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Caregiver perspectives on the long-lasting impact of the COVID-19 pandemic on children with cerebral palsy in Johannesburg, South Africa

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ABSTRACT

Background The COVID-19 pandemic exacerbated challenges faced by children with cerebral palsy (CP), including limited access to therapy services, financial strain and disruptions in schooling and social activities. However, the specific long-lasting impacts of the pandemic on families of children with CP in the South African context remain underexplored.

Aim To explore the long-lasting impact of the COVID-19 pandemic on children with CP in South Africa.

Method A qualitative exploratory approach was used. 14 caregivers of 12 children with CP (aged 4–12) were recruited from various CP-specific schools and organisations in urban Johannesburg, South Africa. Individual semistructured interviews were conducted, and each interview was audio recorded, transcribed verbatim and analysed using inductive thematic analysis.

Results Children experienced significant changes to their physical and emotional well-being during the pandemic that had long-lasting effects on their added weight gain and activities of daily living. Many children experienced regressions during the lockdown due to the closure of schools and therapy centres. However, increased screen time observed among children with CP during the pandemic yielded unexpected positive outcomes, such as the improvement of technological skills and enhanced confidence through activities like vlogging.

Implications The pandemic has had long-lasting impacts on children with CP and addressing the multifaceted challenges faced by children with CP and their families in the post-COVID-19 era requires coordinated efforts from all stakeholders to ensure the holistic well-being and inclusion of this vulnerable population. Further research is warranted to assess the long-term impacts of the pandemic and evaluate the effectiveness of interventions aimed at mitigating its effects on this vulnerable population.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Children with cerebral palsy (CP) faced significant challenges during the COVID-19 pandemic, and many of these challenges have continued postpandemic.

WHAT THIS STUDY ADDS

⇒ This study adds valuable insights into the experiences of caregivers of children with CP in Johannesburg, South Africa, transitioning back post-COVID-19 lockdown. It identifies significant challenges faced by caregivers and their families, including limited access to therapy services, financial strain and food insecurity.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The implications of this study extend to research, practice and policy in several ways. First, the findings underscore the need for comprehensive support measures for families of children with CP in the post-COVID-19 era, including accessible school and therapy services, financial assistance programmes and nutritious food provision. Healthcare professionals and educators can use these insights to adapt their practices and provide remote therapy and educational support while promoting healthy lifestyles for children with CP. Additionally, policy-makers can use these findings to develop targeted interventions and policies aimed at mitigating the impacts of the pandemic on vulnerable populations, ultimately improving the well-being and quality of life of children with CP and their families. Lastly, the findings of this study should serve as foundational research for future studies to develop interventions for caregivers of children with CP.

INTRODUCTION

In March 2020, the WHO declared the COVID-19 outbreak a global public health emergency. This prompted various containment measures worldwide, including lockdowns, social distancing and isolation, aimed at curbing the virus's spread. South Africa implemented its lockdown from March 2020 to April 2022, halting all essential services, including schooling and rehabilitation.[1] This period presented challenges for all individuals, with heightened difficulties experienced by those with disabilities.

Research indicates that the lockdown had a significant impact on children with cerebral palsy (CP).[2–4] Disruptions in access to rehabilitative services, setbacks in educational and developmental progress, and increased strain on caregivers were evident.[3–5] Consequently, many children with CP suffered adverse effects on their physical, mental and psychological health.[2 6] However, the long-term ramifications of COVID-19 remain uncertain, particularly in the South African context, where unique challenges may exacerbate the difficulties faced by children with CP and their caregivers.

Although the national state of disaster related to COVID-19 in South Africa has ended, children with CP and their families continue to grapple with challenges stemming from the pandemic's long-term impacts. These effects are multifaceted, encompassing various aspects such as public health, economic stability and social dynamics.[7 8] The prolonged aftermath of the pandemic may exacerbate existing inequalities in healthcare and support services, further impacting the overall well-being and quality of life for children with CP and their families. Addressing the unique needs of this vulnerable population is crucial, requiring continuous and appropriate care throughout the postpandemic period. Therefore, this study aims to explore the long-term impact of the COVID-19 pandemic on children with CP and their families in South Africa, informing interventions and support systems to mitigate adverse outcomes.

METHOD

An exploratory qualitative research design was employed. Qualitative data were gathered via semistructured interviews were conducted with caregivers of children with CP after the COVID-19 pandemic from June to August 2023.

