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RESEARCH ARTICLE

Experiences of parents of children with cochlear implants in South Africa: an exploratory study

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ABSTRACT

Purpose: Cochlear implantation is a well-established option for early intervention. Children with hearing impairment and their parents are users of intervention services, with parents being more suited to provide insight into their experiences. The purpose of the current study was to describe the experiences of parents of children with cochlear implants (CIs) in the South African context.

Methods: A qualitative research design was employed. Non-probability, purposive sampling was used. Seven, online semi-structured interviews were conducted with parents of children with CIs. Data were analysed using inductive thematic analysis.

Results: Participants expressed feelings of certainty and assurance in the CI journey. Participants extended gratitude to the healthcare professionals involved in their children's CI journey. Feelings of doubt and stress were noted when coming to terms with the decision of cochlear implantation and financial stressors were noted as a challenge. Many participants found it challenging transitioning their children into school.

Conclusions: Parents conveyed having no regrets with their decision of cochlear implantation for their child and were grateful for the support provided by healthcare professionals. However, financial, and educational challenges remain. Findings suggest the need for more financial support for cochlear implantation in South Africa, and for adequate inclusive educational settings.

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KEYWORDS
Parents; children; cochlear implants; experience

IMPLICATIONS FOR REHABILITATION

- Parental involvement and family-centred care are important to the success of cochlear implantation in children.
- Parents do report positive experiences with regard to cochlear implantation
- Financial stressors and schooling remain a challenge for parents to navigate through the CI journey.
- Counselling, provision of information, and ongoing support by healthcare professionals is recommended to assist parents in making informed decisions regarding cochlear implantation and schooling.

Introduction

Hearing impairment has been noted as the fourth most common cause of disability globally and the second most non-fatal disabling condition in low- and middle-income countries [1,2]. Global estimates indicate that one in five people live with hearing impairment of varying degrees. Moderate or higher degrees of hearing impairment account for sixty-five percent of disability, with 34 million comprising children, and nearly 80% of these individuals residing in low- and middle-income countries such as South Africa [3]. Previous data from a national census in South Africa suggests that 0.7% of the population above five years of age present with severe hearing impairment [4]. There are limited population-based studies pertaining to the prevalence of hearing impairment in South Africa and Africa at large [5].

Untreated hearing impairment has an impact on individuals and their family as well as a significant economic impact on society [3]. At an individual level, hearing impairment, if unmanaged can result in challenges with listening, communication, speech, and language development which in turn has an impact on overall development. These communication challenges may negatively impact social interaction with family as well as result in unemployment which has an economic impact. The overall global cost of unaddressed hearing impairment is $980 billion annually, with 53% of societal costs being attributed to low- and middle-income countries [6–8]. Early intervention is important as the impact of hearing impairment on one's life rests on the implementation of clinical and rehabilitative interventions as well as the responsiveness of the individual's environment to their needs [9].

Cochlear implantation is a well-established option for early intervention in children with severe to profound sensorineural hearing loss who have demonstrated limited benefit from hearing aid amplification. The use of cochlear implants (CIs) as an intervention for younger children who are deaf or hard of hearing has continued to increase, and the candidacy and eligibility criteria for this intervention continues to expand [10]. However, it remains a controversial and somewhat unpredictable form of intervention [11,12].

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Although children are considered the primary consumers of CIs and related intervention services, parents are also users of these services and are often more suited to provide insight into their experiences than their children who would usually be too young to do so [13]. There has been heightened interest from researchers from various disciplines including education, psychology, sociology, and economics in obtaining direct accounts and insights from parents of children who have undergone cochlear implantation [12]. This paper focuses on the parental experiences of children with CIs in South Africa. It explores both challenges as well as positive experiences of parents. While there is a body of literature that has explored the experiences of children with CIs, much of the literature in this area has emanated from high income countries with limited literature from low- and middle-income countries [12]. Furthermore, few studies in South Africa [14,15] have specifically reported on the challenges related to the cochlear implantation process, education and support services, or long-term concerns post cochlear implantation, with no focus on the positive experiences of parents of children with CIs.

Experiences of parents of children with cochlear implants

Literature defines parental experiences of having a child with CIs as the emotional, financial, and social impact it has on their lives [16]. Barker et al. [17] suggest that there is a pattern of both positive and challenging experiences within parents' stories of having a child with CIs. Challenging experiences include strain and uncertainty during their child's cochlear implantation process. Parents may also experience detachment should they be unable to cope with the demands of caring for a child with CIs [17].

