

# Parent-perceived challenges related to the pediatric cochlear implantation process and support services received in South Africa

Aaqilah Bhamjee<sup>a</sup>, Talita le Roux<sup>a</sup>, Kurt Schlemmer<sup>b,c</sup>, Jenny Perold<sup>d</sup>, Nicolize Cass<sup>e</sup>, Kelly Schroeder<sup>f</sup>, Dani Schlesinger<sup>g</sup>, Deon Ceronio<sup>h</sup> and Bart Vinck<sup>a,i</sup>

<sup>a</sup> Department of Speech-Language Pathology and Audiology, University of Pretoria, Pretoria, South Africa

<sup>b</sup> Department of Otorhinolaryngology, Head and Neck Surgery, University of Kwazulu Natal, Durban, South Africa

<sup>c</sup> Durban Cochlear Implant Program, Durban, South Africa

<sup>d</sup> Tygerberg Hospital–Stellenbosch University Cochlear Implant Unit, Cape Town, South Africa

<sup>e</sup> Pretoria Cochlear Implant Unit, Pretoria, South Africa

<sup>f</sup> Port Elizabeth Cochlear Implant Unit, Port Elizabeth, South Africa

<sup>g</sup> Chris Hani Baragwanath Academic Hospital Cochlear Implant Program, Soweto, South Africa

<sup>h</sup> Bloemfontein Cochlear Implant Program, Bloemfontein, South Africa

<sup>i</sup> Speech-Language Audiology Department, Ghent University, Gent, Belgium

## ABSTRACT

*Objective:* To determine and describe parent-perceived challenges related to the pediatric cochlear implantation process and support services received.

*Method:* A multicenter survey study across six cochlear implant (CI) programs in South Africa (SA) was conducted. The study sample included 82 parents of pediatric ( $\leq 18$  years) CI recipients with at least 12 months CI experience. A self-administered questionnaire was developed for the purpose of this study, exploring parental challenges regarding the CI process, education of their implanted children and the support services received.

*Results:* The financial implications of cochlear implantation, including CI device maintenance, were identified by parents as the most prominent challenge. Financing issues were the highest scoring reason that attributed to the delay between diagnosis of hearing loss and cochlear implantation, as well as the greatest barrier to bilateral implantation. Parent-perceived educational challenges included finding adequate educational settings specific to the individual needs of their child and a shortage of trained teachers equipped to support children with CIs. The presence of one/ more additional developmental conditions and grade repetition were associated with more pronounced parent-perceived educational challenges. Parents considered speech-

language therapy as the most critical support service for their implanted children to achieve optimal outcomes, while parent guidance was indicated to be the most critical support service required for parents of pediatric CI recipients.

*Conclusion:* A greater understanding of parent-perceived challenges will guide CI professionals to promote optimal outcomes, evidence-based service delivery and on-going support to pediatric CI recipients and their families. Study results imply a call for action regarding financial and educational support for pediatric CI recipients in SA.

**Keywords:** cochlear implant; South Africa; parents; perceptions; challenges; support services.

**Abbreviations:** CI, cochlear implant; CCIPP, Children with cochlear implants: Parental perspectives; SA, South Africa; SASL, South African Sign Language.

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## **1. Introduction**

Over 300 000 deaf individuals worldwide, of which more than 80 000 are children, have received access to sound through cochlear implantation [1,2]. The benefits of early cochlear implantation for speech and language development [3–6] and for broader psychosocial and educational outcomes [7] are well documented. Understandably, parental expectations for pediatric cochlear implantation are high [8]. However, outcomes following pediatric cochlear implantation vary [7,9] and are neither definitively guaranteed nor instantaneous [10]. Varying

outcomes not only initiates parental anxiety but also affects the parenting role [11]. Furthermore, post implantation, parents of implanted children encounter new long-term cochlear implant (CI) related parental responsibilities [7,12,13] which should be recognized by CI teams, since the level of parental commitment towards the implantation and (re)habilitation process affects the outcomes achieved [13–15]. Despite positive parental reported experiences post-implantation [16,17], parents do recognise the long-term nature of CI (re)habilitation and as a result parental stress does not necessarily decrease over time [18].