PARTICIPANTS

The researchers compiled a list of special education schools and organisations catering to the needs of children with CP across Johannesburg to facilitate participant recruitment. Although 10 sites were initially approached, only 6 responded and were included in the study. Subsequently, participant information letters were distributed by the schools/organisations to all eligible individuals within their networks, inviting them to contact the researchers if interested in participating. We were unable to determine the exact number of emails sent because these were distributed by the schools/organisations. However, only 14 participants responded to the call.

Participants were purposively sampled based on the following inclusion criteria: caregivers of a child with a (1) diagnosis of CP; (2) between the ages of 4 and 12 years of age, (3) ability to speak/read/understand English; (3) to be living in South Africa between March 2020 and April 2022. The age range for the children was selected to approximate school-aged individuals while accounting for the heterogeneity in children with CP. This decision also considered the varied organisations working with children across different age groups.

PROCEDURE

Each participant was required to complete a demographic questionnaire, followed by a semistructured interview guided by open-ended questions and probes. The interview guide aimed to elicit the long-lasting impact of the COVID-19 pandemic on children with CP in South Africa, from the perspective of their caregiver. The focus was on the continued challenges, benefits, considerations and any additional support they might require in this context. The guide (online supplemental material 1) allowed flexibility for participants to freely express their thoughts and experiences and was developed by the researchers based on the study objectives. Prior to the main study, the questionnaire and interview guide underwent testing on two mothers, with no modifications made following the pilot interviews.

Interested participants were provided with further information on the study using the participant information sheet. All participants provided signed informed consent. Demographic information was collected prior to the interview. Semistructured interviews were conducted either virtually through Zoom (n=9) or face to face (n=5). For face-to-face interviews, COVID-19 protocols were observed, and suitable meeting times were arranged. Caregivers underwent one interview, lasting approximately 1 hour each (range: 22–48 min). To ensure a comprehensive understanding of the caregiving experience within families of children with CP, multiple caregivers were included in some families. This decision was informed by the recognition of the diverse roles caregivers play in supporting children with CP, including grandparents and fathers, whose perspectives are often under-represented in disability research, particularly in the South African context.[9 10] By intentionally including multiple caregivers, such as grandmothers and fathers, the study aimed to address this limitation and capture a more diverse range of experiences. Therefore, following the initial caregiver interview, participants were asked if any other family caregiver would like to participate in the interviews. Two additional interviews took place. All interviews were audio recorded and transcribed verbatim. To prioritise anonymity and confidentiality, personal details, including names, were excluded from the transcripts.

DATA ANALYSIS

The Braun and Clarke thematic analysis was conducted in several sequential steps.[11] In the initial step, the audio data from the interviews were transcribed, and the dataset was read and re-read by researchers (RB, AM and SNA). Notes were taken to identify patterns within the data, including similarities between topics discussed in the interviews. The data were then organised into meaningful groups based on identified patterns. This involved grouping similar topics expressed by caregivers and generating codes. Themes found within the data were documented, and relationships between the initial codes were identified. This was done independently by all authors (RB, AM and SNA) and a consensus was then decided on the list of codes. The themes were then finalised by ensuring the themes had sufficient supporting data, involved collapsing overlapping themes, and refining certain codes and themes. Researchers collaborated to assess data adequacy and refine thematic structures.

A comprehensive review of the data was undertaken and themes were identified. All researchers are speech-language pathologist who work with children with CP and have had experience working both during and after COVID-19. To ensure the trustworthiness of the data, rigorous measures such as member checking, reflective journaling and regular reflective discussions between the researchers were implemented throughout the data collection and analysis processes.[12]

FINDINGS

The demographic information is summarised in table 1. The majority of participants were female (n=13), and the participants interviewed were predominantly mothers (n=9). Participants had varying types of employment, with most of whom were employed (n=9) with five participants being unemployed at the time of the study and one participant who has continued to experience unemployment due to job loss as a result of the COVID-19 pandemic (Participant 11). Of the participants, most had access to private healthcare (n=9) with five participants having access to public healthcare only.

All families had a child with CP between the ages of 4–12 years (M=7.3 years, SD=2.6) with slightly more being males (n=7) than female (n=5). Ten children had and unknown type of CP, this may be due to the fact that determining the classification type of CP within the paediatric population with accuracy is difficult.[13] Therefore, caregivers may not have been told the type of CP their child has. However, caregivers were able to report on their child's ambulatory status according to the GMFCS (Gross Motor Function Classification System) level. It is important to note that as these were caregiver interviews children were not formally assessed. The ambulatory CP children, that is, levels I, II, III were 41.5%, and non-ambulatory Level IV and V were 58.3%.

