

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

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ABSTRACT

Mothers of pre-school children with cerebral palsy are responsible for the delivery of multiple home therapy programs. Video coaching has been proposed to address the challenges of home therapy delivery, such as the lack of regular contact with professionals and need for continuity of support. Through interviews with seven mothers and four speech therapists we explored the challenges faced, and the views of both mothers and therapists as to the potential for asynchronous video support. Key issues included limitations of existing channels of communication between mothers and professionals, the mothers' social support needs, and level of commitment required to self-deliver home therapy. Based on these results, we conducted three workshops to investigate the feasibility of mobile video coaching to enhance professional support. We conclude with a number of design considerations for such technologies to improve communication and collaboration between professional therapists, mothers and their wider social network.

Author Keywords

Cerebral Palsy; Parents; Children; Coaching; Therapy.

ACM Classification Keywords

H.5.3 Group and Organization Interfaces.

INTRODUCTION

Cerebral Palsy (CP) is a permanent neurodevelopmental disorder which starts in early childhood and affects the child's development [31]. It is estimated that each year, 1,800 pre-school children are diagnosed with CP in UK [36]; up to 1,500 children in US [16]; and approximately 2 to 2.5 CP cases per 1000 births worldwide [8]. During the early stages of childhood, a child with CP can encounter developmental difficulties relating to their speech, feeding, mobility, behavior and learning. Subsequently, these early childhood difficulties can lead to a child's exclusion from social and educational activities. In response, the National Health Service (NHS) provides clinical interventions to support parents and promote the development skills of pre-school children with CP before entering school. Majnemer [23] has demonstrated the importance of early clinical

interventions in order to address developmental difficulties before delays manifest. Clinical services for pre-school children are primarily home-based, this helps in understanding the environment in which children are raised and to establish the importance of the parents' role in their development. The parents' role is fundamental at the pre-school age as the home is the first learning environment for the child and they need to respond to the child and promote these skills on a daily basis [23].

One of the most common developmental delays encountered relates to speech and language [34]. As such, speech and language therapists typically support parents of pre-school children through early Speech and Language Therapy (SLT); also called *home programs, indirect-therapy or parent-delivered* therapy. In UK, the amount of therapy that families receive varies greatly, resulting in infrequent therapy visits [24]. A clinical investigation of parent-delivered therapy for occupational and physical therapy, revealed that parents were overwhelmed and struggled to properly deliver the practices [10,11]. While there have been a number of digital technologies proposed for older children with development delay [6,13,17,18], due to differences in the therapy approaches, it is unclear if these solutions would be suitable for pre-school children.

In this study we present the results of two phases of qualitative investigation with mothers of children with CP and speech and language therapists from the United Kingdom. The first phase was focused on understanding the context of parenting children with CP, their current social communication patterns along with the current home therapy practices. Our findings show several challenges facing mothers at home as the main caregiver and in adapting the home therapy programs. Also the results identify the different levels of support needed by the mothers along with the current communication practices.

The second phase aimed to explore the feasibility of digital solutions to support mothers in home programs. User-centered design methods were used to co-design a video coaching solution based on smartphones. Based on the results, a number of design considerations are discussed

that are relevant to the design of technologies to support these mothers and to improve the current health care model. We discuss the design implications with the aim to provide the basis for designing digital technology supporting mothers of children with CP, which could be relevant for other solutions designed to support mothers of children with special needs.

BACKGROUND AND RELATED WORK

We sample related work from both the fields of healthcare and human-computer interaction. Specifically, we draw on the works exploring early speech and language therapy practices and digital technologies to support child development and communication.

Early Speech and Language Therapy

Children are considered to have speech and language delay if they do not meet particular age-related milestones; e.g. if they cannot combine words at two years old. Speech and language delay is classified as primary (if no other aetiologies are found) and secondary (if associated with other developmental problems or disorders; e.g. CP) [26]. In both cases, early SLT for pre-school children focuses more on working with the family to develop the communication skills essential to the child through playing, reading or talking [37]. Early clinical interventions have demonstrated their effectiveness in enhancing children's communication skills before beginning school [23,33]. The early SLT is indirect-therapy provided by trained parents or other caregivers instead of the therapist, which aims to develop the children's communication skills [28]. Hence, in order to apply this therapy, parents need to be trained for home practices of SLT. Parent training focuses on promoting communication in every interaction by recognizing communication signals, responding to them and developing new communication skills, that can maximize the potential impacts of the therapy [2,5,22].

Some children with CP have a neuro-motor disorders that affects their cognitive and communication development. This creates additional barriers to the delivery of SLT and speech development [12]. The communication speed, strength, range, and movement that is needed to provide the facial expression and gesture along with the speech can also be affected [28]. The neuro-motor disorder complicates the speech and language acquisition process and makes it longer compared to neuro-typical children. Moreover, it has been noted that less clinical attention is given to communication development of children with CP compared to the efforts dedicated to their motor development [12].

