Parent experiences in childhood disability accentuated by the impact of the coronavirus in South Africa.

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Declaration

I, Sashmi Moodley (MDLSAS003), declare that the reported research is based on independent work performed, except where acknowledged otherwise. Neither the whole work nor any part of it has been, is being, or is to be submitted for another degree to any other university. This work has not been reported or published prior to registration for the above-mentioned degree.

I permit the university to use or publish the contents as required.

Signed by candidate

Student signature : Sashmi Moodley

Date: 27 January 2023

Acknowledgements

In the final chapter of this thesis, I present the publication ready format of the research that I undertook during the COVID–19 pandemic in South Africa. It includes a quantitative analysis of a survey for parents of children with disabilities during the COVID -19 pandemic, as stipulated in my research protocol and approved by the University of Cape Town, Human Research Ethics Committee in September 2021. With input from my supervisors, I have crafted the protocol, liaised with the partnering organization, executed the research and written up this aspect towards my MPhil.

I would like to thank my supervisor, Professor Kirsten Donald for her continuous support and encouragement along this journey. Professor Donald sparked my collaboration with Shonaquip Social Enterprise, broadening my perspective of childhood disability as an early researcher and clinician. Her leadership is unmatched! She offered constructive advice on the development of the protocol and encouraged the application for funding via the university. I acknowledge the Department of Paediatrics and Child Health, University of Cape Town, for granting me the Research Award for 2021 which fuelled this work, without which it may not have been possible.

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A huge thank you to my family for renewing my drive!

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Abbreviations

COVID-19	Coronavirus disease
IAACD	International Alliance of Academies of Childhood Disabilities
ICF	International Classification of Functioning, Disability and
LMIC	Health Low-and middle-income countries
SSE	Shonaquip Social Enterprise
SADA	South African Disability Alliance
SAMJ	South African Medical Journal
SDGs	Sustainable Development Goals
UNICEF	United Nations International Children’s Emergency Fund
UCT	University of Cape Town
WHO	World Health Organization

Abstract

Background: Even in the absence of global threat, children with disabilities were underrepresented in monitoring efforts and were less likely to have been included in response strategies during the COVID - 19 pandemic. The harmful effects of the pandemic were expected to be most damaging for those in the poorest countries.

Objectives: Our study aimed to report the impact of the COVID-19 pandemic on families of children with disabling conditions in South Africa.

Methods: Parents from an online parent network, initiated by Shonaquip Social Enterprise during the pandemic, were invited to participate in an online survey in October 2021. A quantitative analysis was conducted using Stata Statistical Software.

Results: Sixty-eight (17%) of 400 parents in the network, completed the survey, 89% were mothers. Children aged 5-12 years represented 43% of the group. Eleven parents (16%) reported child health worsening compared to before the pandemic. Parent concerns included practicalities of infection control measures for their children and concerns about caregivers falling ill. Six (9%) children contracted COVID-19 infection and two (3%) children demised. Few families received telephonic contact from health providers. Indirect effects of the pandemic included loss of income and food shortages in more than half of the families. Twenty-two(32%) families had opted not to send their children back to school even by the third wave of infections. Some positive experiences of lockdown reported by parents included more family time and the opportunity to reach out to other families, however 33 (49%) parents reported being highly stressed, with five (7%) revealing a need for substances to cope. Most parents (n = 50, 74%) reported feeling that care for children with disabilities was not prioritized in South Africa.

Conclusion: This is one of the few studies in South Africa that explored childhood disability during the pandemic. A proportion of caregivers reported deterioration in their children's health during a time of limited access to health services. They have reported loss of family income, reduced access to educational services and challenges to mental health of caregivers. Families did not feel supported. Including the voices of parents highlight a range of challenges that need greater awareness. Post-pandemic, much change in practice is needed for families and children with disabilities.

Chapter 1

Families and children with disabling conditions: life during the COVID-19 pandemic in South Africa.

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Background

The World Health Organization (WHO) reported more than a billion people living with a disability worldwide a decade ago. Recent global reports estimate 240 million children are living with disabilities. [1,2] Childhood disability in low-resource regions of the world impacts family life, presenting well-documented challenges to long-term healthcare, rehabilitation needs, access to education, daily living, and the caregiving responsibilities for families.[3] Prior to the COVID-19 pandemic, published evidence emphasize how children with disabilities faced these greater risks.[4] Scoping reviews in sub Saharan Africa demonstrated barriers to health care access for children with disabilities which included stigma and negative attitudes, poverty and insufficient resources, inadequate policy implementations, physical inaccessibility, lack of transportation, lack of privacy, and inadequately trained healthcare professionals to deal with disabilities.[5] Emotional and social support, including peer support for caregivers, were identified as potential facilitators for better access to health services.[5] The United Nation's International Children's Fund (UNICEF) stated that 'to be a child in South Africa is to walk a fragile path'.[4] Much research suggests that poverty increases the risk of disability due to a lack of health resources in developing countries and disability increases the risk of poverty by placing greater need for caregiving as opposed to allowing parents a chance to seek employment and develop the family's economic growth.[6,7,8] Wide endorsement of the WHO International Classification of Functioning, Disability and Health (ICF) established in 2001, shifted from a focus on the causes of disability to approaching an individual with a disabling condition in the context of the holistic impact on daily living. The ICF provides a balanced approach between the medical and social model of disability, and promotes an expanded view on individual's long-term outcome in terms of physical, mental, or sensory impairments in their specific environment.[1,8,9]

The pandemic proved challenging for the entire world and, further highlighted the difficulty of understanding the impact on children, especially those with disabilities as they were not included in data collection. [10] The stakeholder group of persons with disabilities for sustainable development 2020 showed that persons with disabilities had difficulties in accessing COVID-19 related information, experienced barriers in receiving social protection measures and employment, and the lack of disability inclusion in COVID-19 response efforts in their countries. The global burden of SARS-CoV-2 infections left direct and indirect effects on children with disabling conditions, challenging access to the foundational elements of the nurturing care framework.[11] Australia and Uganda are examples of countries that were able to use surveys to explore the early impact of COVID-19 on children with disabling conditions.[12,13] Several reports describe how health inequities worsened in previous pandemics.[12]

UNICEF stressed that if interventions were not explicitly included in healthcare planning, budgeting and resource allocation from the start, people with disabilities risked exclusion from prevention and response measures.[14] Several organizations in South Africa play a key role in promoting awareness and protecting rights in these vulnerable groups. [15,16] The 2030 agenda towards realizing Sustainable Development Goals (SDGs) further informed these global initiatives to strengthen health systems in taking a human rights approach, enhancing provision of care and addressing inequalities in society through cultural, social and behaviour change targeting countries and communities most at risk.[17,18] The International Alliance of Academies of Childhood Disabilities COVID-19 Task Force was created to share diverse perspectives of countries around the world at different stages of the pandemic. By March 2022, 49 surveys were published with 17230 participants from different countries.[19] Similarly, Australian colleagues published their survey on the impact of COVID -19 on young people with disabilities a lack of information, uncertainty about educational services, mental health decline, lack of social services, lack of household food security, inaccessible COVID testing and telehealth as well as a lack of specific information for children with special needs. Teams in Uganda reported their qualitative study that included telephonic interviews with families caring for children with disability. Families reported having difficulties in meeting basic daily needs, in accessing health care for chronic conditions, and engaging in meaningful home education and learning during this time.[13] In this study we aimed to provide an opportunity for parents of children with disabilities to report challenges experienced by children and families in the context of the COVID-19 pandemic, in the South African setting.