Following the analysis, several core themes emerged from the data illustrating the added challenges experienced by caregivers of children with CP, some of the positive changes that have happened as a result of the pandemic, and the need for additional and continued support. Main themes included (1) long-term regressions and increased muscle stiffness, (1.1) exposure to infection postlockdown, (2) increased weight gain and inability to participate in activities of daily living, (3) (alleviated) food insecurity and (4) technological advancement and vlogging out of lockdown. Responses from the family members are included to support the themes identified. Themes are displayed in figure 1 and presented according to how commonly they emerged within the data across participant narratives from most to least prevalent.

Table 1 Participant summary characteristics

Characteristics of the caregiver	Number (n=14)	%
Relation to the child		
Mother	9	64.3
Father	1	7.1
Grandmother	2	14.3
Sister	1	7.1
Aunt	1	7.1
Employment		
Employed	9	64.3
Unemployed	5	35.7
Healthcare		
Public*	9	75
Private	3	25
Characteristics of the child	Number (n=12)†	%
Gender		
Male	7	58.3
Female	5	41.7
CP type		
Spastic	3	25
Mixed	1	8.3
Unknown	8	66.7
GMFCS		
Level 1	0	0
Level 2	0	0
Level 3	5	41.7
Level 4	6	50
Level 5	1	8.3

*Four of the nine participants accessing public healthcare servic es also used private facilities to some extent (eg, rehabilitation services), despite primarily relying on the public system.
†Participants 2 (mother) and 3 (father) and participants 4 (grandmother) and 5 (mother) were from the same family.
GMFCS, Gross Motor Function Classification System.

Long-term regressions and increased muscle stiffness

Ten caregivers expressed concerns about their child's regression and increased muscle stiffness, attributing it to the continued limited access to schools and therapies. Participant 4 stated how her child is seven and only started therapy last year because COVID-19 caused delays in starting school, '*because of her age we were told she can no longer get therapy at the hospital and only from school. But because of COVID the school was not open and she received no therapy. She was very stiff. Even now she cannot go for regular physio because the school said cannot provide regular therapy and she is still so stiff, even worse than before.*' In South Africa care for children below age 5 is prioritised when accessing