Mobile Technologies and Children's Development

A variety of digital technologies have been proposed to monitor typical children's development and support communication between the parents and pediatricians. Recognizing the importance of development tracking and giving feedback to pediatricians, Kientz et al. [19] explored digital technologies to electronically record developmental milestones and share them with pediatricians. Kientz et al.

proposed the use of either the personal records captured by the parents, or automatically tracking activities with wireless sensor-enabled toys.

Video-based record keeping solutions were also proposed for development tracking, including KidCam [17] and BabySteps [18]. KidCam was based on semi-mobile device that stores continuous recording for a limited duration [17]. This work demonstrated that families that had a history of developmental delay were more willing to use video and photo technologies for tracking. BabySteps explored the barriers to record keeping, which included parents' busyness, forgetfulness and unwillingness to share information with their pediatricians. To promote better record keeping by parents, they proposed to use online sharing, recording photos or videos, and integrating reminders [18]. A similar solution, Estrellita, has been used by parents of preterm infants [7]. In addition to record keeping, Estrellita also promoted better communication with the healthcare providers [6,35], and social interactions with peers, family members and friends [21]. Researchers noted that parent's awareness improved and the supportive feedback provided helped to promote their confidence. While parents benefited from Estrellita, the record keeping and data capture posed an additional burden on their existing responsibilities.

Digital Support for Children with Communication Difficulties

Digital technologies have been used to augment the rehabilitation therapy. One example is MagicLand, an interactive table-top to support play therapy for children with Attention Deficit Hyperactivity Disorder (ADHD) [29]. MagicLand promoted the child-therapist relationship, and showed that collaborative technologies can be used as a means for the child to communicate [30]. Moreover, Kientz et al. [20] have reported on the use of digital technologies to support children with autism, along with their caregiver. The study showed that digital solutions were beneficial for in-clinic session use and can help the therapists to make better treatment decisions, share data between therapists working with the child, as well as help children to communicate their needs through wearable sensors.

Keck et al. [14] discussed the importance of technology in the diagnosis and treatment of communication disorders; noting that therapists have been slow to utilize technologies to expand their services. The majority of telehealth practices start at school age; providing remote therapy between the patient and therapist through either mobile, Skype, or other proprietary systems [14]. Fernandes et al. [4] reported an increased use of mobile devices as Alternative and Augmentative Communication (AAC) devices; by running relevant applications. Also, therapists use mobile devices to collaborate with parents and set up therapy homework [4]. Furthermore, Talkbetter was real-time linguistic analysis system designed to help the parents to adapt the training guidelines at home [13].

ID	Age*	Age at Diagnosis *	Gender	Mother Employment	Partner Employment	No of Siblings
C01	35	25	M	Stay at home	FT job	3
C02	39	37	M	Business Owner	FT job	0
C03	24	18	F	Stay at home	NA (Separated)	0
C04	27	12	F	PT job	FT job	2
C05	13	12	M	Stay at home	NA (Separated)	1
C06	19	12	F	Stay at home	FT job	3
C07	28	6	M	PT job	FT job	0

Table 1. Profiles of children with CP and families - *ages are in months.

Talkbetter, would synchronously analyze their speech and provide guidelines accordingly. The study shows that parents were continuously engaged in using the system, however further investigation was needed to avoid faulty voice detection [13].

Most recently, existing digital solutions were largely focused on the child development tracking or utilizing technology within the SLT sessions or remote direct-therapy delivery. However, as noted above, early SLT programs depend heavily on the parents and support for home therapy practices has received relatively little attention compared to digital support for children receiving direct therapy at school age. Thus, the role of technology to support parents in the indirect-therapy practices, and their communication with health professionals and social networks still needs to be explored.

STUDY DESIGN

The aim of this study was to establish an understanding of the context, experience and needs surrounding current practices of parent-therapist communication and parent-delivered therapy for pre-school children with CP. To explore this space we recruited eight mothers of children with CP and four speech and language therapists through NHS Foundation Trusts (UK).

All of the mothers were experienced in home therapy programs with multidisciplinary professional teams when developmental delay is identified and before receiving specific diagnosis of CP. Unfortunately, one of the mothers had to dropout due to the demanding medical care responsibilities during the study period. Table 1 summarizes the demographic data of the remaining seven families. The therapists were domain experts in working with pre-school children with special needs; with up to 12 years of experience. Three of the therapists were practicing the indirect-therapy based on home visits, while one therapist worked with in-patients. The study was conducted in two phases, the first phase was focused on context exploration, and the second phase aimed at studying the feasibility of video coaching technology.

