

https://dspace.org/

Tremendous burdens often unveil enormous gifts The experiences of South African caregivers implementing speech and language teletherapy for children with cerebral palsy during Covid19

Gabriela Evangelou; Skye Adams

https://hdl.handle.net/10539/40354
SCOPUS

Downloaded from a DSpace repository. https://dspace.org/

Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach Throughout the Lifespan xx (2023) x–xx
DOI:10.3233/PRM-220118
IOS Press

Research Report

"*Tremendous burdens often unveil enormous gifts*": The experiences of South African caregivers implementing speech and language teletherapy for children with cerebral palsy during COVID-19

Gabriela Evangelou and Skye Nandi Adams*
Department of Speech Pathology and Audiology, School of Human and Community Development, University of the Witwatersrand, Johannesburg, South Africa

Received 7 November 2022
Accepted 20 September 2023

CORRECTED PROOF

Abstract.
PURPOSE: In accordance with South Africa's restrictions to mitigate the spread of COVID-19, some speech-language pathologists (SLPs) attempted to engage in novice teletherapy regimes to ensure continuity of care for children with cerebral palsy (CP). This study aimed to explore the experiences of caregivers of children with CP implementing SLP teletherapy during COVID-19 in South Africa. The goal was to shed light on how these families can be better supported and how teletherapy practices can be adjusted for this population.
METHODS: This study employed a qualitative phenomenological research design using in-person and virtual semi-structured interviews with 18 purposively sampled participants with children with CP who received speech and language teletherapy during COVID-19. The data was evaluated using an inductive thematic analysis approach whereby themes elicited from the caregivers' narratives were analyzed.
RESULTS: Interviews ($n = 18$) unveiled the significant understanding caregivers gained by becoming integral and active stakeholders in the provision of teletherapy. Caregivers were able to meaningfully communicate and bond with their children with CP. However, caregivers also assumed the burden that teletherapy placed on them, as they had to renegotiate their role during the pandemic in order to provide routine teletherapy.
CONCLUSION: Findings indicated the need for person-centered SLP teletherapy interventions that utilize contextually and culturally responsive techniques and resources.

Keywords: Cerebral palsy, caregiver, COVID-19, teletherapy, south africa

*Corresponding author: Skye Nandi Adams, Department of Speech Pathology and Audiology, School of Human and Community Development, University of Witwatersrand, 1 Jan Smuts Avenue, Johannesburg, 2193, South Africa, Tel.: +11 717 4484; E-mail: skye.adams@wits.ac.za.

ISSN 1874-5393/$35.00 © 2023 – IOS Press. All rights reserved.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic exacerbated health inequalities for people around the world and increased the divide for persons already experiencing challenges, such as at-risk populations including persons with disabilities and complex communication needs, such as those with cerebral palsy (CP) [1–3]. Children with CP experienced challenges in accessing healthcare and therapeutic services, such as speech-language pathology (SLP) services, due to their vulnerabilities regarding preexisting comorbidities such as respiratory impairments and the presence of recurrent respiratory infections. This population is predisposed to respiratory challenges due to the movement and functioning of their diaphragmatic muscles that are critical for breathing, coughing, and sneezing. Research has proposed that these respiratory impairments may increase risk of complications from COVID-19 [4]. In addition, children with CP also present with motor limitations, making it difficult to travel, especially via public transport [5, 6]. During COVID-19, there was a dramatic decrease in the number of children with CP attending routine outpatient intervention services, as elective therapy appointments were cancelled or postponed during the lockdown period [7, 8]. Lack of access to care has the potential to cause significant health problems for children with CP, including increases in mental health symptoms such as anger and confusion, worsening of physical functioning and mobility such as contractures, stiffening, and tightness, as well as social problems [9]. Therefore, the implementation of teletherapy was dramatically accelerated in order to continue intervention for these children while adhering to the lockdown-imposed restrictions. However, the transition to virtual platforms as a form of management for health care professionals, specifically SLP management, was sudden and unplanned, as face-to-face therapy was the dominant method of service delivery in the South African context, and little was known about the impact teletherapy had on children with CP and their caregivers.

Previous studies have highlighted the importance of teletherapy as a possible solution for children with CP who are unable to receive direct intervention from health care professionals [7, 10]. Teletherapy allows for the provision of health care services through a form of virtual telecommunication, which permitted the continuity of health care amid the COVID-19 pandemic [11, 12]. Teletherapy can be provided synchronously, involving live streaming or video calls (e.g., Zoom, WhatsApp), or asynchronously, such as through home programs, emails or messages. In the current study, both synchronous and asynchronous approaches were explored due to the variable technological access of the participants and to better understand teletherapy in a South African context. Furthermore, SLPs implemented different forms of teletherapy based on the caregivers' access to technological services as well as their own abilities to provide different synchronous and asynchronous forms of teletherapy.

