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Citation: Alabdulqader, Ebtisam, Stockwell, Katy, Montague, Kyle, Jackson, Dan, Monk, Andrew, Pennington, Lindsay, McNaney, Roisin, Lindsay, Stephen, Wu, Ling and Olivier, Patrick (2022) Understanding the Therapeutic Coaching Needs of Mothers of Children with Cerebral Palsy. In: DIS 2022 - Proceedings of the 2022 ACM Designing Interactive Systems Conference: Digital Wellbeing. ACM, New York, US, pp. 1788-1801. ISBN 9781450393584

Published by: ACM

URL: <https://doi.org/10.1145/3532106.3533576>
<<https://doi.org/10.1145/3532106.3533576>>

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Understanding the Therapeutic Coaching Needs of Mothers of Children with Cerebral Palsy

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ABSTRACT

Mothers of preschool children with cerebral palsy are often responsible for delivering multiple home therapy programs. Technology could be a way to bridge some of the challenges of home therapy delivery, such as lack of regular contact with professionals and the need for support continuity. We interviewed seven mothers and four speech therapists to explore their challenges, and the types of support they currently receive (or give). Key issues included limitations of existing communication channels between mothers and professionals, the mothers' social support needs, and the level of commitment required to self-deliver home therapy. Based on findings indicating video sharing as an existing practice among mothers, we conducted three workshops to further investigate how a video-based platform could support home therapy delivery. We conclude with a number of design considerations for such technologies, to improve communication and collaboration between professional therapists, mothers and members of their wider social network.

CCS CONCEPTS

• Human-centered computing; • Empirical studies in HCI;



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DIS '22, June 13–17, 2022, Virtual Event, Australia
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ACM ISBN 978-1-4503-9358-4/22/06.
<https://doi.org/10.1145/3532106.3533576>

KEYWORDS

Cerebral Palsy, Parents, Caregiver, Children, Coaching, Therapy

ACM Reference Format:

Ebtisam Alabdulqader, Katy Stockwell, Kyle Montague, Dan Jackson, Andrew Monk, Lindsay Pennington, Roisin Mcnaney, Stephen Lindsay, Ling Wu, and Patrick Olivier. 2022. Understanding the Therapeutic Coaching Needs of Mothers of Children with Cerebral Palsy. In *Designing Interactive Systems Conference (DIS '22)*, June 13–17, 2022, Virtual Event, Australia. ACM, New York, NY, USA, 14 pages. <https://doi.org/10.1145/3532106.3533576>

1 INTRODUCTION

Cerebral Palsy (CP) is a neurodevelopmental movement disorder that appears in early childhood, affecting muscular control, posture, and balance [58]. It can be classified in terms of the type of motor difficulties that an individual experiences: spastic (i.e., muscle stiffness), dyskinetic (i.e., uncontrollable movement), ataxic (i.e., balance and coordination difficulties), or mixed (i.e., a mixture of motor difficulties). CP can range from mild (e.g., a small amount of stiffness that affects the child's gait but does not require assistance) to severe (e.g., wheelchair-bound with limited speech and significant intellectual disability, requiring long-term care and support) [50]. As most developmental milestones in early childhood are associated with physical and communicative functioning (e.g., rolling over, sitting, crawling, walking, speech production), children with CP can often be considerably delayed in these areas by the time they receive a formal diagnosis. Majnemer [31] demonstrated the importance of early clinical interventions to address developmental difficulties before delays manifest. In the United Kingdom (UK), clinical services for preschool children are primarily home-based,

recognizing both the importance of the environment in which children are raised and the parents' role in the daily development of a child's skills [31].

One of the most common delays encountered in CP relates to speech and language development [54], for which home-based speech and language therapy (SLT) support can be provided for parents of the preschool child with CP (also called home programs, indirect-therapy, or parent-delivered therapy). However, the amount of therapy that families receive varies greatly, and therapy visits can be infrequent [35]. Clinical studies of parent-delivered home therapy also revealed that parents often felt overwhelmed and struggled to deliver the programs [16, 17]. While many digital technologies have been proposed for tracking developmental delay [12, 20, 24, 25], the specific technology requirements to support home-based SLT have not been established. To this end, we present a two-phase investigation conducted with parents of children with CP and speech therapists in the UK. The first phase was focused on understanding the context of parenting children with CP, interpersonal communication patterns, and current home therapy practices. We interviewed seven parents (all mothers) and four SLTs about a) their daily caregiving/professional routines and activities, b) their concerns relating to parent-delivered therapy, and c) how support and communication between therapists and parents, and parents and their wider support networks, were currently facilitated (including any social media and/or digital practices). During Phase 1, it became clear that parents were already engaged in significant amounts of video recording and sharing through platforms such as WhatsApp. Additionally, therapists were often shown captured videos during clinical sessions to evidence developmental progress or challenges. As such, the second phase of our work then focused on leveraging these practices to design a digital solution that would support parent-led home-based SLT therapy using a video-based approach (allowing therapists to provide one-on-one coaching to parents around SLT tasks). We first asked the mothers to spend four weeks capturing short videos of play sessions with their child (they were asked to use their own smartphone to do so, but we provided them with a tripod and Bluetooth button to help facilitate these activities). We then ran three design workshops (two with parents and one with therapists) that explored the captured video content and uncovered each group's needs and expectations around how therapist–parent interaction and communications should be designed (within the context of an asynchronous video and information-sharing environment). The ultimate goal was to meet clinical targets around SLT delivery for young children with CP.

Our study provides a contextual understanding of the support and empowerment needs of mothers of preschool children with CP. Based on this understanding, we propose a number of considerations for designing technologies to support video coaching for home-based SLT, intending to enhance communication and collaboration between parents and therapists. While our study was performed within a relatively niche context, our findings can be extended across broader human–computer interaction work exploring collaborative care, and the facilitation of carer–clinician relationships and communication within this. We highlight the opportunities for video coaching as an approach to supporting home-based therapy across allied healthcare delivery.

2 RELATED WORK

2.1 Early Speech and Language Therapy

Children are considered to have speech and language delay if they do not meet particular age-related milestones. For example, at two years old, a child would be expected to be speaking in 2–3 word phrases or sentences. Speech and language delay is classified as primary if no other aetiologies are found and secondary if associated with other developmental disorders, for example, CP [38]. In both cases, early SLT for preschool children focuses on working with the family to develop the communication skills essential to the child through playing, reading, or talking [59]. This type of therapy is generally 'indirectly' delivered by trained parents or other caregivers (instead of a therapist) and is found to be effective in enhancing children's communication skills before starting school [31, 44, 55]. To apply this therapy, parents need to be trained by an SLT professional on the types of strategies that can be used to promote communication in daily interactions by recognizing communication signals, responding to them, and developing new communication skills [6, 9, 30]. One established parent coaching mechanism is the use of video interaction guidance, where videos are used to provide feedback on parent–child communication and identify areas for improvements [2, 22]. This technique has been proven useful for in-clinic visits, coaching parents of children with language delay in the Hanen Program® [45, 46] (a trademarked early SLT intervention that trains parents in practical strategies to support their child's language development in the home environment), and for preschool autism communication therapy (PACT) [10, 47].