In the United States of America, parents reported an increase in their child's quality of life after implantation [18]. In a more recent study conducted by Barker et al. [17], parents of children with CIs demonstrated stories of personal growth and persistence throughout the cochlear implantation process. Moroe and Kathrada [15] suggest that parents experience a change in family interactions as well as a need for additional support when having a child with CIs. Similar challenges have been reported in studies in Australia and Saudi Arabia [19–21]. Sarant and Garrard [21] found that parents of children with CIs experience a greater amount of stress than parents of children without hearing impairment. This study provides key insight into the stressors of these parents, some of which are related to the child's language development and schooling.

Importance of considering parental experiences

Parents are key stakeholders in their child's early intervention journey. Parental involvement is deemed to be a predictor of a child's language, rehabilitation and educational success [22,23], and a contributor to psychosocial aspects [24]. Their experiences and involvement in the intervention process can influence the outcome. More receptive parents have a greater and more positive impact on a child's ability to succeed post-implantation [25]. However, parents who experience challenges such as financial constraints report less involvement in therapy and activities to promote language development post-implantation [23]. Wiseman et al. [26] suggest that parents of children with CIs experience unique challenges in caring for their child. The importance of considering parental experiences can allow for better service delivery and understanding amongst healthcare professionals about the context specific challenges and additional services needed.

In addition, parents are intrinsically involved in the decision-making process and intervention approaches post cochlear implantation. Insight into the experiences of parents who have already embarked on this journey can facilitate the decision-making process of parents who are confronted with the need to make decisions about these aspects. Obtaining insight into the experiences of parents can also inform CI centres and policy makers regarding aspects that are working well versus aspects requiring attention and improvement [14].

Gaps remaining in knowledge about experiences of cochlear implantation of children

Findings from a recent scoping review by Kecman [12] highlight that much of the research pertaining to parents of children with CIs has made use of questionnaires and has been concentrated in high income contexts such as North America, United Kingdom and Australia. This author highlights the importance of documenting a wide and diverse range of parent focused experiences for purposes of heterogeneity. This lack of diversity can be addressed through the inclusion of parents of adolescents, fathers, and those living in low-and middle-income countries.

South Africa is currently the only country within the low- and middle-income context of sub-Saharan Africa that has an established national CI programme [27]. There is however a dearth of published data on cochlear implantation in South Africa, with existing publications mainly focused on outcomes of paediatric cochlear implantation [14]. The few studies aimed at exploring parental experiences only provide insight into the challenges-through semi-structured interviews or self-administered questionnaires [14,15].

Materials and methods

Research question

What are the experiences of parents of children with CIs who were implanted in the past 18 months within the South African context?

Research aim

To explore the experiences of parents of children with CIs who were implanted in the past 18 months within the South African context.

Research design

A qualitative research design was employed.

Participants

Non-probability, purposive sampling was used. Parents of children with CIs at a CI centre were invited to participate in the study. The researchers were independent of the centre from where participants were recruited. The participant information sheet was sent to a colleague at the centre who forwarded it to parents of children attending the centre. Parents who indicated willingness to participate contacted the researcher.

The sample size comprised seven parents of children with CIs. Parents had children between the ages of 1 and 10 years, with unilateral or bilateral CIs that had been implanted in the past 18 months. The 18-month period was used to (a) include a slightly larger number of participants as not many had been seen at the centre during 2020 and (b) to allow for accurate recall of experiences by participants. The age group stipulated was used as the audiologists at the research site had seen children in this age group in recent months. Additionally, parents over 18 years of age, with English as their first or second language were included in the study.

Data collection

Data was collected through semi-structured interviews. These interviews were conducted via an online platform (Microsoft Teams) and were audio recorded. Semi-structured interviews were used to obtain qualitative, subjective information from parents of children with CIs regarding their experiences. DeJonckheere and Vaughn [28] describe semi-structured interviews as a useful data collection method when having to gather information from key informants who have personal experiences, beliefs, and perceptions about a specific topic. They further describe it as an effective method for collecting qualitative, open-ended data and as a tool to probe into personal and at times, sensitive areas.

A pilot study was conducted prior to the main study and comprised one participant who is a parent of a child with a CI. The objectives of the pilot study were to assess whether questions were relevant and elicited descriptive and valid responses, and to determine whether any questions were repetitive in the responses they elicited. Findings from the pilot study suggested that the interview questions were appropriate.

There were eight interview questions that covered a description of the experiences of parents of children who have CIs (Appendix A). The interviews were 15–30 minutes in length.