Prior to the COVID-19 pandemic, evidence of the implementation of teletherapy was not widespread or common, with only a small subset of SLPs having previously and regularly engaged with this manner of therapy [13]. SLPs address the speech, language, and feeding and swallowing difficulties present in many children with CP [14]. Earlier studies have suggested that a significant number of SLPs have a preference for conducting therapy sessions in person. However, due to the pandemic, there was an abrupt change in therapy methods, and this sudden shift to teletherapy precluded children, caregivers, and therapists from adapting or preparing for its implementation in their own time [15]. Despite this, research has also highlighted several advantages of using teletherapy for interventions, including improved accessibility to services and greater flexibility of when and where therapy can take place. A study conducted by Fairweather et al. explored the effectiveness and feasibility of a speech-language teletherapy program delivered to children in rural Australia [8]. Participating children demonstrated significant improvements throughout the intervention period, and the caregivers appreciated the convenience of this option in a remote region where access to SLPs was scarce. In another study, conducted by Pennington et al., parents and children with CP in the United Kingdom reported that an integral benefit of teletherapy delivery was the fact that it occurred in the home environment, which reduced travel time as well as stressful emotions associated with attending in-person therapy [14]. Although teletherapy during COVID-19 allowed for children to continue with SLP interventions, the shift may also have had a negative impact on them and their caregivers, particularly those living in low-middle income countries such as South Africa.

The COVID-19 pandemic was further challenging and overwhelming for caregivers of children with

CORRECTED PROOF

CP as South Africa's lockdown resulted in hindered access and absence of routine contact services due to travel and social distancing restrictions [16]. In South Africa, SLP services were deemed non-essential, and SLPs were required to devise alternative methods of providing therapy, with one such avenue being teletherapy [17]. In addition, the distribution of teletherapy services in South Africa was already limited prior to the pandemic. Unfortunately, South Africa does not have all of the appropriate infrastructure and support required to implement teletherapy, which is made further challenging by the realities of frequent load shedding (planned power outages), low technological literacy levels, financial instability, and limited access to resources [18]. There is also a paucity of knowledge of the implementation and impact of teletherapy in South Africa for children with CP. Given this, the purpose of this study was therefore to explore the unique experiences of South African caregivers implementing teletherapy, in order to provide insight into the current as well as future implications of teletherapy implementation and service provision during and after the COVID-19 pandemic.

2. Methods

This study was approved by the University of the Witwatersrand Human Research Ethics Committee (HREC Non-Medical; Approval Number: STA 2021). A qualitative phenomenological research design was conducted through semi-structured interviews, which allowed for the holistic and authentic acquisition of participant responses to address the aims of the study. Research was carried out from April–October 2021.

2.1. Participant recruitment

The researcher approached a total of 15 CP organizations and three Facebook support groups for families of children with CP in the Gauteng, KwaZulu-Natal, Western Cape, and Eastern Cape provinces of South Africa. Responses were received from five organizations, as well as from two individual participants from one Facebook support group. The low response rate can be attributed to the then-ongoing COVID-19 pandemic, which resulted in many sites either being closed or not fully functional as a result of governmental lockdown restrictions. After the sites showing interest in the study were identified, they were provided with organizational permission letters and participant information sheets. The management team at each site then distributed these materials to eligible caregivers. Subsequently, the caregivers were invited to participate in the study and were encouraged to reach out to the researchers if they were willing to take part.

Participants were purposively sampled using the following inclusion criteria: participants [1] were the primary caregivers of a child with CP within the age range of 1–13 years old, [2] were primarily engaged with their child in speech and language teletherapy or home programs in South Africa during the COVID-19 pandemic, and [3] had access to an electronic device for potential virtual interviews. Twenty participants were initially recruited to participate. However, two participants withdrew from the study; one mentioned they did not have time to participate, and the other participant's child passed away. Therefore, 18 participants were ultimately included in the study.

2.2. Procedure

All participants were asked to complete a demographic questionnaire. An interview guide consisting of open-ended questions and probes was used. The interview guide was developed to encourage caregivers' perspectives on the implementation of teletherapy, challenges/benefits/considerations, and the additional supports they may require when implementing teletherapy. The interview guide allowed for flexibility, enabling participants to develop ideas and speak freely about their perspectives and experiences. The questionnaire and interview guide were tested on two mothers. Following the pilot study interviews, no changes were made.

Semi-structured interviews were conducted virtually on Zoom/WhatsApp ($n = 11$) or face-to-face ($n = 7$). Caregivers that chose face-to-face interviews were accommodated, COVID-19 protocols were followed, and an appropriate meeting time was set up. Caregivers were interviewed between one and three times. Additional interviews were done for two participants who needed more time to go through all of the interview questions. All interviews lasted approximately one hour (range: 22–48 minutes). Each interview was audio recorded, followed by verbatim transcription. All study participants provided informed consent and were informed of their right to withdraw from the study at any time. All personal information, such as names, was omitted from the

CORRECTED PROOF

transcripts to foreground the premise of anonymity and confidentiality.

2.3. Data analysis

All transcripts were imported into the computer program NVivo for coding and analyzing the text content. Data were analyzed using inductive thematic analysis procedures, as outlined by Braun and Clarke [19]. Firstly, the two researchers (GE and SNA) established the initial coding framework, identifying relevant information pertaining to teletherapy experiences across interviews. The coding framework allowed the researchers to systematically categorize and code the interview transcripts and to ensure rigor and quality of the analytical process [20, 21]. The researchers together reviewed the coding framework using the interview data. Each researcher confirmed the consistency of the individual codes in line with the interview data to check for coherence. After revisions, a final coding framework was applied to the interviews. The codes were then reviewed independently by the two researchers to establish intercoder agreement. Any disagreements were resolved through consultation. Line-by-line coding was done for each interview using an interpretive phenomenological approach, which highlights that each interview needs to be analyzed before moving onto the next. Both researchers reviewed codes across all interview data to identify and organize broader categories, as well as to generate emergent themes. An iterative process was used as the data were interpreted back and forth; also, reflective practices and meetings to discuss the coding and interpretation process were incorporated. Inductive thematic saturation was reached after analyzing all interviews.