When considering early SLT intervention for children with CP in particular, it is worth noting the impact their associated movement difficulties can have on their overall communication development. The muscles required to produce speech (tongue, palate, larynx) may be weak or uncoordinated, causing significant impairments to speech quality or intelligibility. In addition, the speed, strength, and range of movement needed to provide facial expressions and gestures, along with the speech, can also be affected, making supplementary, or indeed complementary, communication through non-verbal means challenging [44]. As such, the neuromotor disorder complicates the speech and language acquisition process, making it a much longer process compared to neurotypical children. Moreover, it has been noted that lower levels of clinical attention are given to the communication development of children with CP compared to the efforts dedicated to their motor development [19]. All this combined means that parents engaging in home-based therapy programs have significant challenges to contend with and require additional support and guidance.

2.2 Mobile Technologies and Children's Development

Studies of technology-based support for children have shown that digital technologies can have positive impact on children's learning and development, especially for children with special needs [61]. Reviews of literature in this space identified that these technologies tend to involve device-based support, often referred to as "assistive

technology”, targeting on specific developmental and learning disabilities for children in educational contexts [62]. The effectiveness of these technologies are often assessed in relation to their functions in assisting students’ cognitive learning (e.g. reading, communication, mathematics), physical development (e.g. vision, hearing and mobility), social skills and daily living [63]. Technological support for children with special needs are mostly developed to directly target the children, however, it has also been identified that there is a need to support parents and educators in order to optimize the health and learning outcomes of the children [61–63]. In addition, various digital technologies have also been proposed to monitor neurotypical children’s development and support communication between parents and pediatricians. Recognizing the importance of developmental tracking, and giving feedback to pediatricians, Kientz et al. [26] explored the use of digital technologies to record developmental milestones and share them with pediatricians. The study proposed the use of either personal records captured by the parents or the automatic tracking of activities with wireless, sensor-enabled toys.

Video-based record-keeping solutions have also been proposed for developmental tracking [13, 24, 25]. KidCam was an integrated video capture device with a user interface that allowed parents to capture, review, and store videos and photographs of their child. The device stored continuous recording for a limited amount of time and provided a way for parents to cut interesting content [24]. It was tested with four families for three months, one of whom had a child with developmental delay, who were particularly enthusiastic about using the device to capture developmental activities displayed by their child. A study by Kientz et al. [25] described a similar video-based system called BabySteps, which focuses on sharing information between parents and pediatricians. The authors explored the barriers to record-keeping, including parents’ time constraints, motivations, and forgetfulness. They found that introducing a digital sharing solution with integrated reminders promoted better record-keeping practices among parents [25]. Finally, an app-based solution called Estrellita was proposed to promote record-keeping and information-sharing between healthcare professionals and parents of preterm infants [12, 13, 55]. Its use for encouraging social interactions with peers, family members, and friends by sharing information has also been explored [28]. Studies of Estrellita’s use indicated that parents’ awareness of their child’s care needs improved and that supportive feedback increased their confidence. However, while parents benefited from Estrellita, the requirement to continuously capture data through the app constituted a significant burden, in addition to their existing responsibilities of caring for a preterm infant.

2.3 Technology to Support Therapy Delivery for Children With Communication Difficulties

When considering the role of digital technologies in supporting the delivery of therapy services to children with neurodevelopmental and communication disorders, a range of studies have explored a variety of different platforms. For example, MagicLand was an interactive tabletop to support play therapy for children with attention deficit hyperactivity disorder [48]. The collaborative nature

of the activities presented on the tabletop was found to promote the child–therapist relationship and supported the child to communicate their needs effectively [49]. Moreover, Kientz et al. [27] have reported the opportunities for using wearable sensor data to give a voice to non-verbal children with autism (i.e., by analyzing behavioral data from the sensors, the parent or clinician can gain an insight into the child’s affective or emotional state). They highlight the benefits of in-clinic session use and helping therapists to make better treatment decisions.

Specific to SLT delivery, Keck et al. [21] highlighted the benefits of using technology to support the diagnosis and treatment of communication disorders, yet noted that therapists have been slow to utilize them to expand their services. The majority of telehealth practices start at school age and deliver remote therapy sessions through either mobile, Skype, or other proprietary systems [21]. Still, there is little work exploring how these types of practices might be implemented for preschool SLT delivery. Fernandes et al. [8] reported increased use of mobile devices as alternative and augmentative communication devices, which can lower the barrier to access for these types of communication aids. Historically, these were (often expensive) standalone devices. Therapists have also reported using mobile devices to collaborate with parents and set up SLT homework tasks to support therapy goals targeted in clinical sessions [8]. Finally, Hwang et al. [20] proposed a real-time linguistic analysis system designed to synchronously analyze the speech of children with speech and language delay and provide therapy guidelines to parents accordingly. Although the system had several voice detection issues, evaluation demonstrated high levels of parent engagement with the system.

In short, while advancements have been made in the space of child development tracking and the use of technology within formal SLT sessions, work directly exploring how to support parents of preschool children with complex needs in delivering home-based therapy programs, where the parent is the primary source of therapy input, is yet unexplored.

3 STUDY OVERVIEW

Our two-phase study was configured to answer the following questions: (i) what are the current experiences and challenges facing parents of children with CP and how do they deliver home-based SLT programs?, and (ii) what potential is there for new or existing technologies to support and respond to these challenges? The first phase of the study focused on context exploration. The second phase aimed to explore the design space surrounding how new or existing technologies might be used to deliver support in this context.

3.1 Participants

To conduct this research, ethical approval was received from a National Health Service (NHS) ethical review board, in addition to an institutional (university) ethics review. Despite the enormous pressure facing the main carers for children with CP and the high dropout rate (up to 77%) from parent training programs [16, 37], we managed to recruit eight mothers of children with CP and four speech and language therapists. While open to working with either the mothers or fathers of children with CP, all the carers in the

Table 1: Profiles of children with CP and families (ages are in months)

ID	Age in Months	Age in Months (at diagnosis)	Child's Gender	Mother's Employment	Partner's Employment	# Siblings
C01	35	25	M	Stay-at-home	Full-time work	3
C02	39	37	M	Business owner	Full-time work	0
C03	24	18	F	Stay-at-home	NA (Separated)	0
C04	27	12	F	Part-time work	Full-time work	2
C05	13	12	M	Stay-at-home	NA (Separated)	1
C06	19	12	F	Stay-at-home	Full-time work	3
C07	28	6	M	Part-time work	Full-time work	0

recruited families were mothers. Parent participants were targeted as the main carers of the child with CP and those who would deliver the home-based SLT program. All mothers were experienced in receiving home-based therapy programs and working with multidisciplinary professional teams. Unfortunately, one mother had to drop out during the study due to demanding medical care responsibilities, leaving seven remaining participants. The therapists who participated in the study were domain experts working with preschool children with special needs, with up to 12 years of experience. All study participants were recruited from SLT clinics across several NHS foundation trusts in the UK.

Table 1 summarizes the relevant demographics of the seven participating families (age and gender of the child with CP, the mother and their partner's employment, and the number of siblings). The sample families were from a range of diverse socioeconomic backgrounds. Four parents (mothers and fathers) held undergraduate degrees, and three held postgraduate degrees (two master's and one Ph.D.). Secondary school was the highest level of educational attainment for three parents, while the remaining four parents left school before completion. The mothers were aged between 28–37.