Methodology

Design

This was a non-experimental, cross-sectional, descriptive study.

Partners

Researchers from the Department of Paediatrics at the University of Cape Town (UCT) collaborated with Shonaquip Social Enterprise (SSE) an organization in South Africa founded in 1992 by Shona McDonald.[20] This organization advocates for inclusion of children with disabilities. A Memorandum of Understanding was drafted between UCT and the SSE.

Participants

During the first months of the pandemic, in March 2020, the SSE fast-tracked the launch of a network aiming to connect families of children with disabilities from various organizations, to share information, advice, referral, remotely through social media groups across South Africa. Four hundred parents were enrolled in the network at the time of the study (personal communication from key facilitators) and were all invited to participate via the REDCAP secure uniform resource locator that was posted on the group. Facilitators within the parent network were excluded from participating in the survey.

Tools

The online survey was designed by the first author around the ICF principles. It incorporated the biopsychosocial model for understanding the impact of the COVID pandemic on the family and child living with a disability. [8,9,19] The survey questionnaire was translated from English into Afrikaans and isiXhosa, and backtranslated. The survey was dissemintated via the parent network of the SSE via whatsapp. Though the parents were previously trained to use online surveys by the network facilitators, challenges in previous uptake were considered in survey design. It was therefore important to include concise questions to facilitate a description of what families experienced in this time. We included an open ended question at the end of the survey for any further descriptions. A UCT REDCAP research database was created. A pin secured device, a mobile phone, a study contact phone number, and a linked social media WhatsApp instant messaging account was dedicated to the study.

Rollout of the survey

During the third wave of infections in South Africa , in October 2021,when national infection control measures eased, parents were introduced to the study on one of their monthly social media WhatsApp group sessions.[24,25] Prepaid connectivity data bundles were purchased for each parent on the network by the SSE, the cost of which was sponsored by the study fund. This was done to enable the support session as well as the survey completion. SM, a paediatrician, presented the study to the 400 parents on one of the parent network support sessions. From previous experiences within the network, video-based discussions consumed excessive data and was not sustainable for the parents, thus a variety of multimedia tools such as voice notes, JPEG slides and texts were used. The 30 min session introduced the parents to the background, aims and objectives of study and the opportunity for live discussion. The numbers of completed surveys were monitored on the REDCAP database and communicated to the SSE facilitators. They were tasked with reposting of the link on a weekly basis and confirmed weekly that this was done over the next 5 weeks.

Data collection

This included family demographics as well as impact of COVID-19 on health conditions, educational, socioeconomic factors and mental health of caregivers.

Data analysis

The results were secured on a REDCAP database and a quantitative analysis was then run using Stata Statistical Software: Release 17 (College Station, TX: StataCorp LLC, 2021). The data were analysed using frequencies and proportions for categorical and numeric variables.

Ethical considerations

The study was conducted when restriction levels were at its lowest and presumed more feasible for high-risk families to participate in research studies. Participation remained voluntary, anonymous and responses were confidentially stored with password access limited to the researchers only. Parents were informed of the study on their parent network and informed consent was obtained on the survey link. Parents were given a study telephone number and study email address to contact the researcher with any queries. In certain instances where parents' priorities prevented them contributing to the research and a decision was made to withdraw, this was respected. The researchers involved in this study within the university and the SSE were given feedback after completion of the study. The Department of Paediatrics and Child Health Research Committee and the University of Cape Town, Human Research Ethics Committee provided scientific and ethical approval for the study (HREC Ref 443/21).

Results:

At the time of the study, the SSE parent network comprised 400 parents, of whom 102 (26%) opened the survey link. The greatest surge in participation included 47 (12% of 400) responseson the day of the introductory presentation by the first author. By the end of the second week this had almost doubled to 90 reviewed (23% of 400). An increase in responses were further noted at the end of the month. Of these parents, the largest proportion chose to answer the questionnaire in English. Fig 1 describes participation within the study.

Sixty (89%) of the respondents were mothers of children with disabilities. One foster parent and seven main caregivers were included. No fathers contributed to the study. Parents collectively described 20 medical diagnoses or causes for their child's disability. Table 1 describes the child demographics that we were able to capture. This includes the distribution of families within the parent network across the country who contributed to this survey. There were participants from 7 of the 9 provinces in South Africa, with no representation from the Limpopo and the Free State. We also describe the ages of the dependents and the heterogeneous descriptions of the medical conditions as reported by families (in some instances multiple conditions listed). When strict lockdown measures were declared in the country, 44 (65%) of these families realized that the COVID - 19 infection was a problem and 17 (25%) families realized this when other countries were affected. A further 4 (6%) parents reported acknowledging the seriousness of the problem when someone close passed away. More than half of the parents (n = 38, 55%) felt that they did not have enough information about caring for their children with special needs in the pandemic. Caregiving at home was described as 'very stressful' (n = 33, 49%) of the parents. Table 2 delineates the impact of COVID-19 on these families.

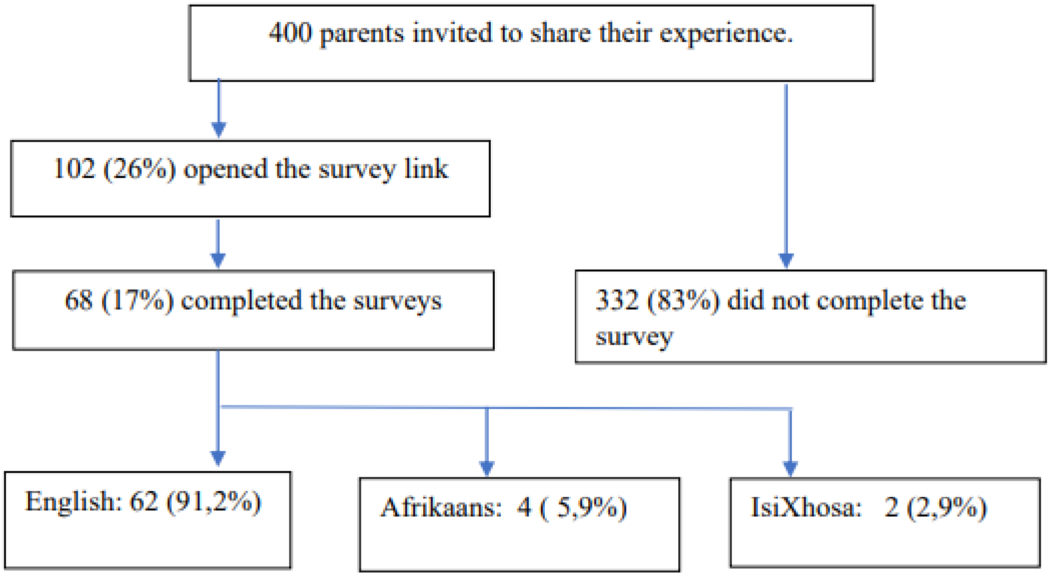

Figure 1. Diagram of participants taking the online survey

Table 1. Demographics and reported medical conditions of dependants.