Data trustworthiness was ensured by using data immersion, field notes, peer debriefing, and reflexive practice. Both researchers (GE and SNA) are speech therapists working with children with CP and have implemented teletherapy and understand the processes involved in providing therapy using alternative means during COVID-19. However, they had not previously worked with the participants in the study and worked at different clinics to those that the participants usually attended. SNA had previous experience with qualitative research, and the two coders had different experiences and knowledge of CP and teletherapy, which meant that preconceived biases were easily identifiable using open discussions and peer debriefings.

3. Results

3.1. Participant characteristics

Participant characteristics are outlined below in Table 1. The participant sample consisted of 18 caregivers (mean [M] = 37.06 years, standard deviation [SD] = 4.33). The majority of the caregivers were mothers ($n = 12$). The study also included four employed caregivers, which refers to trained caregivers who were working at one of the residential care facilities for children with CP; these caregivers were each responsible for 3, 4 children and engaged in all activities of daily living with them, including the implementation of SLP teletherapy. In South Africa, many children with CP are placed in residential care facilities as their families are unable to care for them. As a result, the authors felt it was important to also include these caregivers in the sample and understand their experiences of implementing teletherapy.

Fourteen caregivers were employed at the time of the study (eight full-time, six part-time), indicating that the majority of participants had a source of income. However, it should be noted that the majority of the jobs the caregivers were engaged in were predominantly low-skilled occupations, such as domestic workers, school-kitchen cooks, and cashiers. In addition, 17 of the children acquired therapy from a government organization, with only one receiving private therapy. This context suggests that the majority were from lower socioeconomic backgrounds. However, no formal indicator was utilized in this study to establish this. Moreover, the study characteristics highlighted the existing gender and employment challenges for many mothers in South Africa, particularly during COVID-19 [5]. Children in the study were 4–13 years old. Eleven children had no specific CP classification, while three each had been diagnosed with spastic CP and mixed CP, and one with dyskinetic CP. The caregivers within the study were often unable to differentiate their child's type of CP. This is a notable challenge in the South African population due to the lack of appropriate assessments, access, and limited information from health care professionals made available to caregivers. The aforementioned challenges are further exacerbated by complicated medical terminology utilized by medical professionals, in the patients'/caregivers' non-proficient language. As a result, caregivers often do not understand the information shared and leave appointments confused about their child's condition [6].

CORRECTED PROOF

Table 1
Participant demographic information

Participant Number	Age	Gender	Relation	Residence	Location of Interview	Employment	Child's Age	CP Classification
P1	38	Female	Mother	Gauteng	Zoom	Part-time	4 years old	Mixed CP
P2	33	Female	Mother	KwaZulu-Natal	Zoom	Not seeking employment	7 years old	Spastic CP
P3	38	Female	Mother	Gauteng	In-person	Part-time	4 years old	Mixed CP
P4	36	Female	Mother	Gauteng	In-person	Part-time	13 years old	Unknown
P5	37	Female	Employed Caregiver	Gauteng	In-person	Full-time	12 years old	Unknown
P6	36	Female	Employed Caregiver	Gauteng	In-person	Full-time	7 years old	Unknown
P7	40	Female	Employed Caregiver	Gauteng	In-person	Full-time	13 years old	Unknown
P8	29	Female	Employed Caregiver	Gauteng	In-person	Full-time	12 years old	Unknown
P9	38	Female	Mother	Gauteng	WhatsApp	Part-time	9 years old	Spastic CP
P10	42	Male	Father	Gauteng	Zoom	Full-time	12 years old	Dyskinetic CP
P11	37	Female	Mother	Gauteng	WhatsApp	Part-time	9 years old	Unknown
P12	42	Male	Father	Gauteng	WhatsApp	Full-time	10 years old	Unknown
P13	28	Female	Mother	Gauteng	Zoom	Part-time	7 years old	Mixed CP
P14	32	Female	Mother	Gauteng	WhatsApp	Unemployed	9 years old	Spastic CP
P15	38	Female	Mother	Gauteng	WhatsApp	Unemployed	5 years old	Unknown
P16	38	Female	Mother	Gauteng	WhatsApp	Full-time	6 years old	Unknown
P17	46	Female	Mother	Gauteng	Zoom	Full-time	7 years old	Unknown
P18	39	Female	Mother	Gauteng	In-person	Unemployed	6 years old	Unknown

CP: cerebral palsy.

CORRECTED PROOF

3.2. Thematic findings

Following the analysis, several core themes emerged from the data about caregivers' personal and unique experiences when engaging with teletherapy during COVID-19 in South Africa. The themes included [1] caregiver empowerment through the promotion of their child's communication, [2] difficulty re-negotiating the caregiver role during COVID-19, [3] using available resources that were contextually and culturally appropriate, [4] the need to promote support for the caregiver, and [5] the benefit of teletherapy on children other than the child with CP. Verbatim participant quotes are included to support the themes identified. Themes are presented according to how frequently they emerged in the participant narratives, from most to least prevalent.