In the first phase, we aimed to explore the current practices and experiences surrounding motherhood of children with special needs and home therapy programs. This was achieved through semi-structured interviews and observations conducted individually with the mothers and therapists. All of the mothers were interviewed in their

homes, while the therapists were interviewed in campus offices. Interviews and observations lasted between 60 minutes (with therapists) and 90 minutes (with mothers). All interview sessions were audio recorded and transcribed. The interviews provided a deeper insight into the social support and communication practices of parent-therapists.

Additionally, at the end of the first phase, we explored this behavior further with the mothers and therapists, by introducing the concept of video coaching. We discussed a video coaching solution designed to remotely support the parents' communication with the other caregivers. Through their smartphones, parents would be able to share a video recording of the parent-child interaction annotated with their comments, and get the needed feedback from the therapist. Therapists would equally be able to annotate the recording with comments and engage in coaching discussions via their smartphone.

Moreover, we had noted that WhatsApp was used by many of the mothers for sharing updates about the child's development with their families. Thus, as re-appropriation of the current technology, WhatsApp was used to mimic the experience of video capturing and sharing between the mothers and a researcher. We conducted the WhatsApp pilot, as a preliminary stage for the second phase. The pilot lasted for one month and aimed to sensitize mothers to the experience of mobile video coaching. The mothers were provided with a smartphone, tripods and a bluetooth selfie-button to control the smartphone camera and share some video recordings of their interactions with their children.

In the second phase and after this sensitizing exercise using WhatsApp, we conducted two workshops with the mothers and one workshop with the therapists to reflect on the feasibility of video coaching (mothers only); explore their perception of coaching using predefined persona and scenarios; and co-design through paper prototyping and design mockups. All of the mothers were invited to participate in the workshops. However, three of the mothers did not attend due to unanticipated caregiving responsibilities. Therefore, two workshops were held with two mothers in each and one workshop with the four therapists. Each workshop lasted two hours, and were audio recorded and transcribed. The workshops helped us to establish a better understanding of the feasibility and acceptability of video coaching solution.

Design and Analysis

Qualitative analysis using thematic coding was conducted on the resulting interview, observation and workshop transcriptions [3]. In addition to the transcriptions, we also collected the media files (pictures and videos) that were shared by the mothers during the video coaching pilot and photographs taken during the home visits. Qualitative content analysis was applied to the media files, specifically focusing on the environment, mother-child reactions to the camera and the context of the captured media [25].

PHASE 1: CONTEXT EXPLORATION

Through interviews and observations we explored the mothers' and therapists' experiences of motherhood and the home therapy programs. The focus of the interviews with mothers was around their feelings on the daily caregiving routines and activities; their concerns relating to parent-delivered therapy, support and communication strategies with the various professionals; and their current social media and digital practices. Additionally, with their consent we observed the mothers at home; and received media (photos and videos) relating to the home therapy through a mobile messaging application. The interview sessions with the therapists focused on their current working routines and practices; the issues they experience with home programs; and a discussion on the type of support and communication strategies they use with other professionals and mothers.

The results revealed the main challenges of motherhood of children with special needs concerns surrounding the home programs, the established social support networks, and current communication and digital technology practices. Thus, the results show a need for communication and support to bridge the gap between the infrequent visits.

Motherhood and the Challenges of Disability

Adapting to a New Life Routine

The mothers all emphasized the fundamental change in their lives resulting from having a child with special needs. Most of the mothers discussed that the change is due to their commitment to multiple therapists' visits as well as the demanding daily care routine for children with CP. As one 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.*" [C01]. Thus, in order for the mothers to handle the child needs, some of them (n=5) changed their jobs; either to part-time, taking long leaves, or just quitting. Likewise, some of the mothers (n=3) said that they have less time for their other children and responsibilities.

In addition, all of the mothers described their experience of denial when they realized that there is a problem, followed by a period of hope resulting from the fact that doctors could not provide an exact diagnosis of CP until later in their development. Yet, four of the mothers perceived that they are stronger in accepting the reality compared to the other family members. Most of the mothers expressed that the demanding care routines and the process of waiting for

development helped them to cope. As one explained "*[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.*" [C07].

Do it Yourself

All of the mothers mentioned that they are the main carers of their children, and doing everything by themselves. Also, the mothers stated that their children are very dependent and demanding for physical and emotional support from them even during therapy visits. Most of the mothers felt they know their children attitudes, strengths and behaviors better than other carers and found this understanding is helpful for their collaboration with the therapists to promote their children development skills.

The mothers found themselves attending the therapy visits alone, learning all the time, and trying to make every activity with their child as an opportunity to support their development. Yet they expressed their need to engage other carers and used the child's achievements to encourage other family members to be involved. As one 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.*" [C01]. The therapists (n=3) also confirmed the importance of the parents' role with pre-school children, to promote their independence and improve the whole learning environment for the children.