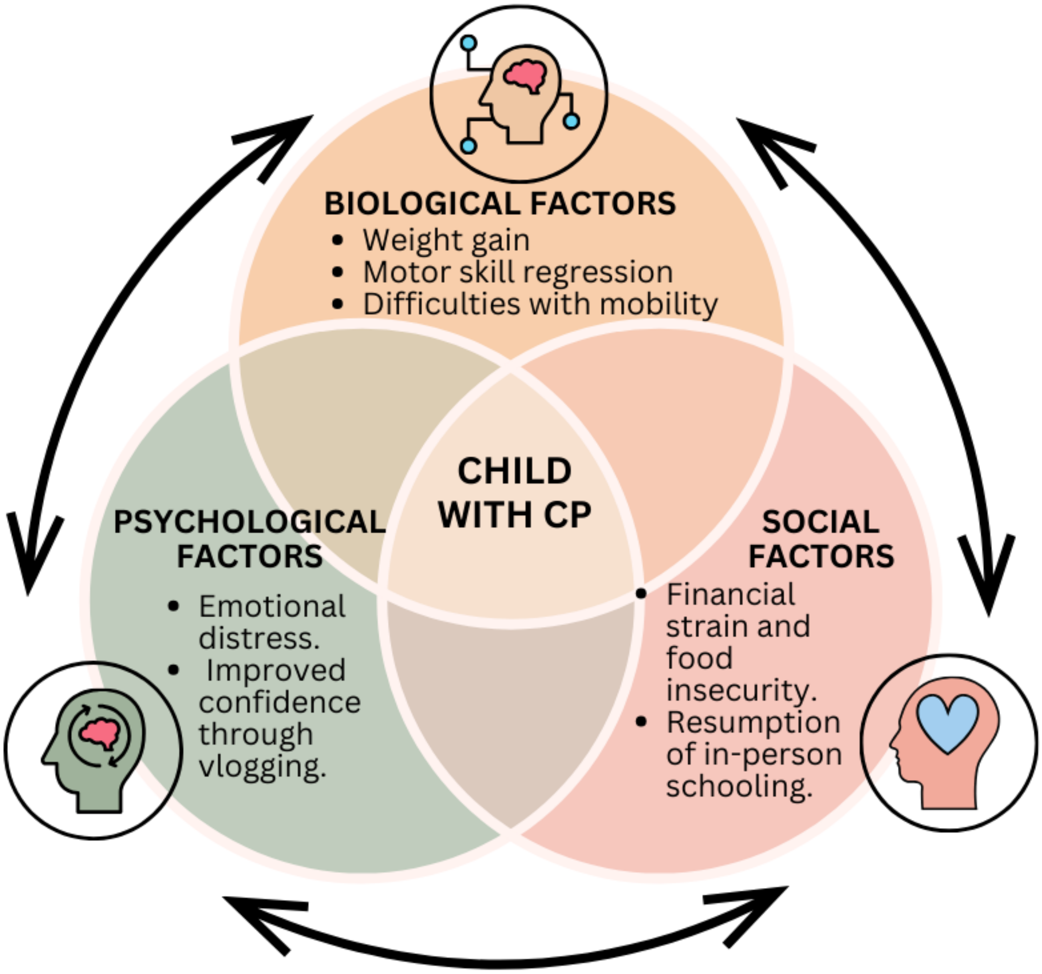

Figure 1 Biopsychosocial framing of children with CP's experience postlockdown. CP, cerebral palsy.

public healthcare[14] and many older children experience a gap in rehabilitation and support if they are unable to access services privately or through their school.

Participant 2 and participant 3 reiterated the delay in finding a suitable school for their child, which exacerbated the regression, stating, '*So she did get delayed on that aspect that COVID did delay it because we might have found the school earlier*' (Participant 2). Participant 3 added that during COVID-19 their daughter made no progress and would '*not move, just sit in one place, we had no support on what to do, how to treat her, speech, or physio, or just being more social*', when they tried to enrol her in a schools post-COVID they were told that the school was unable to handle her and that she was '*too chaotic*'. They are now home-schooling her. Participant 3 further stated that '*I'm sure if we found the school at the time, she would have made progress and been able to go to school*'. Participant 7 had a similar experience where she was told to take her child for therapy at school but he was not getting any therapy at school as the physiotherapist no longer worked there after COVID-19. She noted that, '*Access to medical is a big problem even after COVID. All he has is a unabridged birth certificate, and they classify him as an undocumented child at seven years old. He is stiff, all the muscles are stiff. Worse than before, he can't move them. He is in pain, crying. Pain all over and there is nothing I can do. He's not treated. He's sitting at home*'. Access to school and therapy continues to be an issue for many families resulting in continued difficulties that have still not been resolved.

Exposure to infection postlockdown

Caregivers also reported on the fact that many of them were very cautious during COVID and their children did not get sick. However, since the lockdown has ended and people are no longer required to wear masks and sanitise their children have been very sick as described by participant 6, '*So after the lockdown, it was a relief, but she got very sick. She was very sick last year. She was sick from like January to December. She was sick almost every week. Yeah, with the flu and a cough. She had a cough that just couldn't go away. So during COVID she didn't really get sick. But afterwards, she got very sick*'. Participant 7 reported how their child's continued sickness meant that they were out of school for even longer '*She'd go to school when she wasn't sick. And that was like the only time, in a month, she was going to school for a week,* *or, you know, two weeks at the most. But in every month, she was never attending school for five days.'*

Increased weight gain and inability to participate in activities of daily living

Six caregivers reported that their child experienced increased weight gain during the pandemic due to the lockdown restrictions, particularly affecting those who relied on public transport and were in wheelchairs. Participant 1 described how their child's limited mobility resulted in being confined to one place, leading to unnecessary weight gain, '*And also being disabled in one condition, one place, not moving from bedroom to sitting room, no bathroom, no going out in wheelchair, yes, that affects him and affects us, his health in a way that he gained unnecessary weight'*. Moreover, the weight gain persisted even after the lockdown ended, with caregivers struggling to help their children lose the extra weight. Participant 8 highlighted the ongoing difficulties, stating, '*The weight gain affects him and affect us. His health in a way that he gained unnecessary weight that I am fighting to lose, and there is no chance. It is also difficult to change his pampers [nappies]'*. The caregiver also mentioned the need to seek assistance from a dietitian to address the weight issue, underscoring the ongoing efforts to manage the child's health and well-being, '*His weight in a way is something we are still working. Seeing a dietician on how to bring his weight low [down]'*.