Demographics of Children	
Ages of dependents	**n(%)**
2 – 5 years	7 (10)
5 – 12 years	29 (43)
12 – 18 years	24 (35)
>18 years	8 (12)
Provinces	**n(%)**
Eastern Cape	4 (6)
Western Cape	6 (8)
Northern Cape	15 (22)
KwaZulu Natal	4 (6)
Mpumalanga	5 (7)
North West	3 (4)
Gauteng	31 (46)
Limpopo	0 (0)
Free State	0(0)
Parent-identified medical conditions of dependents	**n(%)***
Albinism	1 (2)
Autism	13 (19)
Brain Damage	2 (3)
Brain Tumour	1 (2)
Behaviour disorder	1 (2)
Cerebral palsy	33 (49)
Congenital glaucoma	1 (2)
Down Syndrome	3 (4)
Epilepsy	12 (18)
Mental	1 (2)
Global Developmental Delay	1 (2)
Physical disability	1 (2)
Intellectual disability	1 (2)
Legg-Calve-Perthes	1 (2)
Pneumococcal meningitis	1 (2)
Spina bifida and hydrocephalus	2 (3)
‘Paralysis’	1(2)
TB Spine	1(2)
Visual impairment/ cortical blindness	1(2)

**Parents described more than one condition affecting each of their children therefore the total responses are more than the 68 individual responses*

Table 2. Impact of COVID-19 on families

Documented COVID-19 infections during the pandemic affecting:	**n (%)** *
- children	6 (9)
- parents	11(16)
- relatives.	14 (21)
- parent and child dyad.	2 (3)
- no one known to have been infected	40 (59)
Description of the child's health during the pandemic was:	
- the same	45 (66)
- better than usual	12 (18)
- worse	11(16)
Child demised	2 (3)
Distribution of conditions reported worsening child health	
- cerebral palsy	5 (7)
- physical disability	3 (4)
- autism spectrum disorder	3 (4)
Families contacted by a professional service provider:	
- no	60 (88)
- yes	8 (12)
These service providers were:	
- Doctors	5 (7)
- Nurses	1 (2)
- Therapists	4 (6)
- NGO's	3 (4)
- social workers	1 (2)
Greatest concerns during the pandemic named by caregivers were:	
- Child not being able to wear a mask	37 (54)
- Risk of getting COVID-19 from the hospital	24 (35)
- Caregivers falling ill	14 (21)

**Parents chose multiple options therefore their responses in some instances equate to more than the 68 families enrolled in the study*

Of the parents, 23 (34%) were unemployed prior to the pandemic; during the pandemic 11 (16 %) lost income, 7 (10%) lost their jobs, and 7 (10 %) could not meet payment commitments. Seven (10%) parents reported being allowed to work from home and 13(19%) families experienced no change in their employment. A total of 22 (32%) parents did not send their children back to school as lockdown regulations eased. Some families reported receiving ideas for home stimulation (n = 15, 22%) from their school. Fourteen parents (21%) did not describe an experience with regard to a care center or a school for their child.

A proportion of children continued to stay at school (n =12, 18), whilst a few children (n= 6, 9%) were able to access online educational support. When enquiring about food supplies, 42 (62%) of families were food insecure, 10 (15%) received non-governmental organization support, 8 (12%) received deliveries by friends and families whereas only 2 (3%) families were able to access groceries online. Accessing groceries was not a problem for 9 (13%) of families.

Of the total 68 responders, 32 (47%) of the families caring for children with disabilities were still able to reach out to other families during the global crisis. Although 19 (28%) parents described receiving support from their families, the period overall was reported as very stressful in 33 (49%). Parents also reported needing to be stronger than usual in 37 (54%) and 19 (28%) reported having a low mood. The positive aspects of lockdown included more family time (n = 26, 38%), slower pace of life (n = 4, 6%), time to reflect on what matters in life (n = 7, 10%), time for hobbies at home (n = 5, 7%), staying healthy as a family (n=14, 21%) and learning to be patient (n = 31, 46%). Nothing positive was reported by 6 (9%) parents and 5 (7%) acknowledged their need for substances to cope during the stressful situation. Amongst the cohort surveyed, 38 (56%) reported that they did not have enough information with 50 (74%) families expressing that care for children with disabilities was not prioritized in South Africa.

Discussion

Our study demonstrated that demonstrates that the majority of parents felt that care for children with disabilities were not prioritized during the pandemic and more than 50 %

felt that they lacked information. Children with disabilities and their families experienced added stresses threatening their ability to cope during the pandemic. Children experienced worsening in health with little outreach from service providers. Families lost income together with suffering food shortages. More than a third of parents were unemployed during the pandemic and a further third lost income during the pandemic. Children were not sent back to education and care centers when infection control measures eased and most neurotypical children returned to in-person schooling. The overall themes have emerged from international studies supporting the understanding of how the pandemic affected families across multiple aspects of their lives, exacerbating previous health, social and economic inequalities. [12,13,22] Our cohort reported few children contracting the infection. Prevalence studies in low- and middle-income countries (LMIC) reported fewer cases of COVID-19 in children compared to adults. In Kenya, 3% of the 2600 confirmed COVID-19 cases are children <10 years of age, and only 1% of deaths among confirmed cases have occurred in children. In South Africa, less than 2% of positive cases were in children, with few requiring hospitalizations. Approximately 12 000 children (persons under 18) contracted COVID-19 in the Western Cape Province, in South Africa between March 2020 and March 2021. This is in keeping with the higher proportion of caregivers to children affected by the virus in our study. [26,27] Children were affected by the illness and death of relative, and by the collateral effects of the pandemic including increased hunger, violence, injury and mental health problems. The negative effects on all children have been also reported widely. [26] This coupled with the disruption of healthcare services, schooling, early childhood development programmes, and social support networks.[26, 27] In our study parents reported a need for substances to cope, lack of support from schools and health services which is in keeping with international data. The study gave us insight into sociodemographic aspects within the parent network dedicated to childhood disabilities during the pandemic whereby the predominant role of mothers is highlighted against the missing participation from fathers.

This supports the known sociocultural differences between the role of the mother and father in the child's life, as fathers are missing in the role of supporting childhood disability and seeking psychosocial support.[28] Almost a third of the cohort were caring for adolescents with disabilities and a further tenth were parents caring for their children who were now in their adult years. As this is a small study, we cannot extrapolate the demographics to the broader population of children with disabilities. This cohort of parents caring for older children may, based on their experience, feel themselves to be in a stronger position to support the parents and families of 13