Learning and Self-Discovery

Most of the mothers showed their eagerness to learn and explore new techniques to support their children's development. Some of them were exploring online resource (n=4) or consulting specialized family members (n=2) to learn more about CP, alternative solutions used by similar families, or suitable mobile applications for their children. Also, some of the mothers (n=3) invented techniques to support their children's development based on the child's interest; e.g. using online videos or Siri application as a playful communication tools. Additionally, other mothers (n=2) developed their own solutions to support their child's independence; e.g. transformed a wooden tray with wheels to a movement tray to support the child's mobility at home. However, some of the mothers (n=2) expressed their fear of exploring online resources due to amount of discouraging information available on their child's diagnosis, yet they were still eager to learn from specific resources when recommended by others.

Uncertainty and Fear of the Future

Different children with CP grew with different developmental delays. The mothers were aware that their children would have developmental difficulties from birth, but that the specific diagnosis would be ascertained only as the child developed. Thus, some of the mothers (n=4) reported the difficulty of waiting for the diagnosis, as one said "*I was always wanting to know what I am dealing with, what I need to do, what I do not need to do.*" [C03].

Additionally, there was an observed variation in the professional support received by each of the mothers and some of the mothers expressed their uncertainty about the available services for children with CP at each stage.

The therapists expressed the challenge of communicating the developmental expectations to the mothers due to their awareness level or high expectations. Thus, the therapists expressed the need for interpersonal skills to understand the parents' and to be realistic in communicating information at the right time. Yet, both mothers (n=5) and therapists (n=4) expressed their focus on the short-term goals to discuss expectation and progress. As one of the therapists said "*I often get out the building blocks of communication and kind of visually talk through this is what we are doing and this is what we need to do to get there, because often they will say: Oh, when do you think they will talk?*" [T02].

Delivering the Parent-Delivered Therapy

Seeing the Big Picture

Due to various developmental delays faced by children with CP, their professional team consists of a number of specialists including occupational health, physiotherapist, and speech therapists. While all of the mothers acknowledged their appreciation of the vast range of information and expertise that was on hand, they equally remarked on the challenges of working with a large team of professionals; specifically the sheer number of therapy activities to do with their child. The mothers were able to establish an overview of the care goals and recognized 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, some of the mothers (n=6) found it difficult and overwhelming to maintain a big picture view of the goals while also being the main carer for the child.

The mothers discussed the challenge of prioritizing practices and addressing each of the child's development issues. This can sometimes mean making tough decisions to progress in one area, at the expense of another. The therapists share in this struggle. As one of the therapists explained they try in each visit to balance their discussions between multiple developmental aspects including feeding, communication and education. The result is to lead the mothers (n=4) to report the visit sessions as hectic, forcing them to rely on other professionals or social groups to seek answers to their questions that otherwise would have been for the therapists.

Visit Frequency and Child Wellbeing

In addition to regular home visits by the therapists, the mothers (n=6) emphasized the need for ongoing phone contact between visits; and the definition of good routines with their children to involve them in as much therapy as possible. However, from the mothers' perspective there are several challenges to establishing this support system. The primary one is the difficulty of having no fixed schedule, as

visits are organized based on the child's progress, parents' learning style, and needs.

Furthermore, there was a controversial discussion around the frequency of visits; with most of the mothers (n=4) insisting they needed more frequent visits from the therapists. Citing that, the long interval between visits meant they often forgot the practices; started having concerns about their progress; and felt the need for reassurance. Moreover, they noted that therapists visiting more frequently had a better understanding of the child's health situation. The desire for more contact was interpreted by all therapists as, "*people thinking that more speech therapy is going to make everything better.*" [T01]. The therapists stressed the importance of the parents' role for delivering the home therapy at pre-school age to promote the child skills; since parents need to be practicing continuously and responding to their children cues all the time. As one said, "*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, that kind of thing.*" [T02].

The challenge of visit frequency is made worse due to the organizational constraints on the therapists; they have predefined working hours in which they can arrange visits according to their geographical location. Therapists often find themselves rushing between places with strict time allocations per visit - this, combined with the reality of working with children, who experience health issues, moods or tiredness during visits; can make it extremely difficult to complete everything within the allotted visit time.

The mothers and therapists discussed how mothers sometimes video recorded some of their interactions with their children and showed them to the therapists during the visits as an evidence of achievements, or to consult a therapist around the struggles they are facing in interacting with their children. Therapists (n=3) found these videos useful, as it led to more discussions around practices and it helped them to reflect and assess the child's wellbeing.

Commitment vs. Forgetfulness

Prior to the first home visit, there was considerable ambiguity in the mothers' minds regarding the role of the therapists; levels of support services; and the expected therapy impact. For the therapists, the first visit is exploratory, the first opportunity for them to learn about the family and their needs; and most importantly to set expectations and establish the flexible support plan.