Data analysis

The semi-structured interviews were recorded via Microsoft Teams, which automatically generated transcripts. These transcripts were downloaded and refined by the second author (L.M.). Thereafter, the first two authors (A.K and L.M), analysed the data independently, using principles of inductive thematic analysis, as outlined by Braun and Clarke [29] (Table 1). Once both authors identified broad themes within the transcripts, the third author (A.C) provided feedback on these themes. The first two authors discussed and refined the analysis to reach a consensus on the broad themes identified. Data saturation was reached once the seventh participant was interviewed, the transcript was analysed, and no new codes or themes were identified [30].

Table 1. Six steps used for thematic analysis.

Step	Implementation
Familiarization	Data was transcribed and read multiple times whereby initial ideas were noted and written down.
Generating initial codes	Initial codes that trended across the data were noted. Codes were substantiated by quotes from the data set.
Searching for themes	Codes were then reviewed, patterns were identified and connected codes were collapsed into relevant themes.
Reviewing themes	Themes were checked in relation to the codes generated.
Defining and naming themes	Ongoing analysis of the data ensured each theme was refined and given names.
Producing the report	Extracts from the data were selected as deemed relevant to the various themes. Final analysis of these extracts were related back to the research question and literature.

Trustworthiness

Trustworthiness was achieved in several ways [31,32]. Credibility was achieved through frequent debriefing and reflective discussions during the data analysis phase. Confirmability was achieved through checking and refining of the transcripts against the audio recordings of the interviews. An audit trail of the decision making between authors was also ensured. Transferability was achieved through a purposive sampling of a particular group of participants, a description of the context of data collection, a description of the content of the semi-structured interviews and methods of analysis. Dependability was achieved through keeping researcher notes and process logs of the research process for the project.

Ethical considerations

Ethical clearance was obtained from the University's IRB (Approval number: STA_2022_13). Informed consent was obtained from all participants. Anonymity was ensured during data analysis and write up phases of the study through the use of participant numbers. A distress protocol was incorporated for participants who may have experienced any distress or discomfort during the interviews. Details of support or counselling services were also provided.

Results

Although most participants' first language was not English, they all preferred for the interviews to take place in English. The average age of participants was thirty-six years, and the average age of their children was four years (Table 2).

Thematic analysis yielded five themes: (1) No regrets, (2) Gratitude for guidance and support from healthcare professionals, (3) Mixed emotions navigating the unknown, (4) Financial stressors, and (5) Transitioning to school is a challenge (Table 3).

Theme 1: No regrets

All seven participants expressed feelings of certainty, positivity, and assurance in the CI journey. When discussing the decision of cochlear implantation, participant 4 whose child was implanted

Table 2. Demographic information of participants and their child with cochlear implants.

Age of participant (years)	Sex of participant	Relation of participant to child	Age at which the child was implanted (years)	Unilateral or Bilateral Cochlear Implant	Home language
43	Female	Mother	6	Unilateral	Afrikaans
24	Female	Mother	2	Unilateral	siSwati
35	Female	Mother	2	Unilateral	Sepedi
31	Female	Mother	6	Bilateral	Afrikaans
44	Female	Mother	2	Unknown	English / Afrikaans
30	Female	Mother	4	Unilateral	Afrikaans
45	Female	Mother	5	Unknown	siSwati

after 2 years of age noted that there was *"no doubt that that's the route that we wanted to go. I know that."* It was evident amongst participants that they wanted their children to hear them and the world around them. Participant 6 whose child was implanted after 2 years of age noted "*The cochlear implants gives me the assurance that he can hear me…So I think having a child with cochlear implants and hearing deficiency has made me very pro cochlear implant".* The lack of doubt and the increased positivity surrounding participants' experiences helps substantiate this key theme. Participants also discussed visible improvements in their child's communication as a positive way forward in their cochlear implantation journey. When participants were able to see notable changes in their child's hearing and speech development, it gave them the assurance they needed that cochlear implantation was the right decision. Participant 5 whose child was implanted at 2 years of age noted *"I'm very happy now seeing the results of her having had them done and how far she's come. I mean that it's remarkable. I would do it again".*

Three of the seven participants made note of how grateful they are that their child has CIs and how innovative the technology truly is. Participant 2 whose child was implanted at 2 years of age noted *"I speak a lot about it because it's such a wonderful thing that she's gone through."* Participant 4 whose child was implanted later (after 2 years of age) also noted *"cochlear implants are deemed as a revelation and this great thing for people that can't hear."* Participant 7 mentioned *"I can't imagine life without cochlear implants"* (child implanted after 2 years of age). Thus, the dependency and gratitude participants have for CIs suggest the positive experiences associated with the process.