Few studies in South Africa are able to involve participants from across the country and we were able to include representation from 8 of the 9 provinces. The use of technology during the isolation period of the pandemic enabled us to reach families and include them into the research agenda. Although designing a short survey aimed to facilitate easy completion of our survey, we were not able to delve deep into the experiences of families. Our research is limited as we only had a small proportion answer the survey. Future studies that involve online surveys should also acknowledge the high risk group of participants due to the possible challenges of daily life in South Africa. It should be respected that research may not be on their agenda. This study was followed by qualitative telephonic interviews of parents of children with disabilities, the data of which is not included here. This may have been a better method of data collection from parents. There was also a low uptake rate of surveys in other languages, implying literacy predominantly in English. As this was not a comparative study, we did not have a control group, so we do not know how much worse things were for families of children with disabilities than their neurotypical peers. We also did not want to classify families according to their socio economic status, so we cannot comment on how different populations within the country experienced the pandemic. Although the majority of parents have reported no change in child health almost a quarter of families did experience the deterioration in child health as well as the lack of outreach, loss of employment, food shortages and impact on their own mental health due to the pandemic which required a dramatic cut in services that these children usually accessed. Evidence into the devastating effects of the COVID-19 pandemic in LMICs, demands efforts from government, world organizations, and non-for-profit institutions to be implemented to ameliorate the effects of this pandemic for all children, especially the vulnerable groups. [33] Post pandemic, service delivery needs to embody change with country level action to address family centred needs. Disability inclusive responses can focus on meaningfully engaging with families and children with disabilities to build resilience at every stage of their journey in and out of hospital settings during multidisciplinary consultations.[34] We need to take into consideration children with neurodevelopmental conditions not tolerating masks, the possibility of telephonic consultation to vulnerable families during times of crisis, prioritizing access to information and care and increased accessibility to mental health support services. These factors may direct future research to evaluate practices which build resilience in families. Transdisciplinary teams are encouraged to tap into the ability of families to self-empower and link families to referral pathways and parent networks.

Conclusion

South African caregivers reported poor access to health services regarding COVID -19, econonic adversity and challenging mental health during study period. A proprtion of parents have also described the deterioration in child health during this time. This is a further reminder of the inequalities experienced by children with disabilities and their caregivers especially those in LMICs. Our study involved caregivers of disabled children to ensure that their experiences were directly represented. This is consistent with accelerating global efforts towards inclusive programming to build resilience in marginalized populations. Follow up studies could be done within this network to assess the long term effects of the pandemic on these families. Clinical practice in the care of children with disabling conditions post pandemic should be facilitated by collaboration between government, community stakeholders and families to effect relevant change.

Author Contributions: KD introduced the team to the SSE. EVDW and SMcD gave insight into the parent network. SM crafted the protocol, the survey and article with supervision from KD and MH. FV helped interface with the parent online sessions. SM introduced the parents to the research and collected the data. The SSE helped with reposting the survey. KR provided statistical support. All authors contributed to the article.

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Appendices

Appendix A: South African Medical Journal Author Guidelines

The *SAMJ* has launched a new submission and tracking system. Authors will be required to register a profile to submit a manuscript. To submit a manuscript, please proceed to: https://samajournals.co.za/index.php/samj To access and submit an article already in production, please see the guidelines.

Author Guidelines

Manuscript preparation

- Preparing an article for anonymous review
- General article format/layout
- Preparation notes by article type
- Illustrations
- Tables
- References

SAMJ Policies

Type of articles considered by the SAMJ

The *SAMJ* will no longer limit the articles accepted to those that have 'general medical content', but is intending to capture the spectrum of medical and health sciences, grouped by relevance to the country's burdens of disease. This content will include research in the social sciences and economics that is relevant to the medical issues around our burden of disease. Please see 'A new vision for the *SAMJ* – and a call for papers' for a full discussion of the new directions for the *SAMJ*.

We accept the following types of articles:
- Research
- Reviews
- Clinical trials
- Editorials
- Case reports
- Correspondence
- Obituaries
- Book reviews
- Ad hoc supplements

*Contact claudian@hmpg.co.za for information on submitting ad hoc/commissioned supplements, including guidelines, conference/congress abstracts, Festschrifts, etc.

Authorship

Named authors must consent to publication. Authorship should be based on: (*i*) substantial contribution to conceptualisation, design, analysis and interpretation of data; (*ii*) drafting or critical revision of important scientific content; or (*iii*) approval of the version to be published. These conditions must all be met (uniform requirements for manuscripts submitted to biomedical journals; refer to www.icmje.org). If authors' names are added or deleted after submission of an article, or the order of the names is changed, all authors must agree to this in writing. Please note that co-authors will be requested to verify their contribution upon submission. Non-verification may lead to delays in the processing of submissions. Author contributions should be listed/described in the manuscript.

Conflicts of interest

Conflicts of interest can derive from any kind of relationship or association that may influence authors' or reviewers' opinions about the subject matter of a paper. The existence of a conflict – whether actual, perceived or potential – does not preclude publication of an article. However, we aim to ensure that, in such cases, readers have all the information they need to enable them to make an informed assessment about a publication's message and conclusions. We require that both authors and reviewers declare all sources of support for their research, any personal or financial relationships (including honoraria, speaking fees, gifts received, etc) with relevant individuals or organisations connected to the topic of the paper, and any association with a product or subject that may constitute a real, perceived or potential conflict of interest. If you are unsure whether a specific relationship constitutes a conflict, please contact the editorial team for advice. If a conflict remains undisclosed and is later brought to the attention of the editorial team, it will be considered a serious issue prompting an investigation with the possibility of retraction.

Research ethics committee approval

Authors must provide evidence of Research Ethics Committee approval of the research where relevant. Ensure the correct, full ethics committee name and reference number is included in the manuscript. If the study was carried out using data from provincial healthcare facilities, or required active data collection through facility visits or staff interviews, approval should be sought from the relevant provincial authorities. For South African authors, please refer to the guidelines for submission to the National Health Research Database. Research involving human subjects must be conducted according to the principles outlined in the Declaration of Helsinki. Please refer to the National Department of Health's guideline on Ethics in Health research: principles, processes and structures to ensure that the appropriate requirements for conducting research have been met, and that the HPCSA's General Ethical Guidelines for Health Researchers have been adhered to.

Patient Consent

Information that would enable identification of individual patients should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) has given informed written consent for publication and distribution. We further recommend that the published article is disseminated not only to the involved researchers but also to the patients/participants from whom the data was drawn. Refer to Protection of Research Participants. The signed consent form should be submitted with the manuscript to enable verification by the editorial team.

Other individuals

Any individual who is identifiable in an image must provide written agreement that the image may be used in that context in the *SAMJ.*

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Ethnic/race classification

Use of racial or ethnicity classifications in research is fraught with problems. If you choose to use a research design that involves classification of participants based on race or ethnicity, or discuss issues with reference to such classifications, please ensure that you include a detailed rationale for doing so, ensure that the categories you describe are carefully defined, and that socioeconomic, cultural and lifestyle variables that may underlie perceived racial disparities are appropriately controlled for. Please also clearly specify whether race or ethnicity is classified as reported by the patient (self-identifying) or as perceived by the investigators. Please note that is not appropriate to use self-reported or investigator-assigned racial or ethnic categories for genetic studies.

Manuscript preparation

Preparing an article for anonymous review

To ensure a fair and unbiased review process, all submissions are to include an anonymised version of the manuscript. The exceptions to this are Correspondence, Book reviews and Obituary submissions.

Submitting a manuscript that needs additional blinding can slow down your review process, so please be sure to follow these simple guidelines as much as possible:

- An anonymous version should not contain any author, affiliation or particular institutional details that will enable identification.
- Please remove title page, acknowledgements, contact details, funding grants to a named person, and any running headers of author names.
- Mask self-citations by referring to your own work in third person.

General article format/layout

Accepted manuscripts that are not in the correct format specified in these guidelines will be returned to the author(s) for correction, which will delay publication.