In spite of the known benefits of early cochlear implantation, a substantial number of children from developed and developing world regions still undergo implantation at a late age [19,20]. In South Africa (SA) specifically, the average age of implantation for children with congenital/ early onset hearing loss was reported to exceed three and a half years of age, with an average delay of more than two years from the time of hearing loss diagnosis to cochlear implantation [20]. Possible factors contributing to delayed cochlear implantation in SA include funding constraints, delays in referrals to specialized CI programs, long travelling distances to CI centers and an overall inequality in healthcare access [20,21].

Parents of pediatric CI recipients not only incur costs directly related to the implantation, but also costs related to supporting optimal outcomes thereafter [22]. In most developed countries, direct medical costs for pediatric cochlear implantation are not incurred by the parents and are instead covered by a national health system [21]. However, in developing countries, the funding of CIs for the pediatric population and the subsequent (re)habilitation thereafter remains primarily on the onus of the parents [23]. With the majority (85%) of the South African population being

reliant on public healthcare for health services [24] and with only four active public sector/ government funded CI programs countrywide, cochlear implantation is considered as a privileged intervention since only a very limited number of individuals with severe to profound hearing loss receive CIs within SA's public health sector [25,26]. This is evident from the statistics reported by the South African Cochlear Implant Group whereby a total of 228 individuals were implanted in SA in 2017, of which only 47 implants were government funded [26]. As a result, most parents of children requiring CIs are necessitated to have access to a private medical aid or sufficient finances to access cochlear implantation [21]. Hence it is evident that within a developing context such as SA, the financial costs incurred by parents throughout the CI process are extensive and are a lifelong financial burden.

After implantation, the issue of education could be a significant concern for families as they often encounter altercations with the education authorities [7]. Children with CIs require educational placement appropriate to their specific needs and requirements [20,27]. As a result, parents need to decide on an educational setting that would best suit their child's individual needs. However, finding such an appropriate school setting is a challenge encountered by many parents [28–31]. Furthermore, obtaining specialized support services in schools is a difficulty experienced by families in developing countries such as SA [29,32] as well as in developed countries such as the United States [7] and the United Kingdom [31]. Consequently, the provision of inadequate educational support for children with CIs and their parents may exacerbate parental anxiety [33].

With the emphasis of international research being predominantly on the medical aspects of implantation and the speech and language outcomes of implanted children [33], available data on parents' perceived challenges regarding the CI process and support services received are limited [34]. Since parents are critical partners in the (re)habilitation process, knowledge and a thorough understanding of their experiences and challenges post implantation is required to ensure that adequate guidance and support is provided in order to obtain the best possible (re)habilitation outcomes [35,36]. Furthermore, parents are the primary decision makers for cochlear implantation. When confronted with the need to make this decision, knowledge regarding the perceptions of other parents who have already experienced the CI process could be beneficial [37,38]. These experienced parents can also assist in keeping CI centers and policy makers well informed regarding their perceived challenges and experiences with the CI process [37].

Currently, SA is the only country in sub-Saharan Africa with an established national CI platform as well as an existing infrastructure for cochlear implantation [35]. However, there is limited published data on cochlear implantation in SA and more contextual data are required.

Information on parents' experiences of the CI process will be valuable to new parents who require authentic CI-related information following enrolment into a CI program [36]. Hence, contextual data are required for the inclusion of evidence-based pre-operative counselling as well as CI intervention and (re)habilitation services post implantation. The aim of the current study was therefore to determine parent-perceived challenges related to the pediatric cochlear implantation process and support services received in SA.

## **2. Methods**

Institutional ethics committee approval was obtained prior to the commencement of data collection.

### *2.1 Study population*

Six CI programs dispersed throughout SA participated in this multicenter study. These CI programs represent five South African provinces, namely the Gauteng Province (Pretoria Cochlear Implant Unit and Chris Hani Baragwanath Academic Hospital-Cochlear Implant Program), the Free State Province (Bloemfontein Cochlear Implant Program), the Province of KwaZulu-Natal (Durban Cochlear Implant Program), the Eastern Cape Province (Port Elizabeth Cochlear Implant Unit) and the Western Cape Province (Tygerberg Hospital-Stellenbosch University Cochlear Implant Unit). Parents of pediatric ( $\leq 18$  years of age) CI recipients, with at least 12 months CI experience, were considered as participants for this study. Only parents who were proficient in English were considered for participation, since the questionnaire that was used for data-collection was developed in English only. No other case selection occurred and children from the complete range of educational and communication environments were included.