Recognizing that each family is unique, the therapists adapt their approaches based on the child, environment, and the mothers' learning style; while practices remaining based in play activities and involving demonstration, explanation and coaching. In addition to supporting the child's development, the training sessions are designed to promote

the parents' confidence, help them identify the priorities, and up-skill them to the point where they only require monitoring from the therapist. This confidence was recognized in some of the mothers, who explained they use the learned knowledge during the visits and tailor the strategies to better suit them. However, to learn these skills the mothers must be persistent in the practices and overcome the challenges of the child's mood, wellbeing, and other life responsibilities. Due to these demanding responsibilities, most of the mothers struggled with forgetfulness; finding themselves forgetting some of the practices they should be doing, and scheduling overlapping appointments with therapists. Some of the therapists (n=3) suggested the forgetfulness was made worse by the lack of other forms of communication, with most information being communicated verbally to the mothers.

Lack of Progress and Frustration

While all of the mothers said that they enjoy doing the 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 can lead to a lack of progress in the child's development, further adding to the frustration. The large investment of time spent doing the practices and the lack of progress causes a number of mothers (n=2) to lose their enthusiasm, yet others (n=3) are able to remain motivated; regardless of noticing progress. Some mothers (n=2) went on to suggest that the progress is sometimes invisible to them because they see the child constantly. From the other side, all therapists confirmed that development progress will plateau and they try to encourage the mothers by having them reflect on their earlier achievements and goals verbally defined earlier. Therapists plan for small steps towards meeting outcomes, and are careful to manage the parents' expectations of progress and avoid frustration.

Social Support and Communication Practices

Family Support

Families played a central role in supporting the mothers in several ways; including support from the child's father, siblings or extended family members. Emotional support often came from the partner or grandmother. Also, the majority of the mothers (n=6) received physical support from their families; looking after the child and being involved in the therapy practices. As one 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."* [C03]. Other mothers (n=2) discussed support for the practices through exchanging conversational videos with other family's kids to promote the child communication skills. Some of the mothers (n=2) had family members with a specialized medical knowledge who were able to give medical advices, additional information or reassurance.

Most of the mothers (n=5) confirmed the limited support received from their partners due to their long working

hours. Some of the mothers (n=4) discussed the difficulties arising from their families' involvement, which include the child's preference for the mother, difficulty in sharing practices updates, rare joint visit with family members, and busyness with work and life commitments. In addition, different sharing practices were noticed within-families for several reasons; that include sharing to teach other family members about the practices (n=5), sharing the child's achievements and looking for mother/child encouragement (n=3), sharing the medical updates (n=3), and sharing and looking for reassurance (n=2). Some of the mothers (n=4) expressed the difficulty in sharing their feelings and development expectations, as one said *"So 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."* [C04].

Peer Support

Some therapists (n=3) and mothers (n=4) confirmed the importance of peer emotional support from the families of children with CP. As one of the mothers said *"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 that is happening for you alone."* [C07]. Some of the mothers (n=2) found it a relief to talk to similar families, as they know exactly what they are going through. In addition, there are different kinds of sharing between peers; which includes sharing experiences around diagnosis, therapy, therapists, services, and medications.

The mothers found it easy to meet peer families through social and therapy playgroups arranged by therapists or other communities. Some of the mothers (n=2) discussed how this communication is extended outside the social groups boundaries either through text messages or Facebook messenger. However, mothers and therapists said that there are some barriers for peer families' communication; which includes stress from hearing other stories (n=2), and comparison between their children and others (n=5).

Professionals Support

Mothers of pre-school children with CP have several contacts with different professionals to track their child's health condition and development progress; these include pediatricians, dieticians, health visitor, speech and language therapists, occupational health, physiotherapists, and early education program staffs (known as portage). Home therapy support starts with referral and extends school age. Similar visits at nursery and community centers are carried out when needed to train the other carers. Mothers also discussed receiving different paper-based guidelines about the practices, as well as equipment and toys for children with special needs to find the suitable support for the child's development.

Different sharing practices between the professionals have been identified, including the multidisciplinary team meeting. Some of the mothers (n=2) mentioned that these

meetings are arranged according to need and suffer from poor attendance by the professionals. Some of the therapists (n=3) said that they were making joint visits with other therapists. Therapists (n=2) mentioned that parents find these meetings and visits helpful especially to avoid needing to repeat a story to each professional in turn. Additionally, therapists collaborate with the more regular services providers like portage to indirectly support the parents outside the home visits. Therapists also reported that professionals sharing practices helped them to discuss the family and child needs, provide feedback to other professionals, integrate therapy plans and shared goals.

In addition to therapy delivery, therapists (n=3) found that mothers use these visits as stress relief for themselves and allow them to share their emotions, concerns, seek advice for support services, or discuss their personal issues. Some therapists (n=3) found these discussions helped them to understand the parents better and provide better services. However, some of the mothers (n=3) mentioned the challenge of visit arrangements, as one said *“My speech and language therapist worked the same days that I did, so we had a bit of difficulty trying to get appointments in.”* [C07]. Mothers and therapists discussed limitations in the professional support available, due to the limited time and the large clinical caseload.