3.2 Study Design

The two-phase study design aims to develop a contextualized understanding of the mothers' lived experiences, their current practice regarding video taking and sharing before the exploration of experimental design solutions. Phase 1 enabled the research team to gain a thorough understanding of the specific needs, challenges and issues that arose through the mothers' daily caring responsibilities for their children with CP. Insights were abstracted from this phase, which informed the design of workshop activities (e.g. props used in the workshop) conducted in Phase 2. The video capture activity was purposely invoked as a preparatory activity for Phase 2. As with methods such as cultural probes [64], we used video capture to explore design ideas that are both contextualized and responsive. Our approach also used the videos to explore experiential aspects of the parents lives, to provoke responses from the therapists, and pedagogical considerations from the research team. Insights derived from both phases were synthesized to identify design spaces and ideas that integrate and respond to the mothers' needs with possible technological solutions which form the basis of the design considerations proposed.

3.2.1 Phase 1: Context Exploration. Phase 1 involved a preliminary context exploration with seven mothers and four therapists. Mothers were visited in their homes and took part in an open-ended semi-structured interview. They were asked about their daily caregiving routines and activities, their concerns about parent-delivered therapy, support and communication strategies with various professionals, and their current social media practices and general technology use. With the parent's permission, materials relating to their child's care were photographed. These included therapy instruction notes, home adaptations and equipment (to accommodate additional child needs), and media shared with other carers (see figure 1). Sessions with the mothers took approximately 90 minutes to complete. The therapists also took part in an open-ended semi-structured interview, which took place on the University campus and lasted approximately 60 minutes. Therapist interview sessions focused on understanding their current working routines and practices, the issues they experienced with home programs, and the type of support and communication strategies they used with other professionals and parents. All interview sessions were audio-recorded, transcribed, and anonymized. The sessions were run by the lead author (a qualitative researcher and interaction designer) and facilitated by the second author (a speech and language therapist).

3.2.2 Phase 2: Design of Video-based Tool to Support Parent-led SLT Delivery at Home. Based on identified practices surrounding the video capture and sharing parents were currently engaged in, the large multidisciplinary research team decided to focus the design stage of this work on exploring how these practices might be leveraged in the future to support parents in delivering SLT at home. The Phase 2 design stage work started with pre-workshop video capture by the parents, and a series of three workshops where the first two involved parents only and the final one both parents and therapists. The aim of pre-workshop video capture was to provide insights and materials for the workshop activities. For example, one of the workshop activities is to use predefined personas (a imagined parent profile that encapsulated the key needs emerged from the data) and scenarios, which was created based on the contextual insights derived from the videos captured by the parents. The intrinsic link between the video capturing and workshops ensures that the design activities are created to realistically reflect the parents' daily challenges, and provoke therapists' responses to these scenarios while at the same time integrating the researchers' interpretation of the context. This process enables abstraction of deeper insights

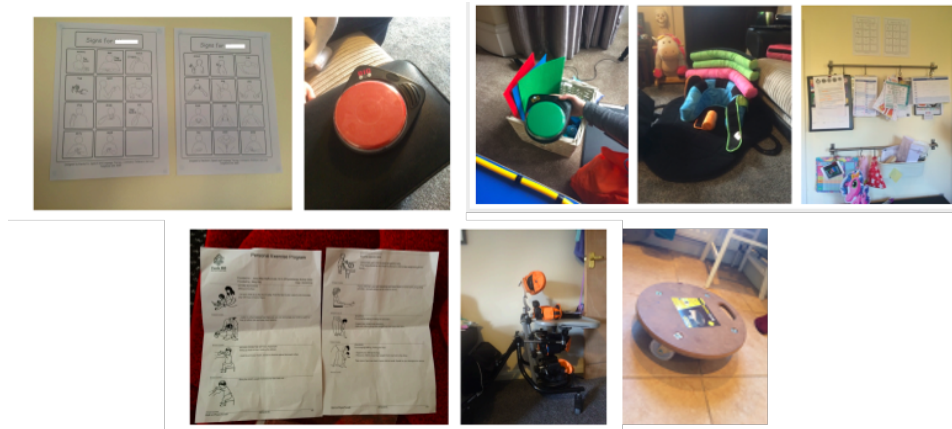


Figure 1: Images collected during home visits. Top row (from left to right) includes: a) sign language sheet, b) switch example 1, c) switch example 2, d) play set-up to support child's balance, e) therapy resource examples. Bottom row (from left to right) includes: f) physiotherapy practice sheet, g) supported high-chair for meal times, h) table on wheels created by mother

that are grounded in parents' reality during the synthesis stage (after the two phases of data collection).

At the start of video capture stage, we asked parents to engage in capturing a series of short videos (approximately two minutes each) depicting play-based interactions with their child. This also served to sensitize the mothers to the experience of capturing and sharing video clips that therapists might provide direct feedback on in the future. The view was that the mothers themselves could reflect on these videos in later workshops (e.g., to explore the type of advice or support they might have liked to receive from a therapist). Further, we could then work with therapists to explore how they would provide coaching and guidance to the mothers, using the videos as a source for discussion.

Each mother was provided with a tripod and a Bluetooth selfie button to control their smartphone camera remotely. The mothers were asked to use their personal smartphones. The recording instructions provided specified that recordings should be less than two minutes in length and clearly show any interaction partners or objects used during the interaction (e.g., sibling or toys). The mothers were asked to send each video to the research team via WhatsApp once they had finished, the aim being to mimic video-sharing they might conduct with a therapist in a future tool. They were advised that no therapy coaching would be provided at this stage of the research. This stage lasted a total of four weeks.

We then conducted a series of three workshops (two with the mothers and one with the therapists). All mothers initially agreed to attend the workshop in advance. However, three mothers were unable to attend due to unanticipated caregiving responsibilities on the day of the workshop. Therefore, we conducted the first set of mother workshops in pairs (with two mothers in each); all four therapists attended the third workshop.

The workshops were structured to allow reflection on the video capture and sharing experience, which allowed us to explore perceptions of coaching in parent-delivered home therapy and possibilities for remote support through video-based technology. The

workshop consisted of three main activities: 1) an open-ended discussion around the video capture and sharing experience (mothers only), 2) using predefined personas and scenarios to discuss current coaching techniques and possibilities for remote coaching, and 3) brainstorming and reflecting on video coaching paper prototypes for technology design. The mothers-only workshops started with discussions on the experience of video capture and sharing: the mothers were asked about the equipment used, their use of different smartphone cameras (i.e., front/back), their integration of data capture into their daily routine, their experience of video editing, and any challenges faced.

A second activity (activity 1 for the therapists) initiated discussions of a possible video coaching application. We presented this as follows: using their smartphones, parents would be able to share a video recording of parent-child interaction, annotated with their comments, and receive feedback from their therapist. Therapists would be able to annotate the recording with comments and engage in coaching discussions via their smartphones. Similarly, this communication channel could be used with other carers (i.e., family, nursery staff) or their professional therapists' team.

Personas and coaching scenarios were then used to engage the participants in reflective discussion. These were developed based on (anonymized) families' collective experiences, as identified in the contextual exploration phase. The focus was on further exploring the participants' perceptions of current coaching practices and the potential of remote asynchronous video coaching to provide support. As an example, one persona focused on Debbie, a part-time working mum of a two-year-old child with CP and speech and language delay. Debbie had been visited twice by an SLT therapist and provided with strategies to work on while playing with her child (e.g., crouching down to be face-to-face with the child, giving the child enough time to respond or react, watching and listening as the child plays).