### *2.2 Materials for data collection*

Data was collected by means of a self-administered questionnaire that was developed specifically for the purpose of this study (Appendix A). In order to ascertain the preliminary validity and reliability of this newly developed questionnaire, a pilot study was first conducted. Pilot study participants included three parents of pediatric CI recipients who fitted the inclusion criteria for

this study, and 5 professionals with expertise in working with parents of pediatric CI recipients. Based on the input received from the pilot study participants, the questionnaire was revised and modified prior to data collection. The questionnaire was used to obtain demographic information as well as information concerning parents' perceived challenges relating to the CI process and support services received. It comprised of five sub-sections (*parental demographics; pediatric CI recipient demographics; CI process; education and support services received*) and included both closed and open-ended questions (36 questions in total). Eight questions included in the questionnaire were adapted from the *Children with Cochlear Implants: Parental Perspectives (CCIPP)* questionnaire [16].

In addition to questionnaire data, supplementary retrospective data was captured from patient files/ clinical records and included demographical, hearing loss and cochlear implant related data (Table 1).

### *2.3 Procedures*

All eligible parent participants were invited to participate in this study either via email or in person by the CI team coordinators of the participating CI programs. In order to improve the initial email/ online response rate, parents were also invited to participate and complete the questionnaire in hard-copy during routine appointments at the respective CI programs. Only parents who consented to participation completed the self-administered questionnaire either online (electronically) or in hard-copy. Once the questionnaire data were collected and captured, the CI team coordinators assisted with the capturing of retrospective data from patient files/

clinical records for those children whose parents completed the questionnaire. Data for this study was collected over a five-month period and the approximate response rate was 28.28%.

**Table 1**  
Characteristics of pediatric cochlear implant recipients.

Demographics	% (n)	Hearing loss and cochlear implant characteristics	% (n)
<b>Age at study (years)</b>		<b>Newborn hearing screening</b>	
Mean (SD)	10.15 (3.97)	No	52.44 (43/82)
Range	2.81–17.27	Yes	39.02 (32/82)
		Unsure	8.54 (7/82)
<b>Gender</b>		<b>Onset of hearing loss (n = 82)</b>	
Male	39.02 (32/82)	Congenital/early onset	85.37 (70)
Female	60.98 (50/82)	Acquired/progressive/sudden onset	13.41 (11)
		Unknown	1.22 (1)
<b>Health sector</b>		<b>Age at diagnosis of hearing loss (months) (n = 62)<sup>a</sup></b>	
Private	74.39 (61/82)	Mean (SD)	16.40 (13.31)
Public	25.61 (21/82)	Range	1.00–48.00
<b>Communication mode</b>		<b>Mode of amplification</b>	
Spoken language only	75.61 (62/82)	Two cochlear implants (bilateral)	57.32 (47/82)
Spoken language and Sign Language (mixed/total communication)	12.20 (10/82)	Cochlear implant with hearing aid in non-implanted ear (bimodal)	21.95 (18/82)
Sign Language only	4.88 (4/82)	Cochlear implant without hearing aid in non-implanted ear	20.73 (17/82)
Manual communication (informal gestures)	3.66 (3/82)		
Other	3.66 (3/82)		
<b>Current educational setting</b>		<b>Age at implantation (months) (n = 70)<sup>a</sup></b>	
Mainstream school	34.15 (28/82)	Mean (SD)	35.08 (20.45)
Special needs school: mainstream syllabus	20.73 (17/82)	Range	6.03–85.30
School for children who are hard-of-hearing: oral (spoken language) approach	12.20 (10/82)	<b>Duration of deafness (time of deafness before implantation) (months) (n = 82)</b>	
		Mean (SD)	36.04 (21.25)
Special nursery school or pre-school for children with hearing loss: oral (spoken language) approach	10.98 (9/82)	Range	5.95–101.50
		<b>Delay from diagnosis to implantation (months) (n = 73)</b>	
Full mainstream nursery school or pre-school	7.32 (6/82)	Mean (SD)	19.34 (14.81)
School for the Deaf: Sign Language or Total Communication approach	7.32 (6/82)	Range	2.07–79.30
Home school	4.88 (4/82)		
Special needs school: special syllabus	1.22 (1/82)		
Doesn't go to school (even though at a school-age)	1.22 (1/82)		
<b>Presence of one or more additional developmental conditions</b>	<b>34.15 (28/82)</b>	<b>Age at second implantation (sequential bilateral implantation) (years) (n = 39)</b>	
Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder	42.86 (12/28)	Mean (SD)	4.40 (2.54)
Visual impairment	14.29 (4/28)	Range	0.83–10.67
Developmental cognitive delay	10.71 (3/28)	<b>Time-lapse between first and second implant (sequential bilateral implantation) (years) (n = 39)</b>	
		Mean (SD)	1.69 (1.57)
Apraxia	7.14 (2/28)	Range	0.10–7.90
Cerebral Palsy	7.14 (2/28)		
Autism/Autism Spectrum Disorder (ASD)	3.57 (1/28)		
Epilepsy	3.57 (1/28)		
Other	10.71 (3/28)	<b>Duration of cochlear implant use (years)</b>	
		Mean (SD)	6.91 (4.17)
		Range	1.01–15.58