(Alleviated) food insecurity

A noteworthy finding was expressed by three caregivers, they expressed the increased expenses during the lockdown due to having to cook food for their child throughout the day. They reported improved experiences since their child is now able to eat at school as stated by participant 13, '*during lockdown the shops were not getting lots of stock in the township so I was worried I would not be able to provide for my children, I used to feel so useless. Now at least food during the day they get at school so I don't have to budget for that extra cost. Sometimes I would go hungry just so that my children can eat.'* This highlights food insecurity in South Africa and the important impact that school has on providing nutritious meals to children at public schools. Participant 1 reported similar experiences stating, '*lockdown was also very expensive because everyone was home and now you have to see to all their meals because they would get breakfast and lunch at school and now those meals were added to my responsibility so we struggled a bit with money and food and internet. So now I'm happy the children are back to school so I don't have to worry so much about food money anymore and I know they are able to eat.'*

However, it is important to note that even though their children are now able to have access to food postlockdown, many families have continued to experience food insecurity as described by participant 7, '*during the lockdown we didn't have lot of food. There is no money, there is no income, there is no job. Even now we are trying to catch up. We haven't settled, we still need more food, more money, and more jobs'*.

Technological advancement and vlogging out of lockdown

Three caregivers spoke about a positive postpandemic regarding how their child spent more time learning different skills during lockdown, particularly related to watching videos on social media and starting to make their own as described by participant 12, '*Her father taught her to navigate onto his phone and use the voice recognition thing to get whatever she wanted to play with or watch. I would make videos of everything. I would make a talking video. That's what she does these days. She makes videos and very interactive'* and participant 10, '*She's big on wanting because she watches a lot of YouTube also. So, you know, she wants and how to vlog on YouTube. So she's big on wanting her own page and she's very open with sharing her disability and watching kids with disabilities'*. It is important to note that all three caregivers had access to private healthcare and online services and resources.

DISCUSSION

The findings underscore ongoing challenges faced by children with CP and their families across biological, psychological and social domains, affecting their overall health and well-being. Despite heightened recognition of their vulnerability during the COVID-19 pandemic and calls for government support, global responses to include disabilities in pandemic strategies have been slow.[15 16] Unfortunately, children with CP continue to experience continued difficulties postlockdown. It is important to note that our study sample, consisting mostly of employed caregivers with access to private healthcare in urban Johannesburg, represents only a portion of the population. Unemployed individuals or those residing in low-resource settings may face additional hurdles. A study by Mwinbam *et al*[17] focusing on children with CP in Ghana highlighted the significant impact of context, revealing that those in lower-resource settings encounter heightened challenges. These include limited access to care, resources, transportation and financial strain. In South Africa, the majority of caregivers rely on public healthcare services.[18] During the pandemic, persons with disabilities and CP were unable to access public healthcare and rehabilitation services and had been placed on long waiting lists. Postlockdown, children with CP continue to experience marginalisation and exclusion as they are still unable to access these services.[18 19] Additionally, many children have been sicker and experienced regressions postlockdown necessitating urgent health and rehabilitation services that remain inaccessible. Therefore, the findings of the study still align with existing evidence and highlight significant contextual and global issues that warrant attention for the development of support systems and relevant interventions.

BIOLOGICAL FACTORS

Our findings indicate that the lockdown had a profound impact on the development of children with CP, resulting in increased weight gain, regressions, muscle stiffness and heightened vulnerability to infection postpandemic. Studies have shown that weight gain in children with CP can lead to difficulties in mobility and independent functioning, underscoring the significance of addressing this issue.[20] Increased weight gain and muscle stiffness are directly correlated with reduced ambulatory ability, greater functional impairment and reduced independence.[21] Without proper intervention, these conditions may worsen and become irreversible. Therefore, there is a pressing need for a shift in hospital policies in South Africa. While care for children aged 5 and below is prioritised, there is a critical gap in services for children with CP who require rehabilitative care beyond this age. This gap becomes even more pronounced in the wake of the COVID-19 pandemic, which has exacerbated the need for additional therapy and support and to mitigate the long-term impacts of the pandemic.

Existing evidence highlights how children with CP may benefit from formal education.[22] However, many caregivers in the study reported the challenges with finding appropriate school placement or therapy post-COVID-19, impacting on continued regressions and causing further problems with development and muscle stiffness. Even with South Africa's inclusive education policy, many schools do not have capacity and are not prioritising education for children with disabilities or do not provide therapeutic services at the school, which majority of children with CP will require.[23] Many caregivers experience challenges in the public healthcare system where their children are no longer prioritised for therapy but are unable to access these services elsewhere.[24] This suggests the need to operationalise educational policies that make formal education more accessible to all, including children with CP, particularly post-COVID-19 knowing the regressions many children experienced, and to assist with the provision of therapeutic services at CP schools in the country.