Theme 2: Gratitude for guidance and support from healthcare professionals

Four participants expressed gratitude to the healthcare professionals involved in their child's CI journey. Two participants discussed their overwhelming gratitude for healthcare professionals. Participant 4 whose child was implanted after 2 years of age noted *"these great audiologists and speech therapists. And you know that guidance… so in many respects we've been fortunate."* Participants also noted the importance of involvement of various healthcare professionals working together to ensure optimal outcomes of cochlear implantation. Participant 5 whose child was implanted at 2 years of age noted *"I just think it's very important to have the education as a parent that is going through this process and to have a team…education along the way and the support structure"*. Two

Table 3. Summary of themes.

Theme	Example Quotes	Age at which child was implanted i.e., before, at, or after 2 years of age
No regrets	*"No doubt that that's the route that we wanted to go. I know that".* [P4]	After 2 years of age
	"The cochlear implants gives me the assurance that he can hear me…So I think having a child with cochlear implants and hearing deficiency has made me very pro cochlear implant". [P6]	After 2 years of age
	"I'm very happy now seeing the results of her having had them done and how far she's come. I mean that it's remarkable. I would do it again". [P5]	At 2 years of age
	"And there's a slight chance that he will maybe need another one for his left side and for me, currently I will not even hesitate if they say he needs another one. So from us, it's positive." [P1]	After 2 years of age
	"I think …I speak a lot about it because it's such a wonderful thing that she's gone through." [P2]	At 2 years of age
	"Because while I can't imagine life without cochlear implants, I didn't know about. It was my first time hearing about it. But I think it's the best. Hey, it's the best. And for the fact that it gives our children a chance to hear." [P7]	After 2 years of age
	"…it is a good thing that we have this option" [P3]	At 2 years of age
Gratitude for guidance and support from healthcare professionals	*"One of the positive things I've experienced with cochlear implants was being able to go to the audiologist."* [P6]	After 2 years of age
	"These great audiologists and speech therapists. And you know that guidance… so in many respects we've been fortunate." [P4]	After 2 years of age
	"I just think it's very important to have the education as a parent that is going through this process and to have a team…education along the way and the support structure". [P5]	At 2 years of age
	"I thank God for doctors and technology." [P7]	After 2 years of age
Mixed emotions navigating the unknown	*"It's a little bit of an emotional rollercoaster up and down sometimes."* [P2]	At 2 years of age
	"Yes, it was a shock initially when we discovered she couldn't hear…" [P4]	After 2 years of age
	"at first it's a scary process" [P1]	After 2 years of age
	"At first it was very hard for me…I was so depressed and everything". [P7]	After 2 years of age
	"Always doubted if we did the right decision. You know, you don't know what's going to happen at the end. You're just trusting the process of she's going to be able to speak…so it's just having those, those discussions with an external party to be able to vent how you're feeling and to get over the process as it happens." [P5]	At 2 years of age
Financial stressors	*"I found the… that implant is quite expensive…then you still have to pay for all the extras that comes after it."* [P3]	At 2 years of age
	"The cost and the maintenance of the device itself." [P4]	After 2 years of age
	"It costs a lot of money. So that was stressful." [P1]	After 2 years of age
	"It's quite expensive, very expensive." [P2]	At 2 years of age
Transitioning to school is a challenge	*"He currently not in school yet because he's got such a … how I can say like, yeah, loss of speech currently. We will need to put him in a special school so that they have more one on one attention to him…"* [P1]	After 2 years of age
	"He doesn't have a lot of vocab. His attending a signed school, so we are still learning to sign… so it's challenging in terms of their speech development". [P3]	At 2 years of age
	"things are sometimes painful to me, but mostly at school, cause sometimes I feel like he notices that he's the only one wearing it" [P7]	After 2 years of age

participants of children implanted after 2 years of age referred to and showed gratitude towards various healthcare professionals such as doctors, speech therapists and audiologists involved in their child's cochlear implantation journey, by stating, *"One of the positive things I've experienced with cochlear implants was being able to go to the audiologist."* (Participant 6). Additionally participant 7 noted *"I thank God for doctors and technology."* Findings suggest that participants valued the emotional support of healthcare professionals in the decision-making process. Healthcare professionals were also reported to have provided information that was helpful, and participants were grateful for the access they had to these professionals.