<sup>a</sup> Only children with congenital/early onset hearing loss were considered.

## 2.4 Statistical analysis

Obtained data were analyzed using a commercially available statistical software package (SAS version 9.4). The parents' responses obtained from the questionnaire, as well as retrospective data collected from clinical files/ patient records, were captured and coded into quantitative data using an excel spreadsheet in Microsoft Excel (2017) for the purpose of statistical analysis. Non-responses in the questionnaire were reflected as missing values. The responses from one open-

ended question (question 27) were transcribed and coded into central themes for the purpose of thematic analysis. Hence, common emerging trends amongst parents' responses were identified.

Descriptive statistics were used to define the parent participants' implanted children in terms of demographical, CI and hearing loss related characteristics (Table 1) and to describe parental perceived challenges encountered during the CI process (questions 22-25) and with education and support services received (questions 30-36).

Inferential statistics were used to identify possible associations between a number of independent variables and two dependent outcome variables, namely *CI process challenges* and *educational challenges*. Question 21 (*CI process challenges*) and question 29 (*educational challenges*) respectively consisted of 6 and 8 statements and parents rated their responses on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). "Not applicable" responses were processed as missing values for question 29. For questions 21 and 29, positive statements were reversed in order for higher average ratings to correspond to a more negative response that reflects a higher degree of perceived challenges. Scores for all items of questions 21 and 29 respectively were averaged to yield an overall mean for each participant in terms of *CI process challenges* and *educational challenges*.

For the main association analyses, Spearman correlation coefficients and general linear models were used. Spearman correlation coefficients were used to assess possible associations between independent continuous variables and two dependent outcome variables (*CI process* and *educational challenges*). For the *age at diagnosis of hearing loss* and the *age at implantation*

variables, only the children with congenital/ early-onset hearing loss were considered (n=70) in order to reflect the current status of early hearing detection and intervention services in SA.

For the purpose of variable selection for regression modelling, bivariate analyses (Pearson's-chi squared test) were conducted in order to determine the existence of possible associations between the independent categorical variables and the two dependent outcome variables. For bilateral implantation, only the children who had at least 6 months experience with their bilateral implant at the time of data collection were considered as bilateral implant users (97.87%, n=46/47). General linear models were constructed to test the effect of all significant independent variables identified through the Pearson's-chi squared test simultaneously on the dependent outcome variables. Statistical significance was considered as  $p < 0.05$ .

Cronbach's Alpha test was used to calculate internal consistency for the scales utilized for questions 21 (*CI process challenges*) and 29 (*educational challenges*) in the questionnaire. The Cronbach's alpha for questions 21 and 29 was 0.74 and 0.84 respectively, indicating good internal consistency.

### **3. Results**

#### *3.1 Demographic and clinical characteristics of the study population*

The final study sample consisted of 82 parents, of whom 78.05% (n=64/82) were mothers and 21.95% (n=18/82) were fathers. Most parents were married (78.05%, n=64/82) and held some form of tertiary qualification (67.07%, n=55/82). Demographic data and clinical characteristics of 82 pediatric CI recipients are presented in Table 1.