General:

- Manuscripts must be written in UK English.
- The manuscript must be in Microsoft Word format. Text must be single-spaced, in 12-point Times New Roman font, and contain no unnecessary formatting (such as text in boxes).
- Please make your article concise, even if it is below the word limit.
- Qualifications, ***full*** affiliation (department, school/faculty, institution, city, country) and contact details of ALL authors must be provided in the manuscript and in the online submission process.
- Abbreviations should be spelt out when first used and thereafter used consistently, e.g. 'intravenous (IV)' or 'Department of Health (DoH)'.
- Include sections on Acknowledgements, Conflict of Interest, Author Contributions and Funding sources. If none is applicable, please state ‘none’.
- Scientific measurements must be expressed in SI units except: blood pressure (mmHg) and haemoglobin (g/dL).
- Litres is denoted with an uppercase L e.g. 'mL' for millilitres).
- Units should be preceded by a space (except for % and ºC), e.g. '40 kg' and '20 cm' but '50%' and '19ºC'.
- Please be sure to insert proper symbols e.g. µ not u for micro, a not a for alpha, b not B for beta, etc.
- Numbers should be written as grouped per thousand-units, i.e. 4 000, 22 160.
- Quotes should be placed in single quotation marks: i.e. The respondent stated: '...'
- Round brackets (parentheses) should be used, as opposed to square brackets, which are reserved for denoting concentrations or insertions in direct quotes.
- If you wish material to be in a box, simply indicate this in the text. You may use the table format –this is the *only* exception. Please DO NOT use fill, format lines and so on.

Preparation notes by article type

- Research
- Editorials
- CME
- In Practice and Case reports
- Reviews
- Clinical trials
- Correspondence
- Obituaries
- Book reviews
- Guidelines

Research *Guideline word limit: 4 000 words*

Research articles describe the background, methods, results and conclusions of an original research study. The article should contain the following sections: introduction, methods, results, discussion and conclusion, and should include a structured abstract (see below). The introduction should be concise – no more than three paragraphs – on the background to the research question, and must include references to other relevant published studies that clearly lay out the rationale for conducting the study. Some common reasons for conducting a study are: to fill a gap in the literature, a logical extension of previous work, or to answer an important clinical question. If other papers related to the same study have been published previously, please make sure to refer to them specifically. Describe the study methods in as much detail as possible so that others would be able to replicate the study should they need to. Results should describe the study sample as well as the findings from the study itself, but all interpretation of findings must be kept in the discussion section, which should consider primary outcomes first before any secondary or tertiary findings or post-hoc analyses. The conclusion should briefly summarise the main message of the paper and provide recommendations for further study.

Select figures and tables for your paper carefully and sparingly. Use only those figures that provided added value to the paper, over and above what is written in the text. Do not replicate data in tables and in text .

Structured abstract: This should be 250-400 words, with the following recommended headings:

- **Background:** why the study is being done and how it relates to other published work.
- **Objectives:** what the study intends to find out
- **Methods:** must include study design, number of participants, description of the intervention, primary and secondary outcomes, any specific analyses that were done on the data.
- **Results:** first sentence must be brief population and sample description; outline the results according to the methods described. Primary outcomes must be described first, even if they are not the most significant findings of the study.
- **Conclusion:** must be supported by the data, include recommendations for further study/actions.

- Please ensure that the structured abstract is complete, accurate and clear and has been approved by all authors.
- Do not include any references in the abstracts.

Here is an example of a good abstract.

Main article

All articles are to include the following main sections: Introduction/Background, Methods, Results, Discussion, Conclusions.

The following are additional heading or section options that may appear within these:

- Objectives (within Introduction/Background): a clear statement of the main aim of the study and the major hypothesis tested or research question posed
- Design (within Methods): including factors such as prospective, randomisation, blinding, placebo control, case control, crossover, criterion standards for diagnostic tests, etc.
- Setting (within Methods): level of care, e.g. primary, secondary, number of participating centres.
- Participants (instead of patients or subjects; within Methods): numbers entering and completing the study, sex, age and any other biological, behavioural, social or cultural factors (e.g. smoking status, socioeconomic group, educational attainment, co-existing disease indicators, etc)that may have an impact on the study results. Clearly define how participants were enrolled, and describe selection and exclusion criteria.
- Interventions (within Methods): what, how, when and for how long. Typically for randomised controlled trials, crossover trials, and before and after studies.
- Main outcome measures (within Methods): those as planned in the protocol, and those ultimately measured. Explain differences, if any.

Results

- Start with description of the population and sample. Include key characteristics of comparison groups.
- Main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks.
- Do not replicate data in tables and in text.
- If presenting mean and standard deviations, specify this clearly. Our house style is to present this as follows:
- E.g.: The mean (SD) birth weight was 2 500 (1 210) g. Do not use the ± symbol for mean (SD).
- Leave interpretation to the Discussion section. The Results section should just report the findings as per the Methods section.

Discussion

Please ensure that the discussion is concise and follows this overall structure – sub-headings are not needed:

- Statement of principal findings
- Strengths and weaknesses of the study
- Contribution to the body of knowledge
- Strengths and weaknesses in relation to other studies
- The meaning of the study – e.g. what this study means to clinicians and policymakers
- Unanswered questions and recommendations for future research

Conclusions

This may be the only section readers look at, therefore write it carefully. Include primary conclusions and their implications, suggesting areas for further research if appropriate. Do not go beyond the data in the article.

*In*clude a correspondence address.

Book reviews *Guideline word limit: 400 words :* Should be about 400 words and must be accompanied by the publication details of the book. Provide a hi-res image of the cover if possible (with permission from the copyright holder).

Obituaries *Guideline word limit: 400 words :* Should be offered within the first year of the practitioner’s death, and may be accompanied by a photograph.

Guidelines should always be discussed with the Editor prior to submission.

Because of the intensive review process required to ensure Guidelines are independent, evidence-based and free from commercial bias, they are usually published as a supplement to the *SAMJ*, the costs of which must be covered by sponsorship, advertising or payment by the guideline authors/association. We will provide a quote based on the expected length of the guideline and whether it is to appear online only, or in print, which must be accepted by the body putting the guidelines together before submitting the work to the SAMJ.

The Editor reserves the right to determine the scheduling of supplements. Understandably, a delay in publication must be anticipated dependent upon editorial workflow. All guidelines should include a clear, transparent statement about all sources of funding and an explicit, clear statement of conflicts of interest of any of the participants in the guidelines about industry funding for lectures, research, conference participation etc. All guidelines should be structured according to Agree II. Please access this website before putting the guidelines together, download the Agree 11 instrument and use this to put the guidelines together. All submitted guidelines will be sent to the local Agree II appraisal committee for review and must be endorsed by an appropriate body prior to consideration and all conflicts of interest expressed.

A structured abstract not exceeding 400 words (recommended sub-headings: *Background, Recommendations, Conclusion*) is required. Sections and sub-sections must be numbered consecutively (e.g. 1. Introduction; 1.1 Definitions; 2.etc.) and summarised in a Table of Contents.