3.3. Caregiver empowerment through the promotion of their child's communication

Sixteen caregivers ascertained that teletherapy increased bonding between them and their child with CP. Prior to teletherapy, caregivers noted that their child struggled to express their needs, specifically when in pain, as P2 explained: "*My daughter doesn't always communicate clearly her needs, her pain and her problems.*" P2 further expressed how this resulted in her feeling disempowered: "*I wasn't able to effectively manage and understand what was wrong or where the pain was coming from.*" Teletherapy encouraged one-on-one time with their child, as described by P3: "*It gave me time with my child, to do things just us.*" This bonding period thereby allowed caregivers to better understand their child, as stated by P4, "*to learn some new things that I didn't know about him because we spent the whole day with him*."

Caregivers felt that the increased understanding of their child stemmed from the additional time spent at home. P18 reported on the ways in which COVID-19 was both a burden and a gift due to the additional time she could spend with her child, stating that "*Tremendous burdens often unveil enormous gifts, as in school I didn't know how she was doing. But now, at home, I can see and help with my child.*" Caregivers reported that, before teletherapy, all therapy was conducted solely with the SLP during allocated scholastic periods. Moreover, P5, who was an employed caregiver, noted that through remote teletherapy, she felt she was able to cultivate and enhance her relationship with the child with CP: "*It also got me to know the child better. It gave me the opportunity to know them at that personal level and try to understand why he sometimes gets angry or upset even when he can't speak*." Caregivers often did not have a good idea of what their child was doing in therapy, as P10 stated: "*I was unable to understand what is actually going on in therapy.*" Caregivers received limited input from the SLPs, and those that did receive information stated that it often related to very general therapeutic techniques, as expressed by P18: "*The SLP showed me videos from which to learn sign language,*" or P1: "*They'll just tell you, 'Okay mama, just read her the book. She will cope*.'" Caregivers reported that they continued to struggle to understand their child's wants and needs due to their child's limited communicative abilities.

A significant shift in the implementation of teletherapy was the way in which SLPs improved their engagement with caregivers, which in turn improved the ways in which the caregivers interacted with their children and were able to understand their needs, as described by P8: "*When you are helping a child, you get to understand them. I can tell you the child wants this, because I understand him better.*" This was further reiterated by P12, who noted that through teletherapy she could understand her child's likes and dislikes, even though he was not communicating verbally: "*I began to understand what he likes, how he reacts to something he doesn't understand, even if it was not verbal.*" P13 shared similar experiences of understanding her non-verbal child and using signs to communicate: "*Now he can call someone using his signs.*" This enhanced communication is a noteworthy finding, as the majority of children with CP in this study were non-verbal and mainly employed facial expressions or vocalizations to express themselves. Training the caregivers not only increased bonding but also facilitated communicative opportunities to better understand their child.

3.4. Difficulty re-negotiating the caregiver role during COVID-19

Fourteen of the caregivers reported on the significant challenges related to their changing role as a result of the pandemic and the implementation of teletherapy. As P15 described, "*We were everything, all at the same time – mothers, caregivers, teachers, therapists; we were every professional*." Caregivers spoke about the demands of teletherapy and the role they had to take on as a therapist – "*Even if you are not*

CORRECTED PROOF

a qualified therapist you now have to" (P10) – as well as the continued household and work responsibilities they were required to conduct on top of teletherapy: "*I had to make extra time to do his activities; I have to clean, I have to do my household jobs, and go to work also*" (P11). As a result, a number of caregivers felt that they were unable to meet the demands of teletherapy, as noted by P12: "*I didn't get to do teletherapy all the time*." Unfortunately, these changing roles and the increased demand to participate in the child's therapy had a negative impact on the caregivers, as they felt they were not doing enough and were hindering their child's progress. As P13 explained, "*Maybe she's lagging behind because I am not a speech therapist.*"

For some caregivers, the implementation of teletherapy was a priority, and many took this role very seriously, although this did perpetuate negative implications such as job loss, as P14 expressed: "*At some points I thought that is maybe why I lost my job, because most of my time I was like filled with my daughter's home program*." Therefore, it is important to acknowledge the added burden, responsibility, and time pressure that teletherapy can place on caregivers, but also to understand the benefits it can have for both the child and the caregiver. Moreover, these findings highlight the need for additional support for caregivers of children with CP implementing teletherapy, especially from their employers, who need to comprehend the demands placed on the caregivers.

3.5. *Using available resources that were contextually and culturally appropriate*

Ten caregivers reported that teletherapy allowed families to use resources and materials that they had available to them, which allowed for better carryover in the home environment. Caregivers conveyed that reusable supplies that could be found within their home environment were used, as P9 revealed: "*Yeah, the therapy is good. It has helped us a lot, and the thing is, most of the time we use the things that we normally use at home*." This sentiment was affirmed by P14, who noted that "*Most of the time I was getting recycling stuff, like empty containers, just anything that I could think of, instead of going to the shop and buying, because money was not a lot for us.*" These findings indicate that the use of contextually available resources ensured that the caregivers did not have to personally acquire or purchase additional resources at their own expense, which was a suitable solution given the financial implications that the prolonged South African lockdown had on some families. In addition, SLP services became centered around the available amenities and toys that caregivers had on hand for their children with CP, as P16 expressed: "*We did the activities at home, and she told me to get some of the stuff ready – like what kind of books he likes, what kind of toys. Then we had to put them all together; then she could talk and use what we had*."