### *3.2 Process of cochlear implantation*

The average age at diagnosis of hearing loss for pediatric CI recipients in this sample was 16.40 months (range:1.00 - 48.00 months; 13.31 SD; n = 62) and the average age at implantation was 35.08 months (range = 6.03 - 85.30 months; 20.45 SD; n = 70). On average, the delay from diagnosis of hearing loss to cochlear implantation was 19.34 months (range = 2.07 - 79.30 months; 14.81 SD; n = 73).

Parents were asked to indicate how their child's first and second CI (applicable to bilaterally implanted CI recipients) were funded. The majority of the parents (86.59%, n = 71/82) indicated that their child's first CI was funded privately, thus either through private funding (no medical aid), medical aid only, medical aid and private funding combined, donations only, sponsor(s), donations and medical aid combined, donations and private funding combined or combined donations, medical aid and private funding. A mere 8.54% (n = 7/82) of the parents in this sample indicated that their child's first CI was funded through public (government) funding and 4.88% (n = 4/82) of parents obtained 'other' means of funding such as a combination of public (government) funding and private funding (sponsors and donations). All 47 bilaterally implanted recipients' parents indicated that the second CI was funded privately. Thus, no parents in this study sample received public (government) funding for the second CI.

Information on parent-perceived challenges that relate to the CI process was obtained by asking parents to rate six statements on a 5-point Likert scale that ranged from strongly agree to strongly disagree. Table 2 summarizes the parental ratings of the statements on challenges encountered during the CI process.

**Table 2**  
Parental responses on challenges related to the cochlear implantation process.

Statements	Agree <sup>b</sup> %(n)	Neutral <sup>b</sup> %(n)	Disagree <sup>b</sup> %(n)
It was a difficult time waiting for the results of the cochlear implant assessment before implantation (n = 81) <sup>a</sup>	74.07 (60)	4.94 (4)	20.99 (17)
It was a problem getting someone to look after the family when we had to go to the cochlear implant centre (n = 82) <sup>a</sup>	23.17 (19)	10.98 (9)	65.85 (54)
The costs of travel to the cochlear implant centre were a problem (n = 82) <sup>a</sup>	32.93 (27)	19.51 (16)	47.56 (39)
It was hard to take time off work for the appointments at the cochlear implant centre (n = 82) <sup>a</sup>	42.68 (35)	14.63 (12)	42.68 (35)
As a family, we were not financially prepared to meet the financial demands of the cochlear implantation process (n = 82)	53.66 (44)	14.63 (12)	31.71 (26)
We are not currently financially able to meet the long-term and continuous financial demands following cochlear implantation (costs relating to habilitation, device maintenance etc.) (n = 82)	45.12 (37)	18.29 (15)	36.59 (30)

<sup>a</sup> Questions adapted from 'Children with Cochlear Implants: Parental Perceptions' questionnaire by Archbold et al., 2008.

<sup>b</sup> Response ratings of 'strongly agree' and 'agree' were grouped together as an 'agree' response, response ratings of 'strongly disagree' and 'disagree' were grouped together as a 'disagree' response, response ratings for 'neither agree nor disagree' are indicated as a neutral response.

Most of the parents felt that they were not financially prepared to meet the financial demands of the CI process (53.66%, n = 44/82), nor are they currently able to meet the long-term and continuous financial demands following implantation, such as costs relating to habilitation and device maintenance (45.12%, n = 37/82).

Parents were asked whether they thought that the timing between the diagnosis of their child's hearing loss diagnosis and eventual cochlear implantation was delayed, and almost half of the parents (46.34%, n = 38/82) indicated that they felt this timing was delayed. The highest scoring reason for this delay was attributed to financial costs and obtaining the required funding for the CI procedure (81.58%, n = 31/38) (Table 3).

Parents of children implanted unilaterally were asked if they would like their child to have a second implant. Two thirds of the parents (68%, n = 24/35) reported that they would like their child to receive a second implant, and for these parents the most frequently reported barrier preventing bilateral implantation, was financial costs and funding of the second implant procedure (91.67%, n = 22/24) (Table 3).

**Table 3**  
Reasons for perceived delay between diagnosis and implantation and barriers to bilateral cochlear implantation.