All the mothers have contacted the therapists through phone calls or email, as one 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.”* [C04]. Yet, another mother discussed the use of a formal sharing system by the nursery to share reports and media about the children developmental progress.

Digital Technology: Sharing and Privacy Concerns

Several mobile applications were used by the mothers to communicate with the family members, and share texts, pictures or videos captured using smartphones. The majority of the mothers confirmed their use of group conversations on WhatsApp (n=6), or private accounts on Facebook or Path (n=4) with family and close friends. Several reasons were mentioned for sharing; which include sharing of joyful moments, achievements, concerns, assessment updates, training other family members, or confirming speech intelligibility. As one of the mothers said *“There was a little puppet of an owl, and she 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 say: Can you guess what she’s saying?. Without the owl being in it, and they guessed it right and I was like, Yes!”* [C04].

All mothers agreed that these sharing channels helped them avoid repeating updates to everyone, especially for tough news. However, most of the mothers stressed that sharing is limited to their family and very close friends; due to their concern about the privacy on social media applications (n=5) or their children’s preference in future about online

presence (n=2). For this reason they found WhatsApp was more trusted for sharing personal information.

In contrast, the communication channels used to share with professionals between their visits were only by phone calls, email/mail when acceptable, or communication through other professionals. Therapists confirmed that other media are excluded from use due to the strict NHS Information Governance rules relevant to patient information confidentiality. Yet, some of the therapists (n=2) confirmed the importance of having an open communication line with mothers for ongoing support especially in this sensitive stage where the time matters.

PHASE 2: FEASIBILITY OF VIDEO COACHING

Building on the needed support for parent-delivered therapy, existing social media behaviors of the mothers, as well as the positive response to the WhatsApp pilot study, we explored the feasibility of video coaching technologies through design workshops with mothers and therapists. Mothers’ workshops started by reflecting on their experience about the WhatsApp trial and discussing the unpredictable practices, including reaction to the camera, technicality of video capturing and sharing, equipment used, and integration in their daily routine. Persona and video coaching scenarios were presented and discussed with therapists and parents in order to gain an insight about coaching understanding and perceptions. All workshops concluded with a co-designing activity using the design mockups and paper prototypes to design a video coaching technology to support their needs.

We found that mothers and therapists had a shared understanding of the coaching concepts, and the challenges surrounding its integration into their daily routines. Moreover, we identified clear benefits and challenges of integrating the video coaching intervention in the current healthcare model.

What is Coaching?

Most of the mothers and therapists reported that mothers were seeking confirmation of strategy understanding, guidance, feedback, encouragement, reassurance of the practice’s correctness, and extending advice about the next goals. As a response to these needs, all agreed that the professionals try to promote the mothers’ confidence through discussion rather than instructing. Therapists and mothers had similar views on coaching approaches adapted in the indirect-therapy. They described coaching as two-way personalized and responsive communication that moves from awareness to implementation of strategies in their daily activities, as they said *“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.”* [T01].

Coaching techniques were found to be helpful to manage parents’ expectation, and to understand the stages needed to

achieve their goals. Additionally, therapists noted that coaching is also about reinforcement and reiteration of advice as a way of encouragement and confirmation of the practice's effectiveness. Mothers found guidance was provided in a way that was not intimidating, easy to cope with, encouraging and builds their confidence in order to point them towards the skills they already have. Learning from watching was discussed by the mothers as better way for learning. As a result, mothers found coaching helped them to explore different ways to approach problem by themselves and thus allowing them to own the ideas and giving them freedom to apply it.

Practicality of Video Coaching

Mothers confirmed that smartphones are part of their daily life, were already engaging with some of the video coaching practices, as one said *"I am constantly taking photos of him and videos [...] It is just what I am already doing. It is maybe just doing it with more of a purpose."* [C07]. The mothers also found it helpful to use the tripods and selfie-button in order to freely play and focus on interacting with their child. Yet, the mothers reported the challenge of getting the right camera angle to capture both of the mother and the child; especially in the first try.

Additionally, the mothers found it easy to share videos through WhatsApp, yet they reported a need to trim the duration of the videos before sharing, to focus the content of the video or delete the distraction from the other children. During the trial, the mothers shared several recordings ranging from one to four videos per mother; these videos typically centered on the child either alone or playing with the father, mother, siblings and/or other relatives. Mothers created these recordings during feeding, exercising or typical playtime. Also, the mothers reported being less anxious about the location of recording, as they discussed that they were more focused on getting a good quality recording than concerning about the location.

Therapists emphasized the importance of context and mother-child presence in the video recording for analysis. The mothers reported that there was no negative reaction from their children during recording, since they mostly would not notice the camera. When one daughter did notice the camera, she begins shying away then posing for the camera. The mothers expressed that they were more focused on the child and forgot about themselves regardless their anxiety in the first trials; except for one of the mothers that was very distracted by the camera.