Illustrations/photos/scans

- If illustrations submitted have been published elsewhere, the author(s) should provide consent to republication obtained from the copyright holder.
- Figures must be numbered in Arabic numerals and referred to in the text e.g. '(Fig. 1)'.
- Each figure must have a caption/legend: Fig. 1. Description (any abbreviations in full).
- All images must be of high enough resolution/quality for print.
- All illustrations (graphs, diagrams, charts, etc.) must be in PDF or jpeg form.
- Ensure all graph axes are labelled appropriately, with a heading/description and units (as necessary) indicated. Do not include decimal places if not necessary e.g. 0; 1.0; 2.0; 3.0; 4.0 etc.
- Scans/photos showing a specific feature e.g. *Intermediate magnification micrograph of a low malignant potential (LMP) mucinous ovarian tumour. (H&E stain).* –include an arrow to show the tumour.
- Each image must be attached individually as a 'supplementary file' upon submission (not solely embedded in the accompanying manuscript) and named Fig. 1, Fig. 2, etc.

Tables

- Tables should be constructed carefully and simply for intelligible data representation. Unnecessarily complicated tables are strongly discouraged.
- Large tables will generally not be accepted for publication in their entirety. Please consider shortening and using the text to highlight specific important sections, or offer a large table as an addendum to the publication, but available in full on request from the author
- Embed/include each table in the manuscript Word file - do not provide separately as supplementary files.
- Number each table in Arabic numerals (Table 1, Table 2, etc.) and refer to consecutively in the text.
- Tables must be cell-based (i.e. not constructed with text boxes or tabs) and editable.
- Ensure each table has a concise title and column headings, and include units where necessary.
- Footnotes must be indicated with consecutive use of the following symbols: * † ‡ § ¶ || then ** †† ‡‡ etc.

Do not: Use [Enter] within a row to make ‘new rows’:
Rather: Each row of data must have its own proper row

Do not: use separate columns for *n* and %:
Rather: Combine into one column, *n* (%)

Do not: have overlapping categories, e.g.:
Rather: Use <> symbols or numbers that don't overlap

References

NB: *Only complete, correctly formatted reference lists in Vancouver style will be accepted. Reference lists must be generated manually and not with the use of reference manager software. Endnotes must* ***not*** *be used.*

- Authors must verify references from original sources.
- Citations should be inserted in the text as superscript numbers between square brackets, e.g. These regulations are endorsed by the World Health Organization,[2] and others.[3,4-6]
- All references should be listed at the end of the article in numerical order of appearance in the Vancouver style (not alphabetical order).
- Approved abbreviations of journal titles must be used; see the List of Journals in Index Medicus.
- Names and initials of all authors should be given; if there are more than six authors, the first three names should be given followed by et al.
- Volume and issue numbers should be given.
- First and last page, in full, should be given e.g.: 1215-1217 **not** 1215-17.
- Wherever possible, references must be accompanied by a digital object identifier (DOI) link). Authors are encouraged to use the DOI lookup service offered by CrossRef:

- On the Crossref homepage, paste the article title into the 'Metadata search' box.
- Look for the correct, matching article in the list of results.
- Click Actions > Cite
- Alongside 'url =' copy the URL between { }.
- Provide as follows, e.g.: https://doi.org/10.7196/07294.937.98x

Some examples:

Journal references: Price NC, Jacobs NN, Roberts DA, et al. Importance of asking about glaucoma. Stat Med 1998;289(1):350-355. http://dx.doi.org/10.1000/hgjr.182

- *Book references:* Jeffcoate N. Principles of Gynaecology. 4th ed. London: Butterworth, 1975:96-101.
- *Chapter/section in a book:* Weinstein L, Swartz MN. Pathogenic Properties of Invading Microorganisms. In: Sodeman WA, Sodeman WA, eds. Pathologic Physiology: Mechanisms of Disease. Philadelphia: WB Saunders, 1974:457-472.

- *Internet references:* World Health Organization. The World Health Report 2002 - Reducing Risks, Promoting Healthy Life. Geneva: WHO, 2002. http://www.who.int/whr/2002 (accessed 16 January 2010).
- Legal references

- Government Gazettes: National Department of Health, South Africa. National Policy for Health Act, 1990 (Act No. 116 of 1990). Free primary health care services. Government Gazette No. 17507:1514. 1996. In this example, 17507 is the Gazette Number. This is followed by :1514 - this is the notice number in this Gazette.
- Provincial Gazettes: Gauteng Province, South Africa; Department of Agriculture, Conservation, Environment and Land Affairs. Publication of the Gauteng health care waste management draft regulations. Gauteng Provincial Gazette No. 373:3003, 2003.
- Acts: South Africa. National Health Act No. 61 of 2003.
- Regulations to an Act: South Africa. National Health Act of 2003. Regulations: Rendering of clinical forensic medicine services. Government Gazette No. 35099, 2012. (Published under Government Notice R176).
- Bills: South Africa. Traditional Health Practitioners Bill, No. B66B-2003, 2006.
- Green/white papers: South Africa. Department of Health Green Paper: National Health Insurance in South Africa. 2011.
- Case law: Rex v Jopp and Another 1949 (4) SA 11 (N)
  Rex v Jopp and Another: Name of the parties concerned
  1949: Date of decision (or when the case was heard)
  (4): Volume number
  SA: SA Law Reports
  11: Page or section number
  (N): In this case Natal - where the case was heard. Similarly, (C) would indicate Cape, (G) Gauteng, and so on.
  NOTE: no . after the v
- *Other references (e.g. reports) should follow the same format:* Author(s). Title. Publisher place: Publisher name, year; pages.
- Cited manuscripts that have been accepted but not yet published can be included as references followed by '(in press)'.
- Unpublished observations and personal communications in the text must **not** appear in the reference list. The full name of the source person must be provided for personal communications e.g. '...(Prof. Michael Jones, personal communication)'.

From submission to acceptance

Submission and peer-review

To submit an article:

- Please ensure that you have prepared your manuscript in line with the SAMJ requirements.
- The following are required for your submission to be complete:
- Anonymous manuscript (unless otherwise stated)
- Manuscript

- Any supplementary files: figures, datasets, patient consent form, permissions for published images, etc.
- Once the submission has been successfully processed, it will undergo a technical check by the Editorial Office before it will be assigned to an editor who will handle the review process. If the author guidelines have not been appropriately followed, the manuscript may be sent back to the author for correcting.

Peer-review process

Production process

Please note that there is a 6-month waiting time for publication, once an article has been sent to the production team.

The following process will follow:

1. An accepted manuscript is passed to a Managing Editor to assign to a copyeditor (CE).
2. The CE copyedits in Word, working on house style, format, spelling/grammar/punctuation, sense and consistency, and preparation for typesetting.
3. If the CE has an author queries, he/she will contact the corresponding author and send them the copyedited Word doc, asking them to solve the queries by means of track changes or comment boxes.
4. The authors are typically asked to respond within 1-3 days. Any comments/changes must be clearly indicated e.g. by means of track changes. Do not work in the original manuscript - work in the copyedited file sent to you and make your changes clear.
5. The CE will finalise the article and then it will be typeset.
6. Once typeset, the CE will send a PDF of the file to the authors to complete their final check, while simultaneously sending to the 2nd-eye proof reader.
7. The authors are typically asked to complete their final check and sign-off within 1-2 days. No major additional changes can be accommodated at this point.
8. The CE implements the authors' and proof reader's mark-ups, finalises the file, and prepares it for the upcoming issue.