The associated scenario described Debbie on the floor playing with a car that her child had chosen and was pushing back and forth. She was face-to-face and mimicked a car sound. The child



Figure 2: Tripod and button set-up provided to mother to capture video (left) and paper prototypes shown during workshops (right)

looked at her and smiled, and then went back to pushing the car. She clicked the selfie button to record this interaction and sent it to the therapist with a text-based note describing what had happened. The therapist responded with a note telling her that she could see the child's reaction and body language by being face-to-face. She reassured Debbie, telling her that she had done the right thing by making the car noise and that the child enjoyed this. She suggested that Debbie wait a little longer next time for the child to respond (counting five seconds in her head) and persevere with more than one attempt at mimicking the sound.

Each workshop concluded with a paper prototyping activity to establish a more focused discussion and identify the design elements of a video coaching technology that responded to participants' needs. The support equipment (i.e., the tripod and wireless button) and the prototype were again shown to facilitate the discussion (see Figure 2). The prototype was sketched using the Balsamiq wireframing tool and replicated the sharing scenarios discussed in the second workshop activity. The workshops were led by the lead author (a qualitative researcher and interaction designer) and facilitated by the second author (a speech and language therapist). Each workshop lasted for approximately two hours, was held on a University campus, and was audio-recorded, transcribed, and anonymized for later analysis.

3.3 Analytical Approach

The study led to the collection of 21 hours of audio recording for the interviews and workshops, which were all transcribed, along with 70 photographs, and 18 shared videos (26 minutes in total: min. duration = 14 seconds; max. duration = 4 minutes). A triangulation approach was applied in this study, where data were collected from various sources (therapists and mothers), and methods (interviews, observations, video sharing) were collated for sensemaking [36, 37]. Our sensemaking process was informed by a design synthesis approach [60], which included a series of sessions where the research team met to discuss the data, and integrate their expert viewpoints in order to formulate, refine and prioritize design spaces that forge a connection between the challenges experienced by the mothers and the possible solutions involving both technology and human elements. The sensemaking and synthesizing process was conducted throughout the study by the research team, where interpretation of the data were shared, organized and prioritized to create speculative design ideas. This iterative process linked and integrated insights derived from Phase 1 and Phase 2 to formulate the final design considerations.

Qualitative analysis using inductive thematic coding was conducted on the resulting interview and workshop transcripts [7]. The transcripts were examined line-by-line to generate open and low-level codes without any underlying theory. This inductive process resulted in approximately 350 distinct codes and categories that the first two authors cross-checked until agreement was reached. Codes were clustered together into recurrent and high-level themes. Themes were then incorporated according to categories such as disability and parent-led therapy challenges, communication and current technological practices, coaching perception, and the practicality of remote video coaching. The codes and themes were discussed and refined iteratively with the entire research team.

4 FINDINGS

4.1 Phase 1: Findings

The first phase results revealed four main areas of challenges related to the motherhood of children with CP, home therapy programs, social support networks, and current communication and digital practices.

4.1.1 Motherhood and the Challenges of Disability. The mothers all emphasized the fundamental change in their lives resulting from having a child with special needs. Most mothers indicated that the change was due to their commitment to many therapy visits, from different specialized therapists, for each condition diagnosed in their child. This was considered an additional commitment facing the mothers, going beyond the distinct, demanding daily care routine for children with CP. As C01 explained, *“Being a mum and your child has got problems with talking, it is not something that is natural, like being a mother comes naturally.”* For the mothers to handle their children's needs, some of them changed their jobs either to part-time ($n = 2$), took extended leave ($n = 1$), or left their job completely ($n = 2$). Three mothers also described having less time for other family members or personal responsibilities.

All the mothers described their experience of denial prior to their child's diagnosis. When they realized that there was a problem, this was followed by a period of hope since doctors could not provide an exact diagnosis of CP until later in their development. Yet, four mothers said that they more readily accepted the reality than other family members. As explained by C07, *“I think it is probably something that you just gradually realize as time is going on that things are not quite right, and he is probably going to have longer-term needs.”*

All mothers mentioned that they are the primary carers of their children and deliver the vast majority of care alone. As C04 stated, *“I do most of it myself, really.”* The mothers’ responsibilities included looking after their children’s needs, tracking development, learning from different therapists, and ensuring that other carers implement what the mothers have learned. The mothers stated that their children were very dependent and demanded physical and emotional support, even during therapy visits. They felt that they knew their children’s attitudes, strengths, and behaviors better than other carers and found this understanding to be helpful for their collaboration with the therapists and in promoting their child’s development skills. For example, C05 said: *“He knows what you are talking about. He knows what is on the telly. If you turn it over to a different channel he does not like it. In that way he is quite clever. If he has finished with a drink he twists his face. If he wants something he will look and cry for it. He is good at communicating in sort of [ways] I know what he wants and what he does not want.”* Moreover, the therapists (n = 3) also confirmed the importance of the parents’ role in improving the whole learning environment for the child.

All the mothers found themselves attending therapy visits alone, learning all the time, and trying to turn every activity with their child into an opportunity to support their development. However, they expressed the need to engage with other carers and use the child’s achievements to encourage other family members to get involved. As C01 said, *“Then for me to try and teach another person is extremely difficult. I feel like I should be recording everything and playing it back to other people.”* Some mothers (n = 5) placed resources such as physiotherapy programs, sign language sheets, and therapy devices in various areas of their houses as a way to engage other carers and siblings (see figure 1).

Most mothers expressed an eagerness to learn and explore new techniques to support their children’s development. Some of them were currently exploring online resources (n = 4) or consulting other family members (n = 2) to learn more about CP, searching for alternative solutions used by similar families, or exploring mobile applications for their children. Three mothers invented techniques to support their children’s development based on their interests, for example, using online videos, or Siri, as playful communication tools. Other mothers (n = 2) developed their own solutions to support their children’s independence, such as transforming a wooden tray with wheels into a movement tray to support the child’s mobility at home (see figure 1h). However, two mothers described their fears of exploring online resources, given the amount of discouraging information about their children’s diagnosis. Still, they were eager to learn from specific resources when recommended by others. As C04 explained, *“I am cautious about finding stuff that is really relevant to us, and also I do not want to know if the future is not what we want. I looked at the internet a lot when she was first diagnosed, and it was terrifying. Maybe that was a good thing, to help me prepare. If somebody recommended me a really good website or something, then I would be really pleased. That would be great.”*

4.1.2 Parents’ Experiences of Delivering Therapy at Home. Due to various developmental delays faced by children with CP, each child has a professional team formed to support them, consisting of several clinical specialists (e.g., SLT, physiotherapist, occupational therapist). While all the mothers acknowledged an appreciation

of the vast range of information and expertise on hand, they also remarked on the challenges of working with a large team of professionals. Specifically, the sheer number of therapy activities to do with their child: *“Just fitting it into all your daily routine. But at the end, it is me who has to do all of that work, which is great, but I sometimes think, ‘How am I going to do all of this?’ You know, they give you all these programs; it is a lot of work!”* [C06]. The mothers were able to establish an overview of the long-term clinical goals and recognize the overlapping roles of these practices. In an attempt to cope with the volume of practices, they began to integrate multiple practices into single play sessions. However, most mothers (n = 6) found it difficult to maintain a big picture view of the goals while also being the main caregiver: *“At the same time, I think it just amazes me how vague the whole thing is, about what they expect, about where they are heading, about what they are going to do to get there”* [C04].