Although the majority of caregivers conducted therapy with resources they had available at home, three of the caregivers conveyed concerns about their limited availability of resources. The accessibility of resources and materials in the home context was a concern for caregivers, in comparison to when therapy was accessed in the SLP's domain, as P3 highlighted: "*Maybe we don't have enough toys and things to work with at home*." Additionally, P2 relayed the fact that her child was more enticed and willing to participate in the SLP's environment as "*she enjoys engaging with the toys – with the physical toys – that they have there, and the physical things, and did more when she was not at home*." P11 expressed how the scarcity of resources hindered the provision of tasks set by the SLPs, "*because we didn't have some of the materials. Like if we had to buy something like cotton wool, I don't have that – small stuff that I don't have at home – it was difficult to do those activities.*"

Caregivers who felt that they did not have adequate resources at home commented on the need to return to in-person therapy. P3 noted her desire to go back to in-person therapy as she felt the therapist would be able to better support her child, and that her child's participation would improve as he would be around other children and have access to more resources: "*It was not easy to implement the programs that they sent us because you find, when you are trying to work with my child when he is alone, he doesn't participate more. Unlike when he is around other kids, it is easier, and they have more toys to play with*." P2 shared a similar sentiment, as she was unable to use specific resources, such as TalkTools, at home: "*We went back to face-to-face therapy this year so they can actually use the TalkTools in therapy*." In addition, P11 felt that the move back to in-person would allow her child to receive more therapy, as she did not have sufficient time available to provide it herself: "*I would just want more time to do therapy with him if I can, but I can't. So going back would be much better*." Therefore, it is important to acknowledge not only the ways in which caregivers are supported but also their personal preferences regarding the mode of therapy and the benefits that in-person therapy does offer.

CORRECTED PROOF

3.6. The need to promote support for the caregiver

Caregivers expressed the increased burden associated with the implementation of teletherapy, the increased demands as discussed in the theme above, and the need for additional support. Due to COVID-19, many caregivers experienced increases in isolation and reduced family and medical support. As P2 explained: "*I, alone, was forced to do everything alone, which was hard. And this was during the harsh lockdown where we didn't have interactions with others*." P1 further explained how the increased isolation perpetuated a feeling of loneliness: "*I was lonely and I didn't have any person to ask*." Many caregivers felt that they required someone to speak to – as P15 stated: "*This journey is not easy, and you need people to talk to, you need people that are there for you*" – and to receive moral support from, with P14 explaining that "*moral support like talking give[s] people strength to carry on*." Caregivers expressed that it was important to prioritize their children, but that this resulted in being unable to care for themselves: "*It is always about the kids first, and only then the caregivers somewhere down the line*" (P5). For this reason, P5 encouraged "*caring for the caregivers and nurturing them*" in order to combat their sense of isolation and reduced support, which was exacerbated by the pandemic. P5 was an employed caregiver and highlighted the challenges experienced by both the biological and employed caregivers, and their need for support in caring for children with CP.

Two of the caregivers noted that they attempted to seek support from social media platforms such as Facebook and WhatsApp as a way to connect with other caregivers whilst still limiting their physical contact, given their concerns that their children were "high-risk." This notable finding highlights the significant need for ensuring that caregiver mental and emotional well-being is foregrounded, as this significantly impacts their provision of care and is an important consideration with regard to the added responsibilities for the caregiver.

3.7. The benefit of teletherapy on children other than the child with CP

An unanticipated yet inspiring reflection of one caregiver's experience demonstrated the profound impact that teletherapy had on their community. P14, who lived in an informal settlement, spoke about many caregivers who were not afforded the resources and support for their children with disabilities: "*Where we stay it's an informal settlement, where other mothers don't have the support that I got, like access to home programs and video sessions with the speech therapist*." P14 felt that she could utilize the skills she was obtaining from the teletherapy to support other children in her community and involve them in activities provided for her daughter with CP, in order to "*take care of the other young ones with challenges in the community with the therapy that I was giving my daughter, so that at the same time it helped the other children*". The virtual teletherapy enhanced this caregiver's skills; the therapist noted her improved abilities in communicating with her daughter and her confidence: "*Now we can hire you as my therapy partner to come and help me as a therapist at the school, because my help went the extra mile to help other children*." This is a novel and notable finding that emphasizes the additional ways that teletherapy can be used to increase support for children with disabilities living in rural and remote areas; it also highlights the importance of being able to train and empower caregivers.

CORRECTED PROOF

4. Discussion

The aim of the study was to explore the experiences of caregivers of children with CP implementing SLP teletherapy during COVID-19 in South Africa. Identified themes were reflected in participants' experiences of the challenges, benefits, and supports that are required when implementing teletherapy in this context. Previous research has acknowledged the responsibilities of caring for a child with CP during the pandemic but has failed to explore the added impact of teletherapy [13, 24]. The presented study highlighted the structural challenges, child challenges, and personal challenges experienced by the caregivers. The impact of the pandemic and the implementation of teletherapy were explored using the six F-Words (fitness, function, family, fun, friends, and future) to contextualize the findings in alignment with the International Classification of Functioning, Disability and Health (ICF) [25].