Reasons for delay between diagnosis of hearing loss and cochlear implantation (n = 38)	% (n)	Barriers preventing child to obtain a second implant (n = 24)	% (n)
Financial costs and obtaining the required funding for the implant procedure	81.58 (31)	Financial costs and funding of the second implant procedure	91.67 (22)
Lack of prompt referral to specialized cochlear implant services	39.47 (15)	Financial costs and funding of the device maintenance	75.00 (18)
Difficulty in taking off from work to attend appointments at the CI centre	31.58 (12)	Uncertainty of the benefits of a second implant for my child	41.67 (10)
Stress of surgery to my child (stress of having my child undergo anaesthesia, drilling into the skull etc.)	28.95 (11)	Stress of having my child undergo a second surgery (surgical anxiety)	33.33 (8)
Family's geographical location/travelling distance to the CI centre	26.32 (10)	Not recommended by the CI team	29.17 (7)
Family's geographical location/travelling costs to the CI centre	26.32 (10)	Concerned about the disadvantage of destroying any residual hearing	25.00 (6)
Clinical issues: medical or presence of additional developmental conditions	26.32 (10)	Family indecision/uncertainty	20.83 (5)
Progressive hearing loss (my child did not meet the audiologic criteria for CI candidacy and later showed a deterioration in his/her hearing levels)	21.05 (8)	Lack of information/support from the CI centre	12.50 (3)
Opted for a second opinion	21.05 (8)		
Family indecision/uncertainty	21.05 (8)		
Lack of information/support from the CI centre	13.16 (5)		
Difficulty in finding someone to look after the family when we go to the CI centre	5.26 (2)		
Cultural/religious beliefs: seeking alternative/traditional treatment	5.26 (2)		

### 3.3 Educational aspects

Most of the pediatric CI recipients enrolled in a formal educational setting attended a public school (62.34%, n = 48/77) whilst 37.66% (n = 29/77) attended a private school (Table 1). A grade/ multiple grades were repeated by almost a third (31.43%, n = 22/70) of the pediatric CI recipients in this sample. Furthermore, 18.99% (n = 15/79) of the pediatric CI recipients were electively (non-compulsory) held back during a grade.

Parental ratings of possible challenges that relate to their child's education were obtained on a 5-point Likert scale (ranging from strongly agree to strongly disagree) for those parents whose implanted children were in an educational setting (Table 4). More than half of the parents agreed that finding an adequate educational setting for their child was a challenge (55%, n = 44/80).

**Table 4**  
Parental responses on general challenges encountered with education.

Statements	Agree <sup>b</sup> %(n)	Neutral <sup>b</sup> %(n)	Disagree <sup>b</sup> %(n)
Finding an adequate educational setting for my child has been a challenge (n = 80)	55.00 (44)	7.50 (6)	37.50 (30)
I am not happy about my child's progress at school currently (n = 79) <sup>a</sup>	7.59 (6)	15.19 (12)	77.22 (61)
My child is not keeping up well with other children (normal hearing) his/her age in school (n = 77) <sup>a</sup>	19.48 (15)	12.99 (10)	67.53 (52)
My child is not able to follow/keep up with the pace at which the teacher presents information (n = 80)	17.50 (14)	21.25 (17)	61.25 (49)
My child is not able to cope academically in a mainstream school setting (n = 73) <sup>a</sup>	26.03 (19)	19.18 (14)	54.79 (40)
The local school and its support services do not adequately meet all our needs concerning the use of my child's implant at school (n = 75) <sup>a</sup>	22.67 (17)	18.67 (14)	58.67 (44)
My child's current school placement is not appropriate for his/her specific needs (n = 77)	6.49 (5)	14.29 (11)	79.22 (61)
There is a shortage of appropriately trained teachers to deliver intervention services, specifically for children with cochlear implants (n = 77)	68.83 (53)	6.49 (5)	24.68 (19)

<sup>a</sup> Questions adapted from 'Children with Cochlear Implants: Parental Perspectives' questionnaire by Archbold et al., 2008.

<sup>b</sup> Response ratings of 'strongly agree' and 'agree' were grouped together as an 'agree' response, response ratings of 'strongly disagree' and 'disagree' were grouped

Furthermore, parents had to indicate 'yes', 'no' or 'not applicable' in response to ten statements pertaining to possible challenges encountered within their child's current educational setting.