The mothers discussed the challenge of prioritizing practices and addressing each of the child’s development issues. This can sometimes mean making difficult decisions to progress in one area at the expense of another. The therapists shared in this struggle as well. As T01 explained, in each visit, they try to balance their discussions between multiple developmental aspects including feeding, communication, and education: *“You have to go to see them with two hats on to figure the communication and the feeding and often you have to solve the feeding first and then you have to say—‘Right, now I cannot come back for another three weeks to talk to you about communication.’”* As a result, the mothers (n = 4) described the visit sessions as hectic and needing to rely on other professionals or social groups to seek answers to their questions that the therapists might have better answered.

The primary challenge identified by the mothers (n = 6) was the absence of a fixed schedule for therapy, as visits are organized based on the child’s progress and support needs. Most mothers (n = 4) described needing more frequent visits from the therapists. They found that the long intervals between visits meant they often forgot practices, developed concerns about their progress, and did not have the opportunity to receive reassurance. Moreover, they noted that therapists who visited more frequently had a better understanding of the child’s health situation. Therapists recognized this as *“thinking that more speech therapy is going to make everything better”* [T01]. Instead, they focused on the importance of continuous practice and responding to children’s cues to promote their skills; as T02 explained: *“One hour a week with me is not going to make that difference. I need to impart that knowledge and skills to you so you can be doing that effectively all of the time. Get grandma in, get dad in.”*

The challenge of visit frequency is made worse due to the organizational constraints on the therapists: they have predefined working hours in which to arrange visits according to their geographical location. Therapists often find themselves rushing between places with strict time allocations per visit. This is combined with the reality of working with children who experience health issues, mood fluctuations, and fatigue during visits, making it extremely difficult to complete everything within the allotted time. Both mothers and therapists discussed how mothers sometimes video recorded their interactions with their children and showed them to the therapists during the visits as evidence of achievement or consulted a therapist

around the struggles they face in interacting with their children. Therapists (n = 3) found these videos useful, as it led to more discussions around SLT-related strategies and helped them to reflect and assess the child's progress: *"Because of smartphones, people do take videos, and show us occasionally video clips of something they have done, especially if they are really proud of something the child has done, which is effective"* [T03].

Therapists explained the uniqueness of each family: they adapt their therapy approaches based on the child's needs and the mother's learning style. They relayed that the practices they promote are based on play activities and introduced by the therapists (to the parents) through demonstration, explanation, and coaching techniques. In addition to supporting the child's development, training sessions are designed to promote the parents' confidence, help them identify priorities, and upskill them to the point where only monitoring is required from the therapist. This confidence was recognized in some mothers (n = 4) who explained how they use the acquired knowledge during the visits and tailored the strategies to better suit them. However, to learn these skills, the mothers must be persistent with the practices and overcome the challenges of the child's mood, their wellbeing, and other life responsibilities. Due to demands arising from their circumstances, most of the mothers described their struggles with forgetfulness. They would find themselves forgetting some of the practices they should be doing or schedule overlapping appointments with therapists. Three therapists indicated that this was made worse by the lack of other communication channels, with most information only being communicated verbally to the mothers. As T03 said: *"We do that verbally with parents, but we do not have written or pictures or evidence of other ways to communicate to the parents. So, I do feel like a lot of things might get given to the parent verbally, but probably get lost in all the other stuff that they are dealing with."*

While all the mothers said they enjoyed doing the SLT practices, they found it frustrating when they could not get their child's attention or if the practices conflicted with a difficult development issue they were facing. This, in turn, could lead to a perceived lack of progress in the child's development, further adding to their frustration. Two mothers (n = 2) described how the investment of time spent doing the practices and the lack of progress was disheartening. Others (n = 3) felt capable of remaining motivated even without apparent signs of progress. For example, *"[The child] has made quite—well, massive progress to me to where she was even six months ago. But it is still very, very slow"* [C06]. In contrast, two mothers suggested that the progress is sometimes invisible to them because they see the child constantly. All therapists confirmed that development progress would plateau. They try to encourage mothers to reflect on their earlier achievements and defined goals, while carefully managing parents' expectations of progress to reduce the likelihood of frustration.

4.1.3 Social Support and Communication Practices. Nearly all the mothers (n = 6) received some level of tangible support from their families, including taking care of the child and being involved in the therapy practices. As C03 explained, *"I think my nana is a really good factor in my life at the minute with [the child]. When my nana's not here anymore I will panic. I will not know what to do, I really will not."* However, all mothers who cohabited with a partner (n

= 5) described limited levels of support received due to their partners' long working hours. Four mothers discussed the challenges of wider family involvement, including the child's preference for the mother, difficulties in sharing updates, and general work and life commitments. However, several within-family sharing practices, and motivations for sharing, were apparent, including sharing video, photo, and text content to teach other family members about therapy practices (n = 5), sharing the child's achievements for encouragement (n = 3), sharing medical updates (n = 3), and seeking reassurance (n = 2). The mothers (n = 4) also described the difficulties experienced in sharing their feelings and development expectations. As C04 noted, *"We share lots of stuff, but I think there is some stuff where you just think it is like opening a can of worms, and it is too difficult."*

Most therapists (n = 3) and mothers (n = 4) highlighted the importance of emotional peer support from other families of children with CP. As one mother described, *"It is quite comforting really to see that you are not alone because I think when you have had no experience of it, you think everything is happening for you alone."* [C07]. Some mothers (n = 2) found it a relief to talk to similar families, as they knew exactly what they are going through, including experiences relating to diagnosis, therapy, therapists, services, and medications. The mothers found it easy to meet with peers through social and therapy playgroups that therapists and support organizations arranged. They discussed how this communication often extended beyond formal channels (e.g., SMS or social messaging apps). However, both mothers and therapists also identified potentially negative issues associated with peer communication. These included the stress associated with hearing others' stories (n = 2) and comparisons between their child and others (n = 5).

In addition to therapy delivery, therapists (n = 3) described how mothers use visits as a form of stress relief, allowing them to share their emotions, concerns, seek advice for support services, or discuss their personal issues. The therapists (n = 3) found these discussions helpful to better understand the parents' practices and provide better services. However, both mothers and therapists discussed the limitations of professional support available due to the limited time and large clinical caseloads. All the mothers discussed contacting professionals involved in their child's care through phone calls or email, as C04 said, *"We had a problem when [the child] was really unhappy in the car, so I videoed her and then I sent the email to the consultant."* Another mother discussed using a formal sharing system by a nursery to share reports and media about her child's developmental progress.