4.1. Fitness and function

The study's findings shed light on the substantial impact of COVID-19 on therapy services and the well-being of children with disabilities. Caregivers expressed concerns about the fitness of their

child, particularly related to communication difficulties. However, the introduction of teletherapy brought about improvements, as it enabled caregivers to better understand their child's needs and engage in more meaningful communication. Teletherapy allows children to repeatedly practice skill development and incorporate parental perspectives as it is done in their home environment [25]. Studies have underscored the importance of a holistic approach to treating children with CP, which extends beyond solely addressing their challenges within a therapy setting and includes a diverse array of activities that therapy can encompass [26]. Therefore, teletherapy can have a positive impact when targeting communication goals within a home environment and the ways in which both children and their caregivers can be better supported and empowered, which in turn can improve the child's psychological wellbeing [10].

4.2. Family

This research study affirmed the notion that many caregivers felt empowered through inclusion in teletherapy, which yielded a positive emotional attachment with their child during the COVID-19 pandemic. Families reported that they spent more time with their child than they did prior to the pandemic. Teletherapy provided access to essential therapeutic interventions and support to both maintain and improve communication abilities. As reported in prior research, the pandemic caused disruptions to both caregivers' and children's lives [7, 11, 27]. Many children in the study depended on their caregivers for daily activities, and the lockdown restrictions prevented them from engaging in outdoor activities. When providing treatment, it is important to consider not only the child, but also the family who are central to the child's contextual environment [25]. Nonetheless, teletherapy presented opportunities for children and their caregivers to address their communication and therapeutic needs even when in-person rehabilitation was unavailable due to COVID-19 restrictions, which aligns with existing literature [27]. However, caregivers in the current study experienced significant changes in their caregiving role as they were required to implement teletherapy and take on additional responsibilities of not only providing care but also assisting in their child's rehabilitation. When targeting family-centred care, it is important to consider the additional burden it may have on the child's caregivers and the need for better support.

Findings showed that caregivers were faced with the challenge of attempting to balance their employment demands with teletherapy, as their children required supervision and facilitation through the duration of the session. This impacted the caregivers' ability to engage and motivate their child during therapy. Many caregivers were not provided with the appropriate supports, particularly by their employers. Reduced employer support is an important factor to highlight, especially as many South Africans lost their jobs during the pandemic and experienced financial difficulties, resulting in food insecurity [16, 29]. However, these findings are not limited to the South African context, but are a global concern [7, 30, 31]. There is an urgent need to advocate for support for caregivers implementing teletherapy, in light of the additional responsibilities it places on them.

4.3. Fun and friends

The child's ability to actively participate in daily activities during COVID-19 was examined in this study [26]. Teletherapy allowed for the inclusion of the child in different aspects of the family's lives. In addition, many families provided adaptations to the home to allow the child to be included and to better support the child's needs. Research has emphasized the importance of environmental adaptations to increase children's independence [10, 25, 26]. In South Africa, adaptations need to be individualized to each family, as they may have diverse backgrounds with different levels of access to services, supports, and resources [27]. Diversity was evident in how and to what extent families had access to toys and resources. Although most caregivers were able to use what they had at home, several reported that they did not have anything to use in therapy and felt that this hindered their child's ability to learn and engage in the activities. The importance of environmental adaptations in family-centered care, and providing therapy that is contextually and culturally appropriate, was reiterated by Chi and Demiris [28], who stated that a positive implication of teletherapy was a better understanding from caregivers of ways to support their child in the home environment.

The ways caregivers were able to provide support to other children and families shows how teletherapy can be used to not only teach but also empower children and provide opportunities for connection with other children with CP [25]. In the current study, a community of care was established, as the conceptualization of the care team was expanded to include not

CORRECTED PROOF

only other professionals (such as physical and occupational therapists) but also caregivers, who play an imperative role in the provision of routine intervention, specifically in the context of COVID-19. The study highlighted additional models of service delivery, including training the caregiver to provide SLP support to other caregivers and children not accessing these services. This is an important consideration in South Africa, where access to SLP is scarce with limited availability of frequent contact services, particularly in rural communities [31]. Therefore, using teletherapy not only to provide care but also to train caregivers should be further utilized, both during and after COVID-19.

4.4. Future

Teletherapy is an important avenue to explore for the rehabilitation of children with CP, especially considering the improvement many families reported in their child's ability to communicate. Previous research has reiterated this improvement and the fact that SLP services generally do not require hands-on support, as is typically needed for physiotherapy or occupational therapy, for example [32–34]. This study promotes not only the caregiver's involvement but also the importance of interdisciplinary care for children with CP and the ways in which different health care professionals can work together to provide holistic care and treatment [29, 30] – especially considering the impact COVID-19 had on all members of the rehabilitation team and their patients. Moreover, future research should explore and compare the use of synchronous and/or asynchronous teletherapy for children with CP, as this may mitigate some of the challenges participants noted, enhance therapeutic outcomes, and improve their future development.