Theme 3: Mixed emotions navigating the unknown

Five participants conveyed feelings of doubt and stress when coming to terms with the decision of cochlear implantation. Participant 4 confirmed this experience by noting *"Yes, it was a shock initially when we discovered she couldn't hear…"* (child implanted after 2 years of age). This initial shock proved challenging for many participants. Initial doubt and uncertainty was common amongst participants as participant 1 mentioned, *"at first it's a scary process"* (child implanted after 2 years of age), and participant 7 noted *"At first it was very hard for me"*. Feelings of initial despair were also noted by participant 7 who mentioned *"I was so depressed and everything"* (child implanted after 2 years of age). Although positive experiences were noted, some participants experience a range of emotions throughout the cochlear implantation journey, as noted by participant 2 who stated *"it's a little bit of an emotional rollercoaster up and down sometimes."* (child implanted at 2 years of age)

Theme 4: Financial stressors

During the interviews, four participants identified financial stressors as a challenging experience throughout their child's CI journey. Participants referred to additional expenses post-implantation as well as the cost of the implant itself. Participant 3 whose child was implanted at 2 years of age noted *"I found the… that implant is quite expensive…then you still have to pay for all the extras that comes after it."* Participants placed emphasis on the expense of the surgery and device itself, where participant 4 stated *"the cost and the maintenance of the device itself"* (child implanted after 2 years of age) and Participant 1 also noted *"it costs a lot of money. So that was stressful"* (child implanted after 2 years of age). These stressors such as the maintenance of the device post-implantation support the theme of financial stressors.

Theme 5: Transitioning to school is a challenge

Due to delayed speech and language development, three participants found it challenging transitioning their child to school and/or selecting the type of schooling their child would need. These responses varied depending on the participant and their child's language development. Children being implanted at different ages resulted in variations in speech and language development. For example, participant 1 whose child was implanted after 2 years of age noted a lack of speech development as a challenge by stating *"he's currently not in school yet because he's got such a … how I can say like, yeah, loss of speech currently."* When thinking of their child's future schooling, participant 1 went on to say *"we will need to put him in a special school so that they have more one on one attention to him…"* Other participants also suggested that the lack of language has a direct impact on schooling options. Participant 3 whose child was implanted at 2 years of age noted *"He doesn't have a lot of vocab. He is attending a signed school, so we are still learning to sign… so it's challenging in terms of their speech development"*. Participant 7 whose child was implanted after 2 years of age noted another challenge with schooling in suggesting *"things are sometimes painful to me, but mostly at school, cause sometimes I feel like he notices that he's the only one wearing it."* This suggests that aesthetics and interactions with others also presents a challenge in terms of the transition to schooling.

Discussion

Current study findings present a positive picture of cochlear implantation in a single province in South Africa, specifically as participants expressed no regrets with their decision to have their child undergo cochlear implantation as an early intervention option. Participants' gratitude for the support provided by health care professionals was another positive finding. However, coupled with these positive experiences were challenges, two of which were personal challenges related to finances and emotional aspects, and one of which pertained to a broader challenge of transitioning to school because of the child's speech and language development.

Fluctuating emotions pre and post cochlear implantation

The decision of cochlear implantation is initially a difficult and stressful one for most parents of children with severe to profound hearing impairment, as highlighted by participants in the current study who noted initial emotions of shock, fear and depression. Dillon and Pryce [33] suggest that there is a large emotional response when coming to terms with hearing loss and the possible need for cochlear implantation. Individuals experience feelings of stress and emotional inundation when presented with this life-altering decision. These emotions are noted to fluctuate throughout the implantation process, with feelings of relief and excitement reported post implantation, and during the habilitation process [34]. It is important for health care professionals to acknowledge these emotions and to provide relevant support, resources and/or referrals for counselling to help address these emotions, as doing so can assist in addressing the emotional needs of parents, thereby facilitating their navigation through the rehabilitation and habilitation process of their child with CIs.

Positive feedback was provided by participants in the current study regarding their decision for cochlear implantation. Similarly, Porter et al. [35] and Sukonthaman et al. [36] reported that most parents were happy with their decision related to cochlear implantation. Possible reasons for not having any regrets with the decision may be due to notable changes in their child's ability to hear. Kumar et al. [18] suggest that parents value the positive outcomes and seem to have no regrets with regards to the decision to implant. These feelings of certainty and assurance amongst parents stem from their child's ability to hear [18]. Several studies have also noted that a CI is viewed by parents as an option that allows their child to interact socially, thereby affording them the opportunity to interact with the hearing world and the possibility of mainstream schooling [34].

