover because OT had "given me the tools I need to help him exercise his muscles in the right

way" (#4). When asked what helps them carryover what is done in therapy at home, Participant #6 reported, "the ease of the techniques shown and how I can do them in everyday routines." To effectively carryover the recommendations at home, parents responded that they found it helpful to focus on specific strategies, utilize easy-to-follow techniques, and maintain consistent communication with their child's therapist(s). Overall, parents reported positive feelings regarding telehealth education.

Subjects also reported barriers with some of the information they received. Participant #4 reported that her child's therapist provided age-appropriate checklists and "to tell you the truth, I've gone through lists and lists. Most of them work, but 55% of the time they don't because he's just not there yet." Subjects also noted that therapists tended to provide verbal feedback at the end of sessions, which could be challenging to recall. When using other sources not provided by their child's therapist (e.g., social media groups), parents were concerned about the potential for misinformation or recommendations that could be harmful to their children. They reported difficulty with determining the validity of the overabundant information available.

### Discussion

The findings, which support the use of telehealth resources, were congruent with previous research. Previous studies found both parents and therapists had positive opinions of telehealth education delivery models.<sup>8,13,17</sup> Telehealth delivery for parental education has also been found to be effective for pediatrics, echoing the sentiments of this study's subjects.<sup>6</sup>

The results from this study add to the understanding of how telehealth educational content can be developed and utilized by rehabilitative professionals to benefit families and promote the carryover of therapeutic strategies at home. Based on the results, it is recommended that information be created for specific diagnoses, challenges (e.g., picky eating), and skills (e.g., potty training) as milestone/age-appropriate information may not be applicable for parents of children with developmental delays.

Information should be presented in multiple formats to meet different learning styles, be simplified to be accessible to parents with minimal medical knowledge and promote positive parenting strategies.<sup>23</sup> Therapist-moderated parent forums may also be appropriate to encourage supportive relationships and address any misinformation.

This study had the unique advantage of having a diverse group of subjects, even though the majority resided in Florida. For instance, two participants were fathers; a population frequently neglected.<sup>24-25</sup> The study also had a decent sample size for a qualitative study with participants who provided quality, elaborative data.

This study lacked a quantitative component that could be evaluated with statistical analysis. Likewise, since a questionnaire did not exist prior to this study, one had to be created based on feedback from content experts. This study was also limited to Florida, which may limit its generalizability to other countries with different healthcare systems.

Future studies may use a larger, more diverse sample size to elaborate on the findings of this study. Telehealth content made from this study's recommendations should be assessed for efficacy. Additionally, new content should be qualitatively assessed for continued improvement of telehealth service delivery.

## Conclusions

This research study aimed to address the current knowledge gap by qualitatively assessing what parents need for telehealth education programming to be accessible, useful, and beneficial for their families. Qualitative data from 18 parents of children receiving therapy services revealed three themes: current resource utilization, desired resources, and finally educational supports and barriers. Parents used various online resources primarily to connect with other caregivers and to enhance their child's skill sets. The subjects desired easy-to-use resources, session notes with visuals, and online forums for support. Consistent communication and resources from pediatric rehabilitation therapists were greatly

valued. Telehealth content generated from these findings should be evaluated by future research.

## Declaration

There are no funding sources to disclose. The authors received institutional review board (IRB) approvals from Gannon University (#GUIRB-2023-3-7075 and #GUIRB-2024-1-7207) on 3/22/2023 and 7/22/2024, prior to the commencement of this study. The authors declare no competing interests.

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