4.1.4 Digital Technology: Sharing and Privacy Concerns. The mothers used several mobile applications to communicate aspects of a child's development and therapy with family members through texts, pictures, or videos captured using their smartphones. Most mothers confirmed their use of group conversations on WhatsApp (n = 6) or via private Facebook or Path accounts (n = 4) with family and close friends. Additionally, captured and shared media (videos and photos) were reviewed during therapy visits using either a smartphone's image gallery or other applications like Instagram, WhatsApp, Facebook, Path, a nursery portal, and/or mobile messaging applications. Several reasons for sharing included sharing

joyful moments, achievements, concerns, assessment updates, confirming speech intelligibility, or training other family members. For example, C04 said, “[The child] said: Owl. I could not believe it. Then I spent the whole time getting her to say it again and I videoed it. I sent the video to everyone and said, ‘Can you guess what she’s saying?’ and they guessed it right, and I was like, ‘Yes!’”.

All mothers agreed that these sharing channels helped avoid repeating updates to everyone, especially with tough news. However, most mothers stressed that sharing was limited to their family and very close friends due to concerns about the privacy of broader social media platforms (n = 5) or unknown preferences around their child’s online presence when they had grown up (n=2). For this reason, they mainly used WhatsApp for personal information sharing: “It is easier on WhatsApp to do it somehow. You do not have to fiddle about with [thinking] who is going to be on it” [C01]. In contrast, communication channels used to share with professionals between their visits were limited to phone calls, email/mail (when acceptable), or communication through other professionals. Therapists confirmed that they are very restricted regarding the media and applications they can use due to the strict NHS Information Governance Policy relevant to patient information confidentiality. Yet, two therapists confirmed the importance of having an open communication line with mothers for ongoing support, especially at sensitive stages where timely responses are important: “Some things you go on a visit, and you think, I wish you would phoned me about this. Especially on the feeding side” [T04].

4.2 Phase 2: Findings

The Phase 1 findings highlighted how mothers often felt isolated as the primary caregiver for their child and the multiple roles they fulfill throughout their day (therapist, carer, family member, mother). They highlighted how mothers sought and received social, emotional, and informational support by remaining connected with family with friends with similar caring responsibilities and the therapists engaged in their child’s care. This was done via a range of communication platforms, with video sharing a particularly useful way to share their child’s progress or challenges and demonstrate the use of certain strategies to support their child’s development. The therapists in the study also highlighted the value of different forms of communication with parents outside of face-to-face therapy sessions: improve their understanding and memory of therapy tasks (outside of verbal instruction), enhance support to parents at times when particularly needed, and develop a shared understanding and measures of success (when reviewing video content).

Building on the mothers’ articulated needs (Phase 1) existing video-sharing practices (pre-workshop video capture and Phase 2 workshops) and the value that therapists saw in this to support parents (Phase 2 workshops), our Phase 2 work helped develop a shared understanding of implications for designing asynchronous video-based tools that would allow therapists to coach parents through delivering therapy at home with their child. In this section, we report the mothers and the therapists’ perspectives on coaching as a component of SLT delivery, the practicality of data capture and sharing, and several insights into the feasibility and challenges

of a remote video coaching solution. These findings are foundational elements for the sensemaking process that led to our design considerations articulated in the discussion section of this paper.

4.2.1 Perspectives of Coaching in SLT. Most of the mothers and therapists reported that mothers were looking for confirmation on their understanding of therapy strategies and guidance, feedback, encouragement, and reassurance around the correctness of their practice. In response to these needs, all agreed that professionals should foster the mothers’ confidence through discussion rather than instruction. Therapists and mothers both had similar views on coaching approaches and how these could be adapted in the context of parent-led SLT delivery. Coaching was described as two-way personalized and responsive communication that moves from strategy awareness to implementation in their daily activities. As T01 described, “Coaching is more about actually looking at what they are doing, and bringing out more of the positive stuff, and tweaking, and kind of helping them to adapt some of the things that would not be as useful.”

When considering the coaching scenarios and personas during the workshops, participants discussed how different techniques could help manage parents’ expectations and develop an understanding of the stages needed to achieve goals. Therapists also noted that one of the goals of coaching is to reinforce and reiterate advice while encouraging mothers and confirming the effectiveness of their practice. The mothers found that the type of guidance provided in the scenarios was unthreatening, easy to cope with, encouraging and increased their confidence by building on existing skills: “Something you already know, but to coach you as to how you maybe could improve it and do it better” [C07]. The mothers discussed learning from observing as the preferred and most effective form of learning: “Rather than being told something, it is easier to see and learn from somebody doing it. It has made it easier for me by seeing them doing it to them telling me how to do it. Watching is definitely a better way of learning” [C02]. As a result, mothers found coaching helped them to explore different ways to approach problems by themselves, to “own” new ideas, and have the freedom to apply them.

4.2.2 Practicality of Capturing and Sharing Videos. Mothers confirmed that smartphone use is an integral part of their daily lives. They were already engaging in some of the video capture practices that could be integrated into a video-coaching tool, as C07 explained: “I am constantly taking photos of him and videos [...] It is just what I am already doing.” The mothers were provided with tripods and selfie buttons to facilitate the video capture task during Phase 2 of the study. They found these helpful to play and focus on interacting with their child freely. Yet, they reported challenges finding the right camera angle to capture both themselves and their child, especially on the first attempt. The mothers reported finding it easy to share videos through WhatsApp, but they needed to trim the video duration before sharing to focus the content of the video or delete distractions such as the appearance of other children in the family. During the trial, the mothers shared several recordings. These ranged from one to four videos per mother (one video [C03], two videos [C06, C07], three videos [C1, C04, C05], and four videos [C02]) and from 14 seconds to three minutes in length. The videos

typically centered on the child alone or interacting with the father, mother, siblings and/or other relatives. Mothers created these recordings during feeding, exercising, or playtime.

Therapists emphasized the importance of context and the mother–child presence in the videos when their recordings were being used to assess practices and provide specific guidance. As T03 said: *“If you are looking to support communication and interaction, then you need to look at both partners [...] how is the parent responding to this? It might be great that we have seen a child say a word on a video clip, but if you do not know the context you do not actually know how useful that was. Was the child copying the word? Or did they see something? Have they commented on it? Have they requested that thing? And all those things are very different.”*

The mothers reported that their children were not distracted while recording since they mostly would not notice the camera—except for one who initially shied away when she noticed the camera, but then posed for the shot later. In general, the mothers said they were more focused on the child and forgot about themselves, regardless of any initial anxiety. However, one mother described herself as being very distracted by the camera. As C05 said, *“I think it’s just like anything. You just eventually get used to doing it.”*

Various recording opportunities were identified based on the mother–child time for playful practices, varying between families according to the mothers’ responsibilities and working hours. While the mothers felt they could fit video coaching into their daily routines, they expressed a need for reminders and prompts. Therapists suggested that having the video coaching solution as part of a therapy approach would integrate well into their work routine. Still, they wanted to reduce expectations that parents would receive an immediate response by setting a weekly slot for video reviews, which would be communicated to the parent. Similarly, therapists further expressed their preference for asynchronous interaction as it can be logistically difficult to manage review timings within the parents’ availability.

4.2.3 Perceptions of Parent-led Video Coaching. Parents reported that video coaching would be beneficial to provide ongoing support and feedback between and during the visits, and to help parents remember what they would like to discuss: *“You are not waiting for the next visit at your door or the next time you see your therapist, which then you may have forgotten these things you want to discuss.”* [C05]. Therapists revealed they were expected to be easy to contact between home visits, as this is considered part of their job. They valued video coaching for providing a channel to monitor the mother–child activities and schedule additional visits when needed: *“to facilitate your visits and also to know when to time the visits, because you could see how they are doing.”* [T04]. Moreover, further sharing of content through group conversations with the multidisciplinary team was discussed as potentially helpful to maintain a holistic view of the child’s development.