Various recording opportunities were identified based on the mother-child time for playful practices, which varied according to mothers' responsibilities and working hours. While the mothers were able to fit video coaching into their daily routines, they expressed their need for reminders and prompts. Therapists suggested that having the video coaching as part of a therapy approach will simplify the integration into their work routine; by setting a weekly slot for video reviews and communicate the scheduled review

times to the parents. This would reduce the expectation for immediate responses to parent queries. Therapists also show their preference for asynchronous interaction, since it is logistically hard to manage the review time directly in line with the parents' availability.

Perceptions of Video Coaching

Parents reported that video coaching would be beneficial for providing ongoing support and feedback between and during the visits. Therapists said that they are very contactable between the home visit as that is considered this contact part of their jobs. Additionally, therapists confirmed that the video coaching would be useful to provide a channel for monitoring the mother-child activities and scheduling of additional visits when needed.

Moreover, further support through group conversations with the multidisciplinary team was found to be helpful to maintain a holistic view of the child's development. The therapists and mothers found video coaching useful for recording advices, which would possibly result into better understanding and application of the strategies. Also, all agreed that reviewing videos is helpful to refer to previous progress for encouragement when the child's progress plateaued, as well as for self-reflection. As one 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."* [C01]. Additionally, therapists and mothers emphasized the benefit of having a video focused on specific interaction to establish a visual and concrete discussion, rather than relying on verbal communication alone. Likewise, therapists expressed that videos would provide a realistic example for better understanding of the context of the interaction and planning suitable coaching strategies. Also, all liked the use of video coaching during visits to reflect and reinforce skills as well as share new strategies with other carers.

Challenges for Video Coaching

Therapists reinforced that video coaching is a support to home visits but not a replacement. Also, therapists and mothers agreed about the current lack of visual resources to introduce new strategies. All agreed that it would take time for the mothers to be comfortable about recording and capturing their videos without distracting the children. Some of the therapists expressed the challenge of false interactions due to the possible child's awareness of the camera or parents' self-consciousness around filming. Furthermore, therapists suggested that written comments lack non-verbal communication, which is needed to ensure the parents understanding and explore their feelings before responding. Moreover, text based conversations can result in miscommunication, which might result from the perceived tone of a message or issues of literacy level.

Finally, therapists discussed the organizational challenges of integrating into the NHS systems, which include the equipment cost and the organizational polices. Therapists

explained that Information Governance Polices of the NHS restrict their use of any digital technology due to privacy and patient confidentiality concerns. However, these constraints applied to sharing but not to using parents' personal devices during the visits.

DISCUSSION AND DESIGN CONSIDERATIONS

Previous studies of home programs [10,11] demonstrate improvement in therapy outcomes where mothers can integrate therapy programs into their daily routines (e.g. play time). Yet, these studies also found that mothers were unaware of their embedded practices, and their concerns about lack of time and the effectiveness home therapy, impacted on their engagement in home programs. By contrast, our study points to higher levels of mothers' awareness and stronger engagement with the parent-delivered programs. The mothers strived to improve the therapy outcomes and, with therapist support, innovatively incorporated the multiple learned strategies from different therapists into their daily play routine. However the infrequency of therapist visits was a significant challenge.

Additionally, prior studies discussed that home visits were based on prescribing therapy programs and suggested assisting the mothers in the strategies' implementation rather than teaching [10,11]. However, our study indicates that the therapists are adapting the coaching principles for delivering the home programs and embed the therapy practices in their child's daily routine. Coaching principles involve guiding the individuals to increase the competence, commitment and confidence; and facilitate the achievement of their goals [1,27]. Rush et al. [32] described that observation, reflection and assessment are part of the coaching process; where our study shows that mothers' and therapists' are adapting these principles and stages in their home programs.

Moreover, 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, and our design recommendations point to the associated values, capabilities and challenges.

Pledge to Empower and Support

Changes in how home therapy programs have been delivered have resulted in greater levels of engagement on the part of mothers. However, the irregularity of visits still leads to a perception of a lack of support. Coaching continuity was recognized as a fundamental factor for achieving coaching goals [1,27,32] and our findings indicate that mothers need more support rather than more therapy. 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 finding confirmed the importance of physical visits for introducing new strategies and critical matters discussion, but also revealed the need for remote support during the long intervals between visits for

coaching elements, including: reassurance, encouragement, promoting confident and commitment, reinforcement and reiteration. The acceptance of telepractice in school settings has previously been demonstrated by Hines et al. [9], and our findings point to the potential value of extending this to include pre-school programs. We identified the need for a remote communication platform that would scaffold the existing relational model through collaboration and partnership with therapists. Subsequently, empowered mothers can recognize their expertise, helping to surpass their challenges of raising a child with special needs.