PSYCHOLOGICAL FACTORS

This study highlighted that children with CP are at a continued risk for psychological and emotional difficulties. Research has also indicated that children with neurodevelopmental disabilities are at a higher risk for continued psychological challenges such as increased anxiety and depression postpandemic.[25 26] Additionally, many caregivers have also experienced continued emotional strain, which may impact their ability to adequately care for their children without appropriate support.[25 27] Therefore, it is important that psychological support is continued and monitored for children with CP and their caregivers.

One positive aspect regarding children's well-being was the ways in which online platforms like YouTube provided avenues for empowerment and social connection for children with CP, emphasising the importance of leveraging digital resources.[28–30] However, it is crucial to acknowledge that this positive outcome is not accessible to all families, as those in the study all access private healthcare services only and had access to additional resources, technology and services not afforded to all participants. This underscores the need for policy changes to ensure equitable access to digital resources, especially for individuals with disabilities, to enhance their overall well-being and further research is required to understand the innovative ways in which technology can be used to provide emotional and psychological support to children with CP in South Africa and other low-resource settings. Future research could explore the utilisation of artificial intelligence to support socioemotional and communicative functioning.

SOCIAL FACTORS

Financial strain and food insecurity emerged as significant concerns among caregivers, underscoring the broader social determinants of health affecting families of children with CP. In the current study, families experienced food insecurity, although this was alleviated for the children as they have gone back to school, this continues to be an issue for many caregivers and families. School feeding programmes played a critical role in addressing food insecurity, highlighting the importance of educational institutions in supporting vulnerable populations.[31] However, the financial burden on families remains substantial, and many South Africans have reported on the continued socioeconomic difficulties, which have disproportionally affected those who are already living in poverty or with disabilities which has intensified and increased inequality, unemployment, hunger and food insecurity.[32–34]

Notably, families of children with CP, already a vulnerable population continue to experience challenges with restricted access to healthcare, public services and supports.[3] Additionally, those relying on public transportation have faced additional challenges postpandemic, highlighting the intersecting issues of disability, socioeconomic disadvantage and transportation inequality. In South Africa, there are vast inequalities in those living with socioeconomic disadvantages and their access to resources and services. Majority of South Africans use minibus taxi's, however, these are not accommodating for wheelchair users where often persons are not able to bring their wheelchair onto the taxi or being charged an additional fare.[18] As a result, persons with disabilities continue to experience social and economic exclusion.[35] This is noteworthy as majority of children in this study levels IV and V on the GMFCS requiring wheelchairs. The lack of accessible transportation and infrastructure exacerbates these difficulties, particularly for families with limited financial means who rely on public services. Therefore, even though these challenges are not new, they are continuous and have been exacerbated and there is a call for accessible, sustainable and inclusive transport provision to address the needs of children with disabilities.

The study had several limitations. First, it focused on a small geographical area, limiting the experiences to caregivers in Johannesburg. Second, the study did not specifically target rural populations, which are underrepresented in the literature and often experience barriers to accessing healthcare services. Third, due to the unique sociocultural context of South Africa, including cultural perceptions surrounding disability and access to healthcare, may have influenced caregiver experiences in ways that differ from other settings. Lastly, although various caregivers were included, the sample was predominantly mothers, reflecting a common trend in research where mothers are often the primary caregivers. This highlights the need for a more inclusive approach in future research, such as those from fathers and grandparents. Future studies should aim for a broader representation of families from different countries and contexts postpandemic, considering the long-term experiences of participants.

CONCLUSION

In conclusion, the findings of this study underscore critical issues concerning the long-lasting impact of COVID-19 on children with CP in South Africa. Specifically, the study highlights challenges related to physical care for children with CP, access to health information and educational needs. Addressing these challenges requires comprehensive and inclusive approaches that prioritise the needs of this vulnerable population, especially those facing socioeconomic disadvantage and systemic barriers to access and inclusion. Efforts to enhance support systems, promote digital literacy and address structural inequalities are crucial in ensuring the holistic well-being of children with CP and their families in the postpandemic era.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by the Human Research Ethics Committee (HREC Non-Medical) (STA_2023_49). All participants provided written informed consent. Participants gave informed consent to participate in the study before taking part.

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