The therapists and mothers agreed that reviewing videos would allow reference to be made to previous progress, as a source of encouragement when a child’s progress plateaued, and for self-reflection. C01 explained, *“We noticed [the child] saying a word on that video that I did not even pick up on him saying [. . .], but we did not notice until we watched the video again.”* Additionally, therapists and mothers emphasized the benefit of having a video focused on

specific interactions to establish a visual and concrete discussion rather than relying on verbal communication alone. T03 expressed that *“It is better, because it is recorded, and it is the focus on the bits that you want to comment on which is good for us.”* Likewise, therapists proposed that videos would provide a realistic example to better understand the interaction context and plan suitable coaching strategies. All liked the use of video coaching during visits to reflect and reinforce skills and share strategies with other caregivers. For instance, C04 commented: *“My mother-in-law has done it [...] I think she has videoed [the child] with the therapist for herself; for her own, sort of, reference, so that she feels more confident with stuff.”*

4.2.4 Anticipated Challenges of the Parent-led Video Coaching. By engaging with our video collection activity and reflecting on their own experiences of receiving different degrees of coaching during therapy visits, participants were able to anticipate several potential challenges needing to be overcome for parent-led video coaching to be a viable solution moving forward. Therapists reinforced the view that video coaching would be a way to support home visits but not a replacement. Further, therapists and mothers agreed that, when considering SLT in particular, there was a current lack of visual resources that could be used to introduce new strategies. This poses a challenge when receiving coaching around new techniques; as C05 reported: *“It’s easier to learn from somebody doing it, like I have with physio. It’s made it easier for me by seeing them doing it to them rather than telling me how to do it.”* Additionally, all participants agreed that it would take time for mothers to be comfortable recording and capturing their videos without distracting the children. Some therapists expressed concerns about the challenge of “false” interactions due to a child’s awareness of the camera or a parent’s self-consciousness when filming. Further, therapists suggested that written comments lack non-verbal communication, which is needed to ensure the parents’ understanding and explore their feelings. T02 said: *“You cannot quite read a parent’s facial expressions, so sometimes you might give them a piece of advice, and then you can tell by their face that they think you are talking rubbish... so you do not get that bit of feedback from them.”* Moreover, text-based conversations can result in miscommunication, resulting from the perceived tone of a message or issues around the parents’ literacy levels. Finally, therapists discussed the organizational challenges of integrating a video-coaching platform into clinical settings, including equipment costs and organizational policies. The therapists explained how Information Governance policies often restricted their use of digital technologies due to privacy and patient confidentiality concerns. That said, these constraints apply mainly to sharing and, more critically, storing data; this would not apply to the use of parents’ personal devices during home or clinical visits.

5 DISCUSSION AND DESIGN CONSIDERATIONS

The vast majority of primary caregivers of children with CP are women [4]. In this study the mothers played multiple roles simultaneously, including caregiving, delivering therapy, and coaching other carers in their immediate network. Previous studies of home therapy programs [16, 17] demonstrate improvement in therapy outcomes when mothers can integrate therapy programs into their daily routines (e.g., playtime). These studies also found that mothers

were unaware of their embedded practices. They had significant concerns about a lack of time and the home therapy's effectiveness, impacting their engagement in such programs. By contrast, our study points to higher levels of mothers' awareness and stronger engagement with parent-delivered programs. The mothers strived to improve therapy outcomes and, with therapist support, innovatively incorporated the multiple learned strategies from different therapists into their daily routines. However, the perceived infrequency of therapist visits was considered a significant issue by the mothers.

Prior studies have also discussed that therapy home visits were traditionally based on 'prescribing' therapy programs. These have highlighted the need to find alternative ways to assist parents in developing skills for implementing strategies into their day-to-day lives, rather than teaching strategies on a higher level [16, 17]. However, our study indicated that the therapists we worked with were already beginning to adapt coaching style principles into the delivery of home programs, ultimately enhancing parents' ability to embed therapy practices into their child's daily routine. Coaching principles involve guiding individuals to increase their competence, commitment, and confidence, thus facilitating the achievement of their goals [1, 39, 42]. Rush et al. [48, 51] described that observation, reflection, and assessment are major aspects of the coaching process; our study shows that mothers and therapists are already adapting these principles and stages in their home programs.

Video coaching technologies were perceived as having the potential to offer valuable support to mothers of children with CP and their therapists, both between and within visits. Video technologies have been introduced in various ways to support different therapy practices. Video modeling introduced by Custodio et al. [5, 53, 56] was designed to allow youths with autism to develop learning skills by watching peer videos that they could then imitate. Video capture has also been adopted in different contexts and within the space of special needs as part of video feedback interventions [2, 10, 22]. The video recording itself provides concrete material for reflection. Other video-based solutions were designed for direct intervention and behavioral assessment but were not controlled by the parents or designed to capture the whole context of the interaction [11, 18, 32, 33, 38, 40]. In contrast, to this previous work, our study focused on socially supporting parents rather than delivering a specific training approach. Without adequate support, we found that the mothers struggled to develop a holistic view of their child's development. They often found it difficult to integrate and share multiple therapy programs while maintaining their commitment, building confidence, and identifying progress. Our study sought a more appropriate solution that fitted common technology practices and parent-child activities and was controlled and led by the mothers, while facilitating the required level of detail for support from a therapist. Our design recommendations point to the associated values, capabilities, and challenges.

5.1 Pledge to Empower and Support

Changes in how home therapy programs have been delivered have resulted in greater levels of engagement on the mothers' part. However, the irregularity of visits still leads to the perception of a lack of support. Coaching continuity was recognized as a fundamental

factor in achieving coaching goals [1, 39, 42, 48, 51]. Our findings indicate that mothers need more support rather than more therapy. This is particularly relevant given that the therapist's main focus is to coach and support parents rather than directly conduct therapy sessions with the child. While technology might have an essential role in resolving the debates and demands for more frequent visits, it must be designed to empower mothers and promote these interactions without risking the values of coaching and home programs. Our findings confirmed the importance of physical visits for introducing new strategies and discussing critical matters and revealed the need for remote support during the long intervals between visits for coaching elements, including reassurance, encouragement, promoting confidence and commitment, reinforcement, and reiteration. The acceptance of telepractices in school settings has previously been demonstrated by Hines et al. [15], and our findings point to the potential value of extending this to include preschool programs.

We identified the need for a remote communication platform that would scaffold existing relational models of care through collaboration and partnership with therapists and other carers for their children. The importance of designing for social support and recognizing the non-professional caregiver's expertise has been identified in related areas of caregiving [12, 50, 53]. In this study context, communication practices existed across the social network of the mothers, yet in an often complex and overwhelming manner, in which multiple online or offline techniques were employed. With the multiple roles that mothers play, a centralized digital solution has the potential to empower the mothers and allow them to control their roles through information sharing, communication, and collaboration with professionals and other responsible carers. Subsequently, empowered mothers can self-recognize the importance of their role and expertise and surpass the challenges of raising a child with special needs. A multiple, cooperative communication channel, led by mothers, can facilitate both the provision of professional support and collaboration with other caregivers in integrating therapeutic techniques in daily interaction routines with the children.