Positive impact of guidance and support from healthcare professionals

Coping with the emotions and decisions along the CI journey is usually possible with support. Parents have reported their need for both informational and emotional support [37,38]. Being able to access this support allows parents to come to terms with their child's hearing impairment and begin the necessary steps towards implantation [39]. Hyde et al. [40] recommends that parents have readily available access to objective, unbiased information, and ongoing support. Participants from the current study expressed gratitude for the support received by health care professionals. Similar findings were reported by Edwards et al. [13] and Hyde et al. [40] where parents reported that professionals within the implant team provided useful support and information, and where a high level of satisfaction was noted regarding the support received when making the decision about a CI for their child. Current study findings do however differ from those by Barker et al. [17] and Sukonthanam et al. [36] where parents often reported a lack of support from healthcare professionals. These findings highlight the need for health care professionals to provide the necessary support to parents, acknowledging that the type of support required (i.e., informational versus emotional) may vary at different points along the CI journey.

Finances and schooling remain challenges

Participants in the current study noted financial stressors related to the cost of the implant itself and/or for the maintenance of the device. These findings are consistent with those reported in several other studies, including previously published literature in South Africa [14,15,20,41,42], and have implications for access to early intervention options for children with severe to profound hearing impairment. Bhamjee et al. [14] report financial difficulties as the leading challenge amongst parents of children with cochlear implants. These difficulties are attributed to the lack of financial support for cochlear implantation in low- and middle- income contexts such as India, South east Asia, and South Africa [41,43]. In contrast, government systems in high income countries such as Finland, Canada, and the United Kingdom cater for the costs associated with paediatric cochlear implantation and/or habilitation costs post implantation [41,44]. These findings highlight the need for cochlear implantation to be made more financially accessible in low- and middle- income contexts, which may be facilitated by mandated programmes for early hearing detection and intervention.

Additionally, literature suggests that parents experience stress when considering their child's language development and schooling post-implantation. Parents of children with CIs exhibit more stress related to schooling than that of parents with children without hearing impairment [26]. This was evident in the current study as participants noted feelings of uncertainty when considering the transition to schooling for their children. Similarly, parents in another study in South Africa reported challenges in finding a school for their children, as well as challenges related to the availability of teachers who are adequately trained to provide early intervention services for children with CIs [14]. These findings highlight the gaps in early intervention services in South Africa and have implications for the continuum of care for children with CIs.

Limitations

This study comprised a small sample size. Participants were only recruited from a single CI centre, in a single province in South Africa.

Conclusions

Parental experiences of having no regrets regarding cochlear implantation for their child may be influenced by the change and progress noted in their child's ability to hear, as well as their speech and language development. Current study findings highlight the advantage and need for health care professionals to provide guidance and ongoing support to parents. Financial and educational aspects remain key challenges to ensuring access to timely intervention post diagnosis of hearing impairment. Health care professionals can play a key role in providing parents with information pertaining to schooling, and counselling could be offered to facilitate the transition to school. There is a definite need for more financial support for cochlear implantation in the South African context, as well as a need for adequate, inclusive educational settings for children with CIs. The specific financial needs should be explored further through research with parents of children with CIs. Future research should also focus on the implementation of policies related to inclusive education.

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Data availability statement

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available.

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References

[1] Cunningham T, Tucci D. Hearing loss in adults. N Engl J Med. 2017;377(25):2465–2473. doi: 10.1056/NEJMra1616601.

[2] WHO. Addressing the rising prevalence of hearing loss. 2018. https://apps.who.int/ iris/bitstream/handle/10665/260336/9789241550260-eng.pdf?sequence=1&ua=1.

[3] WHO. World report on hearing: executive summary. 2021. https://cdn.who.int/media/docs/default-source/documents/health-topics/

deafness-and-hearing-loss/world-report-on-hearing/wrh-executive-summary.en.pdf?sfvrsn=feb8d533_30&download=true.

[4] Statistics South Africa. Census 2011: profile of persons with disabilities in South Africa. 2011. http://www.statssa.gov.za/publications/Report-03-01-59/ Report-03-01-592011.pdf.

[5] Mulwafu W, Kuper H, Ensink RJ. Prevalence and causes of hearing impairment in africa. Trop Med Int Health. 2016;21(2):158–165. doi: 10.1111/tmi.12640.

[6] Hall WC. What you don't know can hurt you: the risk of language deprivation by impairing sign language development in deaf children. Matern Child Health J. 2017;21(5):961–965. doi: 10.1007/s10995-017-2287-y.

[7] McDaid D, Park A, Chadha S. Estimating the global costs of hearing loss. Int J Audiol. 2021;60(3):162–170. doi: 10.1080/14992027.2021.1883197.

[8] Vas VF. The biopsychosocial impact of hearing loss on people with hearing loss and their communication partners. University of Nottingham; 2017.