Almost two thirds of the parents (63.38%, n = 45/71) agreed that they do not always have adequate finances to pay for all the additional academic support services their child require, while more than a third (40.79%, n = 31/76) agreed that teachers and therapists are often unsure of how to support their child's individual needs

When asked which professional(s) assisted parents in obtaining a school for their child, most parents indicated that the audiologist (44.87%, n = 35/78) assisted them. However, 28.21% (n = 22/78) of the parents reported that they did not receive assistance from any professional to obtain a school for their child.

### *3.4 Support services received*

When parents were asked which professional on the CI team provided the most continued support from the time of implantation until presently, 71.64% (n = 48/67) of the parents indicated that it was the audiologist, 16.42% (n = 11/67) reported that it was the speech-language

therapist, 5.97% (n = 4/67) reported that it was the ear, nose and throat specialist, and 4.48% (n = 3/67) reported that it was the parent-guidance therapist.

Parents were asked to rate the support services that their child with a CI(s) received since the first implantation. Ratings ranged from ‘support service not available’ (for children requiring a particular support service however it was not available), ‘received limited support’, ‘received adequate support’ and ‘received exceptional support’, with an additional ‘not applicable’ response for children not requiring a particular support service (Figure 1).

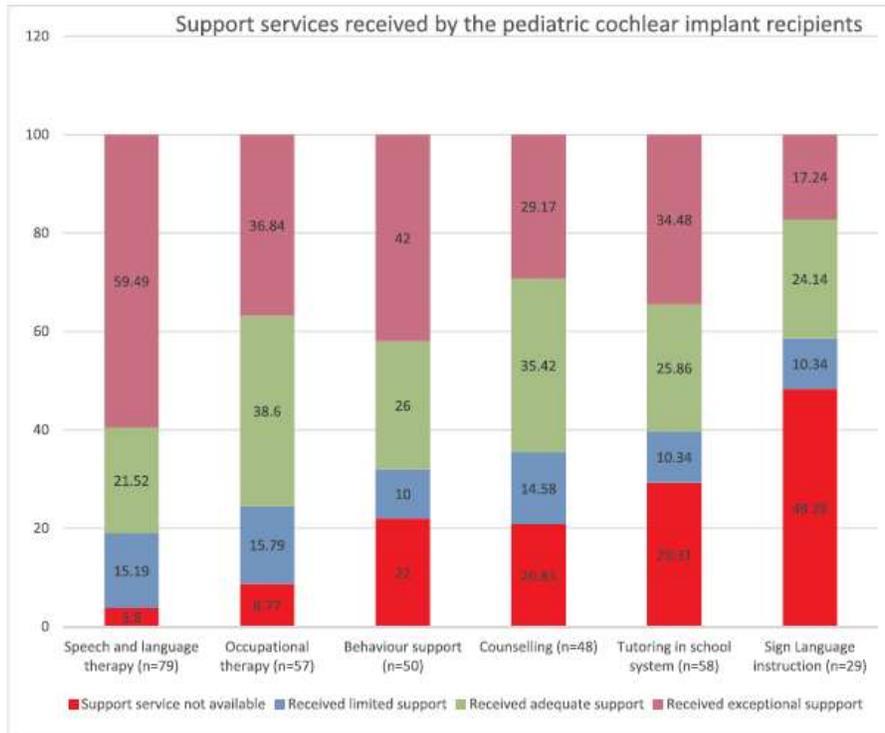


Fig. 1. Support services received by the pediatric CI recipients. The x-axis illustrates the support services and the total number of responses for each support service (speech and language therapy, occupational therapy, behavior support, counselling, tutoring in school system and Sign Language instruction). The y-axis display parent ratings for each of the support services (support service not available, received limited support, received adequate support and received exceptional support).

The support service which ranked the highest in terms of ‘exceptional support’ received was speech-language therapy (59.49%, n = 47/79), whilst the highest-ranking support service not

available to children requiring that particular service was Sign Language support (48.28%, n = 14/29).

Similarly, parents were also asked to rate the support services received by them as parents of a child with a CI(s) since their child was implanted (Figure 2).