Changing contact details or authorship : Please notify the Editorial Department of any contact detail changes, including email, to facilitate communication.

Publication

Online v. print The *SAMJ* is an online journal. The online version of the journal is the one that has the widest circulation, is indexed by bibliographic databases including PubMed and SciELO, and is accessible in academic libraries. A printed edition , containing material selected by the Editor is also published each month and distributed to the membership of the South African Medical Association.

Online

- The full text of all accepted articles is published in full online, open access.
- Citation information of each article is based on its online publication.

- You may want to make use of the advantages of online publication e.g. specify web links to other sources, images, data or even a short video.

Print

- Not all articles will be selected for print.
- An article may be selected for print in a different month from that in which it was published online.
- Research articles will appear *in abstract form only*, if selected for a print edition.

Errata and retractions

Errata Should you become aware of an error or inaccuracy in yours or someone else's contribution after it has been published, please inform us as soon as possible via an email to publishing@samedical.org, including the following details:

- Journal, volume and issue in which published
- Article title and authors
- Description of error and details of where it appears in the published article
- Full detail of proposed correction and rationale

We will investigate the issue and provide feedback. If appropriate, we will correct the web version immediately, and will publish an erratum in the next issue. The correction will be indexed, as PubMed has a function for linking errata back to the original article. All investigations will be conducted in accordance with guidelines provided by the Committee on Publication Ethics (COPE).

Retractions of an article is the prerogative of either the original authors or the editorial team of SAMA. Should you wish to withdraw your article before publication, we need a signed statement from all the authors. Should you wish to retract your published article, all authors have to agree in writing before publication of the retraction.

Send an email to publishing@hmpg.co.za, including the following details:

- Journal, volume and issue to which article was submitted/in which article was published
- Article title and authors
- Description of reason for withdrawal/retraction.

We will make a decision on a case-by-case basis upon review by the editorial committee in line with international best practices. Comprehensive feedback will be communicated with the authors with regard to the process. In case where there is any suspected fraud or professional misconduct, we will follow due process as recommended by the Committee on Publication Ethics (COPE), and in liaison with any relevant institutions. When a retraction is published, it will be linked to the original article.

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Published articles are covered by the following major indexing services. As such articles published in the *SAMJ* are immediately available to all users of these databases, guaranteed a global and African audience:

- Index Medicus (Medline/PubMed)
- ExcerptaMedica (EMBASE)
- Biological Abstracts (BIOSIS)
- Science Citation Index (SciSearch)
- Current Contents/Clinical Medicine
- Scopus
- AIM
- AJOL
- Crossref
- Sabinet
- Scielo

Sponsored supplements Contact claudian@samedical.org for information on submitting ad hoc/commissioned supplements, including guidelines, conference/congress abstracts, Festschrifts, etc.

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Appendix B: UCT Human Research Ethics Committee Approval letters

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

27 September 2021

HREC REF:443/2021

Prof K Donald
Department of Paediatrics
Red Cross Children's Hospital
Email: kirsty.donald@uct.ac.za
Student: Sashmi.moodley@yahoo.com

Dear Prof Donald

PROJECT TITLE: PARENT EXPERIENCES IN CHILDHOOD DISABILITY ACCENTUATED BY THE IMPACT OF THE CORONAVIRUS IN SOUTH AFRICA. A QUALITATIVE AND QUANTITATIVE ANALYSIS-MPHIL CANDIDATE-DR SASHMI MOODLEY

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020: 06 July 2020 & 01 July 2021.

Approval is granted for one year until the 30 September 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Dr Sashmi Moodley will also be involved in this study.

Please quote the HREC REF 443/2021 in all your correspondence.

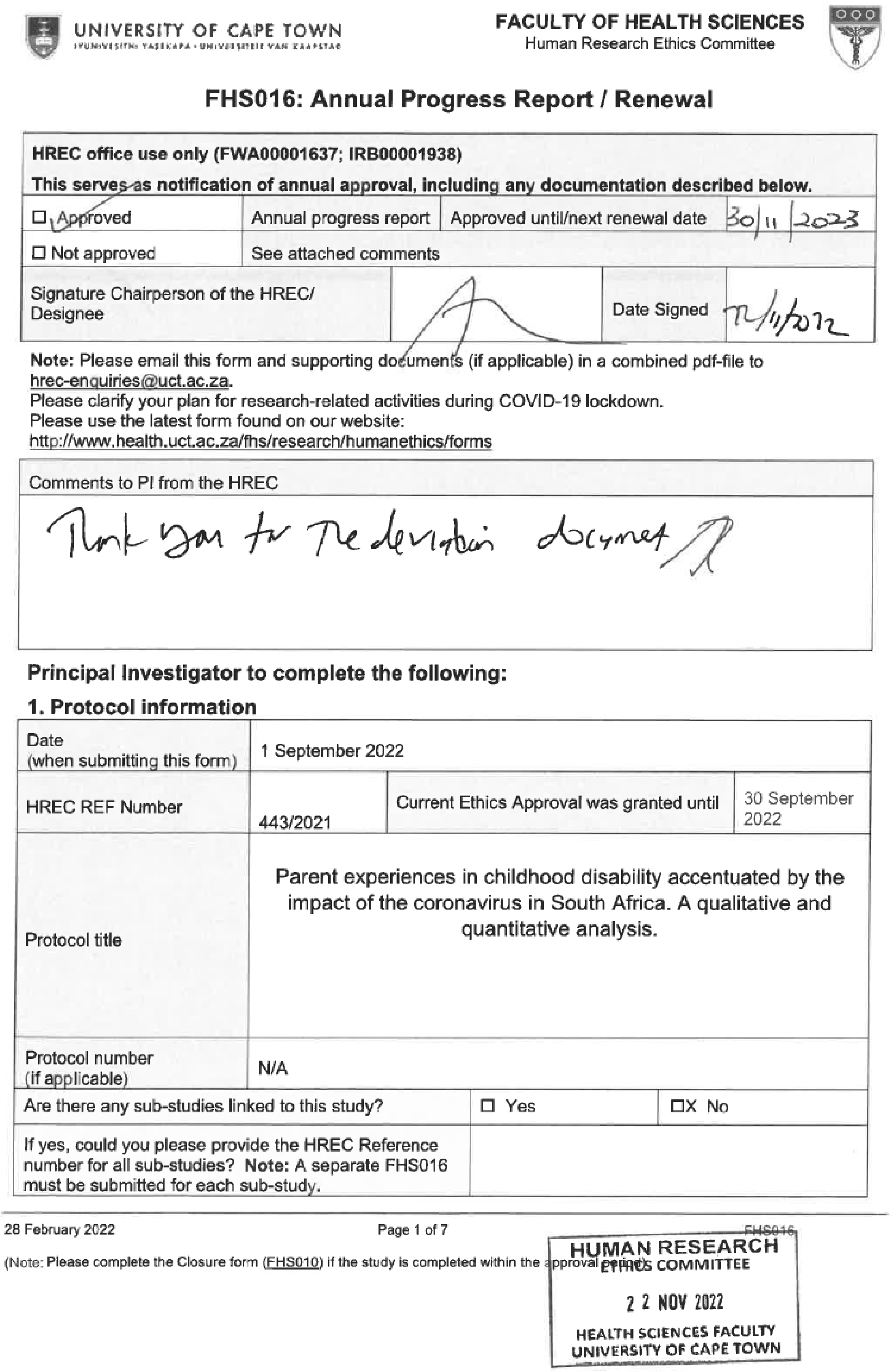
Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.