[9] Bhamjee A, Mahomed-Asmail F, Perold J, et al. Cochlear implantation in South Africa (part 1). SAMJ. 2021;112(1):8–10. doi: 10.7196/SAMJ.2021.v111i1.16017.

[10] Varadarajan VV, Sydlowski SA, Li MM, et al. Evolving criteria for adult and pediatric cochlear implantation. Ear Nose Throat J. 2021;100(1):31–37. doi: 10.1177/0145561320947258.

[11] Humphries T, Kushalnagar P, Mathur G, et al. Global regulatory review needed for cochlear implants: a call for FDA leadership. Matern Child Health J. 2020;24(11):1345–1359. 24(11),1345–. doi: 10.1007/s10995-020-03002-5.

[12] Kecman E. Research about parents of children with cochlear implants: a scoping review. J Deaf Stud Deaf Educ. 2022;27(3):214–233. doi: 10.1093/deafed/enac005.

[13] Edwards LC, MacArdle BM, Doney A, et al. Parental experiences of a paediatric cochlear implant programme. Cochlear Implants Int. 2000;1(2):95–107. doi: 10.1179/cim.2000.1.2.95.

[14] Bhamjee A, Le Roux T, Schlemmer K, et al. Parent-perceived challenges related to the pediatric cochlear implantation process and support services received in South Africa. Int J Pediatr Otorhinolaryngol. 2019;126:109635. (doi: 10.1016/j.ijporl.2019.109635.

[15] Moroe N, Kathrada N. The long-term concerns post cochlear implantation as experienced by parents/caregivers of prelingually deaf children between the ages of 3 and 5 years in Gauteng province, South Africa. S Afr J CH. 2016;10(2):126–129. doi: 10.7196/SAJCH.2016.v10i2.1049.

[16] Vieira SDS, Dupas G, Chiari BM. Cochlear implant: the family's perspective. Cochlear Implants Int. 2018;19(4):216–224. doi: 10.1080/14670100.2018.1426406.

[17] Barker BA, Scharp KM, Chandler KL, et al. Exploring the types of stories hearing parents tell about rearing their children who use cochlear implants. Ear Hear. 2021;42(5):1284–1294. doi: 10.1097/AUD.0000000000001011.

[18] Kumar R, Warner-Czyz AS, C H, et al. American parent perspectives on quality of life in pediatric cochlear implant recipients. Ear Hear. 2015;36(2):269–278. doi: 10.1097/AUD.0000000000000108.

[19] Aloqaili Y, Arafat AS, Almarzoug A, et al. Knowledge about cochlear implantation: a parental perspective. Cochlear Implants Int. 2019;20(2):74–79. doi: 10.1080/14670100.2018.1548076.

[20] Bodington E, Saeed SR, Smith MC, et al. A narrative review of the logistic and economic feasibility of cochlear implants in lower-income countries. Cochlear Implants Int. 2021;22(1):7–16. doi: 10.1080/14670100.2020.1793070.

[21] Sarant J, Garrard P. Parenting stress in parents of children with cochlear implants: relationships among parent stress, child language, and unilateral versus bilateral implants. J Deaf Stud Deaf Educ. 2014;19(1):85–106. doi: 10.1093/deafed/ent032.

[22] Bruin M. Parental involvement in children's learning: the case of cochlear implantation—parents as educators? Scand J Educ Res. 2018;62(4):601–616. doi: 10.1080/00313831.2016.1258728.

[23] Cejas I, Mitchell CM, Barker DH, et al. Parenting stress, self-efficacy, and involvement: effects on spoken language ability three years after cochlear implantation. Otol Neurotol. 2021;42(10S):S11–S18. doi: 10.1097/MAO.0000000000003374.

[24] Sarant JZ, Harris DC, Galvin KL, et al. Social development in children with early cochlear implants: normative comparisons and predictive factors, including bilateral implantation. Ear Hear. 2018;39(4):770–782. doi: 10.1097/AUD.0000000000000533.

[25] Silva JDM, Yamada MO, Guedes EG, et al. Factors influencing the quality of life of children with cochlear implant. Braz J Otorhinolaryngol. 2020;86(4):411–418. doi: 10.1016/j.bjorl.2019.01.004.

[26] Wiseman KB, Warner-Czyz AD, Nelson JA. Stress in parents of school-age children and adolescents with cochlear implants. J Deaf Stud Deaf Educ. 2021;26(2):209–222. doi: 10.1093/deafed/enaa042.