5. Limitations of the study

This is one of the few qualitative studies that have explored caregiver experiences of implementing teletherapy for their child with CP. While qualitative research allows for the in-depth exploration of experiences, the study had several limitations. Firstly, participant recruitment was challenging given lockdown restrictions as a result of COVID-19 and the fact that this research took place during the third wave of COVID-19 in South Africa. Secondly, all interviews were conducted in English, which was restrictive for certain participants given South Africa's multilingual environment. Thirdly, despite this being a qualitative study in nature, a larger sample from diverse regions located in South Africa would be beneficial to improve the understanding of teletherapy in the broader South African context. All caregivers who participated in the study were located in metropolitan domains, while caregivers with children with CP in rural communities were not well represented. For this reason, this study should be replicated in other provinces and regions in order to comprehensively evaluate the effect of teletherapy for caregivers of children with CP in South Africa. Lastly, this study was not multidisciplinary, and future studies should involve caregivers as well as other service providers to get a better perspective of teletherapy. Moreover, given the nature of CP and the presentation of multiple challenges requiring SLP, physiotherapy, and occupational therapy, it would be beneficial to further expand this research study in order to obtain a holistic understanding of the continuation of therapy during COVID-19. The ways in which not only communication and feeding difficulties, but also difficulties with seating, visual, and fine motor skills were managed could be explored in future research.

CORRECTED PROOF

6. Conclusion

The research findings of this study add to the growing body of literature on the implementation of teletherapy during COVID-19 for children with CP and their families. In less than a year, the advances in technological SLP services have increased accessibility by providing therapy from a distance, which has enabled caregivers to acquire skills that promote their ability to meaningfully communicate as well as bond with their child. The pandemic has rapidly altered the landscape of teletherapy in South Africa, allowing children with CP living in remote communities to have continuity of care. While the immediate crisis of the pandemic and its physical restrictions have passed, comfort with and ease of use of technology is likely to improve through the implementation of necessary support structures to facilitate caregivers in alleviating the burdens noted in this study. The establishment of a new normal in which teletherapy has a prominent place in SLP intervention needs to be acknowledged, and strategies need to be developed to improve care and access to children with CP and their families.

Acknowledgments

We thank all of the caregivers of children with CP who participated in the research study and colleagues at the University of the Witwatersrand, who offered advice and support in conducting this study.

Disclosure statement

No potential conflict of interest was reported by the authors. This research received no external funding.

References

[1] Pionke JJ. Disability in the time of COVID. J Libr Adm. 2022;62(2):259-65. doi: 10.1080/01930826.2022.2026129

[2] Shahbazi M, Shahbazi F. COVID-19 and children with special healthcare needs: Recommendations for helping parents and caregivers of young children. Arch Pediatr Infect Dis. 2021;9(4):e107357. doi: 10.5812/pedinfect.107357

[3] Lima MBS, Cardoso VDS, Silva SSDC. Parental stress and social support of caregivers of children with cerebral palsy. Paid (Ribeirão Preto). 2016;26(64):207-14. doi: 10.1590/1982-43272664201608

[4] Brandenburg JE, Fogarty MJ, Sieck GC. Why individuals with cerebral palsy are at higher risk for respiratory complications from COVID-19. J Pediatr Rehabil Med. 2020;13(3):317-27. doi: 10.3233/PRM-200746

[5] Bertamino M, Cornaglia S, Zanetti A, et al. Impact on rehabilitation programs during COVID-19 containment for children with pediatric and perinatal stroke. Eur J Phys Rehabil Med. 2020;56(5):692-4. doi: 10.23736/S1973-9087.20.06407-2

[6] McKinney EL, McKinney V, Swartz L. Access to healthcare for people with disabilities in South Africa: Bad at any time, worse during COVID-19? S Afr Fam Pract (2004). 2021;63(1):e1-5. doi: 10.4102/safp.v63i1.5226

[7] Cankurtaran D, Tezel N, Yildiz SY, Celik G, Unlu Akyuz E. Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine. Ir J Med Sci. 2021;190(4):1473-80. doi: 10.1007/s11845-021-02622-2

[8] Fairweather GC, Lincoln MA, Ramsden R. Speech-language pathology teletherapy in rural and remote educational settings: Decreasing service inequities. Int J Speech Lang Pathol. 2016;18(6):592-602. doi: 10.3109/17549507.2016.1143973

[9] Bhaskar AR, Gad MV, Rathod CM. Impact of COVID pandemic on the children with cerebral palsy. Indian J Orthop. 2022;56(5):927-32. doi: 10.1007/s43465-021-00591-3

[10] Pizzighello S, Uliana M, Martinuzzi M, et al. The perceived impact of Covid-19 pandemic on the children with cerebral palsy: the parents' perspective explored within the "6-F words" framework. Child Adolesc Psychiatry Ment Health. 2023;17(1):24. doi: 10.1186/s13034-023-00569-z

[11] Ben-Pazi H, Beni-Adani L, Lamdan R. Accelerating telemedicine for cerebral palsy during the COVID-19 pandemic and beyond. Front Neurol. 2020;11:746. doi: 10.3389/fneur.2020.00746

[12] Dimer NA, do Canto-Soares N, Dos Santos-Teixeira L, de Goulart BNG. The Covid-19 pandemic and the implementation of telehealth in speech-language and hearing therapy for patients at home: an experience report. Codas. 2020;32(3):e20200144. doi: 10.1590/2317-1782/20192020144

[13] Dhiman S, Sahu PK, Reed WR, Ganesh GS, Goyal RK, Jain S. Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. Res Dev Disabil. 2020;107(103790):103790. doi: 10.1016/j.ridd.2020.103790

[14] Pennington L, Stamp E, Smith J, et al. Internet delivery of intensive speech and language therapy for children with cerebral palsy: a pilot randomised controlled trial. BMJ Open. 2019;9(1):e024233. doi: 10.1136/bmjopen-2018-024233