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FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) **This serves as notification of annual approval, including any documentation described below.**			
☑ Approved	Annual progress report	Approved until/next renewal date	30/11/2023
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	22/11/2022

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Comments to PI from the HREC
Thank you for the deviation document

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	1 September 2022			
HREC REF Number	443/2021	Current Ethics Approval was granted until	30 September 2022	
Protocol title	Parent experiences in childhood disability accentuated by the impact of the coronavirus in South Africa. A qualitative and quantitative analysis.			
Protocol number (if applicable)	N/A			
Are there any sub-studies linked to this study?		☐ Yes	☐X No	
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.				

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(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

HUMAN RESEARCH ETHICS COMMITTEE
22 NOV 2022
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Principal Investigator	Kirsty Donald
Department / Office Internal Mail Address	Department of Paediatrics and Child Health Kirsty.donald@uct.ac.za

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐X No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-submission@uct.ac.za)	☐ Yes	☐ No

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Ethics Renewal Fee

Please **(tick ✓)**appropriate box for billing purposes:

Submission Type	***Description***	***New fee (Vat Incl.)***	***tick ✓***
Research funded solely from UCT departmental/ divisional/group budget	Annual evaluation of research progress report for re-certification	**R0,00**	☐√
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Annual evaluation of research progress report for re-certification	**R0,00**	☐
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R7000,00**	☐
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Expedited review	**R3 710.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National grant funded research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R6000.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National Grant funded research for Annual evaluation of research progress report for re-certification for Expedited review	**R1 500,00**	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for Invoicing, either complete section 1 or 2 :

1. **Invoice billing – Directly to Sponsor**

Sponsor's name	

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	332

6. Cumulative summary of participants

Total number of participants who provided consent	**68**
Number of participants determined to be ineligible (i.e. after screening)	-
Number of participants currently active on the study	-
Number of participants completed study (without events leading to withdrawal)	68
Number of participants withdrawn at participants' request (i.e. changed their mind)	-
Number of participants withdrawn by PI due to toxicity or adverse events	-
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	-
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	-
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	-

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
The data collection was completed in December 2021. Analysis of Covid survey completed in Jan 2022. Ongoing data analysis of the Family Quality of life Questionaire, Resilience Scale and Parent interviews.

8. Protocol violations and exceptions (tick ✓ all that apply)

☐√	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

☐√	No Prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
N/A

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	☐X Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	☐ No	☐ X Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☐ No	☐ X Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ Not applicable

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

	DSMB report attached	☐ Yes	☐ No	☐ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☐X No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☐X	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
N/A

13. Insurance

Please confirm that valid no fault insurance is still in place? **(tick ✓)**			
☐ Yes	☐ No	☐X Not Applicable – N/A	
If yes, please complete the following:			
Insurer's name:			
Policy no.		*Coverage Period:	
For UCT sponsored studies please liaise the Insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate.			

14. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	☐X No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

15. Signature

My signature certifies that the above is complete and correct.			
Signature of PI		Date	21.11.22

Appendix C: COVID–19 survey with consent

Parent experiences in childhood disability accentuated by the impact of the coronavirus in South Africa. A Survey.

Researchers: Dr. Sashmi Moodley, Dr Kirsten Reichmuth, Professor Michael Hendricks and Professor Kirsten Donald

Affiliation: Red Cross War Memorial Children's Hospital, Department of Paediatrics and Child Health, Division of Developmental Paediatrics, University of Cape Town

In collaboration with Shonaquip Social Enterprise

Why are we doing this?

In this study want to understand the experience of parents caring for children with disability in South Africa how you have coped. We recognize that the coronavirus pandemic affected all areas of your child's life. Many reports have been published around the world in medical journals including Africa regarding the impact of coronavirus on childhood disabilities. We want to be able to report the extent of the impact on your family in our country. Hearing your perspective, puts us in a position to report on your challenges as a group. These important aspects of the effect of stressful situations on childhood disability and how you approach them, are important areas that the parent program may be able to use to build support for parents of children with disabilities in the future.

Informed consent

Kindly note the following

- Your name and your child's name will not be used nor published
- Your responses may be used or published
- Being a part of this study is your own free will
- You will not receive any payment.
- You can refuse to answer any question

I agree to complete this survey

Demographics

Child’s Age:
less than 2 years
2 - 5 years
5 - 12 years
12 - 18 years
More than 18 years

Province/ Town:
Eastern Cape
Free State
Gauteng
Kwa Zulu Natal
Limpopo
Mpumulanga
Northern Cape
North West Province
Western Cape

Relationship to child:
mother
Father
Grandparent
relative
Foster carer
Other

What is your child’s condition?

For the next set of questions please choose options :

1. When did you realize that the coronavirus was a problem in South Africa?
    a. when other countries were affected early
    b. When the president declared a lockdown
    c. When my family at home was affected
    d. When someone close to me passed away

2. Who tested positive for coronavirus?
    a. Your child
    b. Yourself
    c. Relative at home
    d. None of the above

3. During the pandemic your child's condition
    a. Was better than usual
    b. was the same.
    c. Worsened.

4. Did you receive a telephone call from a health professional?
    a. yes
    b. no

    c. If yes, please specify which health professional.

5. How was your employment affected?
    a. I worked like usual.
    b. I worked from home.
    c. I lost my job.
    d. My family lost income.
    e. I was forced to find a new job.
    f. I could not make payments.
    g. None of the above.

6. My groceries were
    a. not enough.
    b. bought online.
    c. delivered by friends/family.
    d. given by social services.
    e. not a problem to access.

7. With regard to educational facilities and care centers closing:
    a. my child stayed at school.
    b. my school sent ideas for activities to us.
    c. we had online contact with them.
    d. I did not send my child back when it opened.

8. How did you experience caregiving at home?
    a. I lost my extra help.
    b. My family was very supportive.
    c. I enjoyed having more time with my child.
    d. I was very stressed.

9. Select all options that describe your concern during the pandemic:
    a. Your child was not able to protect himself by wearing a mask.
    b. Someone else would have to care for your child if you got sick.
    c. Going into hospital for his/her usual sickness will give him coronavirus.
    d. My family moving out would get the virus.
    e. other

10. Did you have enough information about a childhood disability in the pandemic?
    a. Yes
    b. no

11. Were you able to reach out to other families with childhood disability?
    a. Yes
    b. No

12. My mental health/ mood and motivation
    a. Was low because of my added stress.
    b. had to be stronger than usual
    c. was the same.
    d. needed alcohol/ cigarettes/drugs to keep cool.

13. What was positive about lockdown?
    a. More family time.
    b. Slower pace of life.
    c. Time to reflect on the on what matters in life.
    d. Time for hobbies at home.
    e. We stayed healthy as a family.
    f. I learnt to be more patient.
    g. Nothing really.
    h. other

14. Was the care for children with disabilities prioritized in the country?
    a. Yes
    b. No

15. Any information you would like to add about COVID in your child's world?