[27] Emmett SD, Tucci DL, Smith M, et al. GDP matters: cost effectiveness of cochlear implantation and deaf education in Sub-Saharan Africa. Otol Neurotol. 2015;36(8):1357–1365. doi: 10.1097/MAO.0000000000000823.

[28] DeJonckheere M, Vaughn LM. Semistructured interviewing in primary care research: a balance of relationship and rigour. Fam Med Community Health. 2019;7(2):e000057. doi: 10.1136/fmch-2018-000057.

[29] Braun V, Clarke V, Hayfield N, et al. Thematic analysis. In P. Liamputtong, editor. Handbook of research methods in health social sciences. Singapore: Springer; 2019.

[30] Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893–1907. doi: 10.1007/s11135-017-0574-8.

[31] Connelly LM. Trustworthiness in qualitative research. Medsurg Nurs. 2016;25(6):435.

[32] Tracy SJ. Qualitative quality: eight "Big-Tent" criteria for excellent qualitative research. Qualitative Inquiry. 2010;16(10):837–851. doi: 10.1177/1077800410383121.

[33] Dillon B, Pryce H. What makes someone choose cochlear implantation? An exploration of factors that inform patient decision making? Int J Audiol. 2020;59(1):24–32. doi: 10.1080/14992027.2019.1660917.

[34] Peñaranda A, Suárez RM, Niño NM, et al. Parents' narratives on cochlear implantation: reconstructing the experience of having a child with cochlear implant. Cochlear Implants Int. 2011;12(3):147–156. doi: 10.1179/146701010X12711475887397.

[35] Porter A, Creed P, Hood M, et al. Parental decision-making and deaf children: a systematic literature review. J Deaf Stud Deaf Educ. 2018;23(4):295–306. doi: 10.1093/deafed/eny019.

[36] Sukonthaman R, Bowen SK, Detchanarat T. Perceptions and experiences of Thai parents who have a child with a cochlear implant. Communication Disorders Quarterly. 2023;44(2):98–106. doi: 10.1177/15257401221076810.

[37] Gilliver M, Ching TYC, Sjahalam-King J. When expectation meets experience: parents' recollections of and experiences with a child diagnosed with hearing loss soon after birth. Int J Audiol. 2013;52(Suppl 2):S10–S16. doi: 10.3109/14992027.2013.825051.

[38] Scarinci N, Erbasi E, Moore E, et al. The parents' perspective of the early diagnostic period of their child with hearing loss: information and support. Int J Audiol. 2018;57(suppl 2):S3–S14. doi: 10.1080/14992027.2017.1301683.

[39] Rapport F, Hughes SE, Boisvert I, et al. Adults' cochlear implant journeys through care: a qualitative study. BMC Health Serv Res. 2020;20(1):457. doi: 10.1186/s12913-020-05334-y.

[40] Hyde M, Punch R, Komesaroff L. Coming to a decision about cochlear implantation: parents making choices for their deaf children. J Deaf Stud Deaf Educ. 2010;15(2):162–178. doi: 10.1093/deafed/enq004.

[41] Kerr G, Tuomi S, Müller A. Costs involved in using a cochlear implant in South Africa. S Afr J Commun Disord. 2012;59(1):16–26.

[42] Umat C, Wahat NHA, Ross SC, et al. Quality of life of parents and siblings of children with cochlear implants. J Otol. 2019;14(1):17–21. doi: 10.1016/j.joto.2018.11.004.

[43] Le Roux T, Vinck B, Butler I, et al. Predictors of pediatric cochlear implantation outcomes in South Africa. Int J Pediatr Otorhinolaryngol. 2016;84:61–70. doi: 10.1016/j.ijporl.2016.02.025.

[44] Raine C. Cochlear implants in the United Kingdom: awareness and utilization. Cochlear Implants Int. 2013;14(Suppl 1):S32–S37. doi: 10.1179/1467010013Z.00000000077.

Appendix A

Semi-structured interview schedule

Broad section:

1. Could you please describe what it is like having a child with cochlear implants?

2. What are your positive experiences associated with having a child with cochlear implants?

3. Please give an example of a positive experience of having a child with cochlear implants.

4. What are your challenging experiences associated with having a child with cochlear implants?

5. Could you please give an example of a challenging experience of having a child with cochlear implants?

Detailed section/probing questions:

1. How have these positive experiences influenced your feelings towards cochlear implantation?

2. How have these challenging experiences influenced your feelings towards cochlear implantation?

- Elaborate on initial answers: help describe factual/specific events (feelings).

Closing off/Concluding section:

1. Is there anything you want to share that I have not asked you about?