[15] Tambyraja SR, Farquharson K, Coleman J. Speech-language teletherapy services for school-aged children in the United States during the COVID-19 pandemic. J Educ Stud Placed Risk. 2021;26(2):91-111. doi: 10.1080/10824669.2021.1906249

[16] Stiegler N, Bouchard J-P. South Africa: Challenges and successes of the COVID-19 lockdown. Ann Med Psychol (Paris). 2020;178(7):695-8. doi: 10.1016/j.amp.2020.05.006

[17] Adams SN, Seedat J, Coutts K, Kater K-A. 'We are in this together' voices of speech-language pathologists working in South African healthcare contexts during level 4 and level 5 lockdown of COVID-19. S Afr J Commun Disord. 2021;68(1):1-12. doi: 10.4102/sajcd.v68i1.792

[18] Tar-Mahomed Z, Kater K-A. The perspectives of speech-language pathologists: Providing teletherapy to patients with speech, language and swallowing difficulties during a COVID-19 context. S Afr J Commun Disord. 2022;69(2):e1-e7. doi: 10.4102/sajcd.v69i2.902

[19] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa

[20] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117. doi: 10.1186/1471-2288-13-117

[21] Saldana J. The coding manual for qualitative researchers. 4th ed. London, England: SAGE Publications; 2021.

[22] Casale D, Posel D. Gender and the early effects of the Covid-19 crisis in the paid and unpaid economies in South Africa. National Income Dynamics Study (NIDS) – Coronavirus Rapid Mobile Survey (CRAM); 2020. Available from: https://www.wits.ac.za/media/wits-university/faculties-and-schools/health-sciences/wits-wethu/documents/Gender%20and%20the%20early%20effects%20of%20the%20Covid-19%20crisis%20in%20the%20paid%20and%20unpaid%20economies%20in%20South%20Africa.pdf

[23] Pretorius C, Steadman J. Barriers and facilitators to caring for a child with cerebral palsy in rural communities of the western cape, South Africa. Child Care Pract. 2018;24(4):413-30. doi: 10.1080/13575279.2017.1347146

[24] Vadivelan K, Sekar P, Sruthi SS, Gopichandran V. Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. BMC Public Health. 2020;20(1):645. doi: 10.1186/s12889-020-08808-0

CORRECTED PROOF

[25] Rosenbaum P, Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think! Child Care Health Dev. 2012;38(4):457-63. doi: 10.1111/j.1365-2214.2011.01338.x

[26] Toro J, Martiny K. New perspectives on person-centered care: an affordance-based account. Med Health Care Philos. 2020;23(4):631-44. doi: 10.1007/s11019-020-09977-w

[27] Sarti D, De Salvatore M, Pagliano E, Granocchio E, Traficante D, Lombardi E. Telerehabilitation and wellbeing experience in children with special needs during the COVID-19 pandemic. Children (Basel). 2021;8(11):988. doi: 10.3390/children8110988

[28] Akpinar P, Aktas I, Ozkan FU, Atici A, Kaysin MY, Cambekli K. Rehabilitation status of children with cerebral palsy and anxiety of their caregivers during the COVID-19 pandemic. North Clin Istanb. 2021;8(6):545-53. doi: 10.14744/nci.2021.32068

[29] Arndt C, Davies R, Gabriel S, et al. Covid-19 lockdowns, income distribution, and food security: An analysis for South Africa. Glob Food Sec. 2020;26(100410):100410. doi: 10.1016/j.gfs.2020.100410

[30] Farajzadeh A, Dehghanizadeh M, Maroufizadeh S, Amini M, Shamili A. Predictors of mental health among parents of children with cerebral palsy during the COVID-19 pandemic in Iran: A web-based cross-sectional study. Res Dev Disabil. 2021;112(103890):103890. doi: 10.1016/j.ridd.2021.103890

[31] Modi J, Sharma P. Approaches in improving hand function in cerebral palsy via telerehabilitation: A review. J Pediatr Rev. 2022;10(3):239-46.

[32] Allison K, Levac D. Impact of the COVID-19 pandemic on school-aged children with disabilities: Changes in therapy service delivery and functioning. Dev Med Child Neurol. 2021;63(S3):94-5.

[33] Mbunge E. Integrating emerging technologies into COVID-19 contact tracing: Opportunities, challenges and pitfalls. Diabetes Metab Syndr. 2020;14(6):1631-6. doi: 10.1016/j.dsx.2020.08.029

[34] Chi N-C, Demiris G. A systematic review of telehealth tools and interventions to support family caregivers. J Telemed Telecare. 2015;21(1):37-44. doi: 10.1177/1357633x14562734

[35] Allison KM, Levac DE. Impact of the COVID-19 pandemic on therapy service delivery and functioning for school-aged children with disabilities in the United States. Disabil Health J. 2022;15(2):101266. doi: 10.1016/j.dhjo.2021.101266

[36] Mineo BA. Communication in children and youth with cerebral palsy. In: Miller F, Bachrach S, Lennon N, O'Neil M, editors. Cerebral Palsy. Springer Cham; 2020. p. 2883-902.

[37] Pillay M, Tiwari R, Kathard H, Chikte U. Sustainable workforce: South African Audiologists and Speech Therapists. Hum Resour Health. 2020;18(1):47. doi: 10.1186/s12960-020-00488-6

CORRECTED PROOF