We identified a clear need and desire to share visual media that conveys mothers' concerns, for example, through video sharing and communication solutions. Video-based records can support discussion between therapists and the mothers based on individualized context-based interaction. Such videos of mother-child interaction would leverage the therapists' understanding of the real context and interactions patterns that cannot be achieved during a home visit because of time constraints. Videos can allow observation of parents' behaviors and be used as a basis for more personalized coaching techniques and plans. Moreover, the ongoing support would facilitate the need to focus on short-term goals and progressively extending to the next goals through the video-centered discussions, as well as opening up new opportunities for therapists to monitor the progress between the home visits and coordinate additional visits when needed.

In addition to ongoing support between visits, the video element of the coaching system can support interaction within the visits. Videos and photos have been identified as useful tools that people can reflect on their practices [15]. Furthermore, in addition to the value of video to mothers seeking to reproduce learned strategies (rather than relying on paper-based guidelines), therapists can create short segments of videos where each segment focused on specific actions noticed in the mother-child interaction. Hence, the short videos have the potential to scaffold reflection both between and during home visits.

Enabling Self-Management and Full Control

In our study, mothers expressed the importance of self-reflection and self-discovery through the use of videos of mother-child interaction, and found the experience of self-review particularly useful in identifying their children's skills and progress. Thus, technology must support the collection of videos in a way that allow parents to self-observe and self-correct through examination, reflection, and discussion of these videos. Systems should enable the parents to employ self-coaching strategies, which have the added benefit of raising self-esteem. The self-collected video can therefore serve as both an evidence-based (for achievements or concerns) but also scaffolds professional discussion when a child's progress is not readily apparent to parent (as a result of their proximity and the slow nature of development).

Our study also identified the different communication practices with professionals and family members using different digital applications. The mothers looked for support from professionals or shared their experiences with their family members to engage them in the therapeutic practices. Mothers also played the roles of many different therapists and sought confirmation their integration of the different roles with the corresponding therapists. Therefore, technology designed to support mothers needs to integrate their different communication practice in one tool through either individual or group conversations. Group conversation would allow more informal discussions with a child's multidisciplinary team, address the challenge of arranging and conducting physical meetings, but also, provide opportunities for the mothers to engage other relatives and easily share updates.

On the other hand, the mothers' concerns about the privacy of the shared personal information pointed to the need for them to have full control of these communication channels. Conversation management mechanism must allow only mothers to have control over who can see and contribute without giving contributors any ability to export any information beyond the system. Notably, therapists already delegate these responsibilities to the mothers due to legal and professional constraints on information sharing.

Embedded and Limiting Stress

Mothers expressed their motivation to gain the needed support through the remote coaching technologies. Yet, this interest should not interfere with challenges of adapting technology in their demanding care routines. Our study confirmed previous accounts [10,11] of the overwhelming nature of caregiving and therapy management of children with CP. Any addition or augmentations of existing therapies must be wary of introducing additional burden. In this respect coaching based on parent-collected video has the advantage that smartphones are already a tool of everyday life for mothers. Further, we can build on existing practices (videoing) and support the mothers by using familiar and standardized (familiar) interfaces both for video capture and associated messaging.

More specifically, our study indicated that children with CP demand high levels of physical support and attention, which makes the creation video content, while maintaining their position and engagement with their child, particularly challenging. Therefore, video-based solutions should allow on demand retrospective video recording from a buffered video content using a selfie-button for example. These recording solutions should "feel" like videoing and integrate non-disruptive recoding alerts to minimize demands on mothers and enable focused content that facilitates concrete and purposeful discussions. Also, due to the unpredictable situations that are captured the videoing element should allow for flexible and expanded duration of video segments. Furthermore, technology should have a level of automation to support both mothers and therapists.

Thus, these solutions should be designed to automatically communicate the expected therapists response time to avoid the challenge of immediacy of interaction found in messaging applications. Also, to easily support mothers of children with CP the system should include prompts for video capturing and reminders.

Following, Kientz et al's findings that record keeping and tracking cause stress for the parents of young children [18], coaching technologies should allow tracking of achievements based on the video shared by both of the therapists and mothers without boosting stress. Thus, video records, and associated communications must focus on supporting parents to reflect on their child's progress based on the previous videos and to understand their child development without introducing a competitive burden. In this respect parent-collected video records are particularly appropriate.

CONCLUSION

Our findings add substantially to our understanding of the issues surrounding the parent-delivered therapy and the mothers' communication needs in terms of engagement, reassurance, and feedback about home practices. We found that there is a real potential for developing less formal communication platforms to support the mothers through their social channels and not just for care service delivery. The study also identifies a number of design implications for future digital solutions to support mothers of pre-school children with special needs, from 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 taking account of the genuine opportunities for such digitally augmented therapy regimes, we also need to address the many barriers to incorporating coaching technologies in the current National Health Service (UK) clinical practices and regulations.

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