We identified a clear need and desire to share visual media to convey mothers' concerns, for example, through video sharing and similar communication solutions. Video-based records can support discussions between the therapists and mothers based on individualized context-based interactions. Such videos of mother-child interactions would leverage the therapists' understanding of the real-life contexts and interaction patterns that often cannot be achieved during a home visit due to time constraints or the state of a child's health. Videos can allow observation of parents' behaviors and be used as a basis for more personalized coaching techniques and plans. Moreover, video-based tools could facilitate the need to focus on short-term goals and progressively extend to subsequent goals through the video-centered discussions and open new opportunities for therapists to monitor progress between home visits, coordinating additional visits when needed.

In addition to ongoing support *between* visits, the video element of a coaching system can support interaction *within* visits. Videos and photos have been identified as useful tools that people can use to reflect on their practices [22]. However, our participants also expressed value in having visual media that could help them "learn by seeing" when developing competency around new strategies

(rather than relying on paper-based guidelines). As such, future systems could consider having the capability for therapists to create short annotated segments of videos, with each segment focused on specific actions they have noticed in the mother–child interaction (whether these be positive or require further development of strategies). In addition, aside from supporting the parent, future video-based tools with this feature could also facilitate information and skill-sharing across the child’s professional team by providing an opportunity to support training other professionals on the best ways to interact with the child.

5.2 Enabling Self-Management and Full Control

In our study, the mothers expressed how reviewing videos of their interactions with their child enabled them to reflect on their practice. The process of self-review is particularly useful in identifying their child’s skills and progress. Technology must support the collection of videos in a way that allows parents to observe and self-correct through examination, reflection, and discussion of these videos. The videos themselves can serve as an evidence-base for achievements or concerns and scaffold discussion when a child’s progress is not readily apparent to the parent, due to their proximity to the child of the slow nature of development (particularly when the child has complex developmental needs). Visual media has been shown to support memory, facilitate recall, and monitor progress [24, 25, 31, 32]. With several systems highlighting information-sharing and reflective thinking capabilities based on digital record keeping [22, 24, 31, 32], systems that further employ capabilities to enable individuals to experiment and reflect on strategies that do (or indeed do not) work when supporting their child’s development have added benefits of raising parents’ self-esteem and providing them with a greater sense of control.

Our study also identified participants’ different communication practices with multiple professionals, family members, and broader social networks through different digital communication channels. The mothers looked for support from professionals or shared their experiences with family members to engage them in therapeutic practices. Technology designed to support parents must integrate different communication practices in one tool, through either individual or group conversations. Group conversations would allow more informal discussions with a child’s multidisciplinary team, address the challenge of arranging and conducting physical meetings, and provide opportunities for the mothers to engage other relatives and easily share updates. Conversely, the mothers’ concerns about the privacy of sharing personal information pointed to the need for them to have full control of these communication channels. Conversation management mechanisms must allow only mothers to control who can see and contribute, without giving contributors the ability to export information beyond the system. Notably, therapists already delegate these responsibilities to mothers due to legal and professional constraints on information sharing [39].

5.3 Embedded and Limiting Stress

Mothers expressed their motivation to gain needed support through remote coaching technologies. However, care needs to be taken

to address the challenges of embedding technology into their demanding care routines. Our study confirmed previous accounts [16, 17] of the overwhelming nature of caregiving and therapy management of children with CP. This is also extended to the literature exploring carer burden more broadly (e.g., [29, 41]). Any addition to, or augmentation of, existing therapies must be wary of introducing additional burdens. In this respect, coaching based on parent-collected video has the advantage that smartphones are already a tool used in the everyday lives of mothers. Further, we can build on existing practices (videoing) and support mothers by using familiar and standardized interfaces for video capture and associated messaging. Indeed, our study indicated that while the mothers often felt isolated in their caring responsibilities, the process of sharing videos with their extended social support networks helped them feel connected.

More specifically, our study indicated that children with CP demand high levels of physical support and attention, which makes creating video content while maintaining their position and engagement with their child particularly challenging. The early video capture exercise, conducted with the mothers at the beginning of Phase 2, provided insights into some of the mothers’ difficulties around capturing high-quality video clips. As such, video-based solutions should consider allowing ‘on-demand’ retrospective video recording from the buffered video content using a selfie button. For example, allowing the user to press a button that would start the recording a minute before the button press would allow parents to capture the moment they might have missed. For example, the child saying a word or performing an action, as opposed to attempting to get the child to do it again. These recording solutions should retain the qualities of standard videoing approaches. Still, they should integrate non-disruptive recording alerts (e.g., a flashing light or brief beep) to minimize demands on mothers needing to check if their phones are recording successfully. This would enable the collection of focused content that facilitates concrete and purposeful discussions. Also, due to unpredictable situations that can be captured during the videoing process, future solutions should allow for the flexible and expanded duration of video segments. That said, based on the duration of the collected videos during our trial, therapists agreed that 1–2 minutes was sufficient to capture an interaction for review by a professional.

Finally, future technologies should also have a level of automation that will support the interpersonal relationship between parents and therapists. Solutions should be designed to automatically communicate the expected response time from therapists (e.g., based on their predefined working hours). This would avoid any challenging perceptions of the immediacy of interaction commonly expected in messaging applications.

6 LIMITATIONS

The exploratory nature of this study has led us to consider and acknowledge a few limitations and pointing to further investigation and future research. The focus of this paper is to understand the needs and challenges for parents who are caring for children with CP. While we would like to broaden the design considerations to parenting children with special needs more generally, we acknowledge that the insights are derived from this very specific

groups of mothers alone. Parent-led video coaching provides in-depth and contextualized understanding of the experiential aspects involved in caring for their child with CP, however, the small sample of mothers recruited, and their geographic collocation, mean they may not be representative of mothers in other family structural, geographical, cultural, economic and health systems contexts. In this study, the social-emotional support for mothers—especially for themselves on a personal level—can be explored further. The video capture element, despite our effort to minimize its impact on parents' daily activities, may have added load on the mothers, which prompt the consideration to multiply the purposes for the video capturing process by adding additional prompts for parents' self reflection. That is, the mothers can use these videos as materials to facilitate their collaboration with therapists, but also autonomously use this opportunity as a reflection point on their parenting with scaffolding prompts provided to them.

7 CONCLUSION

Our findings add substantially to the development an understanding of the issues surrounding parent-delivered therapy and parents' needs in terms of engagement, reassurance, and feedback about home therapy practices. We found real potential for developing less formal communication platforms, led by parents, to support them through their own social channels, not just for professional care service delivery. In parent-delivered therapy, the parents play both the coach's role with the professional and subsequently that of the coach for their child's other caregivers. Designing for co-operation and social support is crucial in different contexts for the direct coaching of patients [31, 43, 53] or caregiver coaching [24, 28, 33, 53]. Our study has several design implications for future video-based digital solutions, led by caregivers to support them in delivering home-based therapy programs. These include augmenting the current healthcare model and enhancing the communication with health professionals to better social support and sharing with their families and peer network. However, even when considering the genuine opportunities for such digitally augmented therapy regimes, we must also address the many barriers to incorporating coaching technologies in the current clinical practices and regulations of health care services.

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