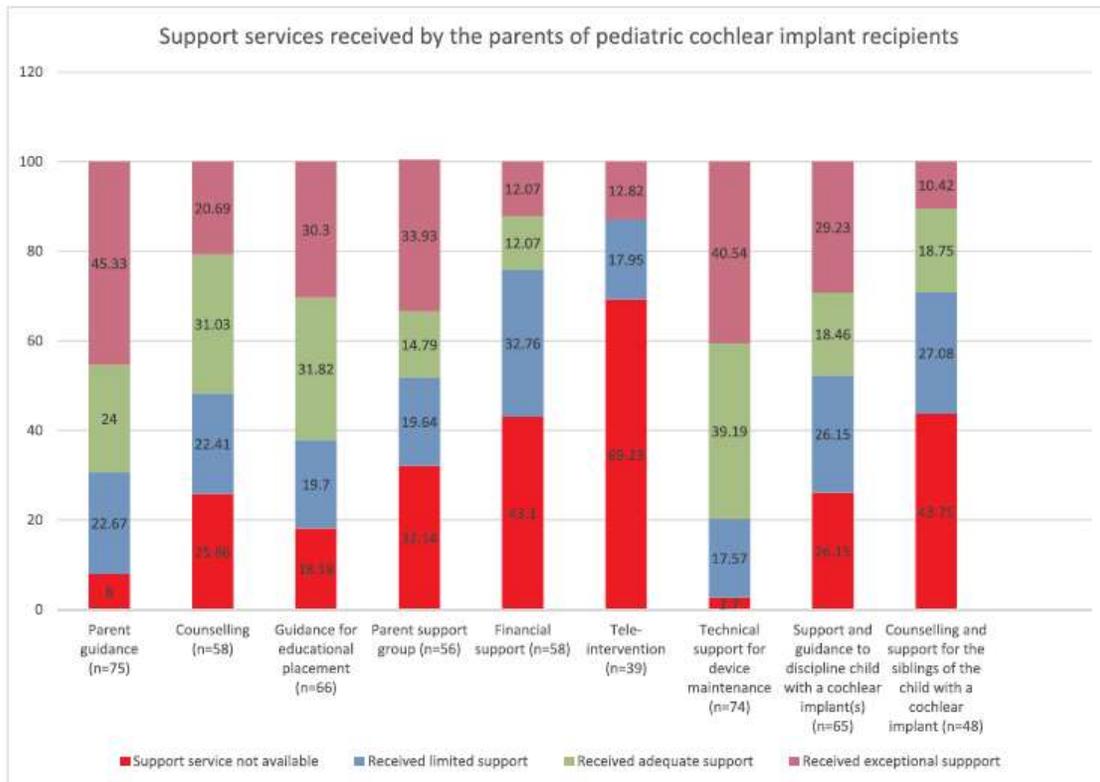


Fig. 2. Support services received by the parents of the pediatric CI recipients. The x-axis illustrates the support services and the total number of responses for each support service (parent guidance, counselling, guidance for educational placement, parent support group, financial support, tele-intervention, technical support for device maintenance, support and guidance to discipline child with a CI(s), counselling and support for the siblings of their child with a CI(s)). The y-axis display parent ratings for each of the support services (support service not available, received limited support, received adequate support and received exceptional support).

The support service that ranked the highest in terms of ‘exceptional support’ received was *parent guidance* (45.33%, n = 34/75). In contrast, the highest-ranking support service not available to parents requiring that particular service was *tele-intervention* (69.23%, n = 27/39).

Consequently, parents were asked to select from a list three support services (in order of importance) which they deemed as critical for a child with a CI(s) to ensure optimal outcomes

and three support services which they deemed as critical for parents of a child with a CI(s) in order to ensure optimal outcomes for their child.

Regarding the services for children with a CI(s), *speech and language therapy* was deemed as the most important service by parents (88.6%, n = 70/79), followed by *tutoring in a school system* (26.6%, n = 21/79) and *counselling* (25.6%, n = 20/78). Regarding services for parents of children with a CI(s), *parent guidance* was deemed as the most important service (44.9%, n = 35/78), followed by *financial support* (24.4%, n = 19/78) and *support and guidance to discipline their child with a CI(s)* (16.5%, n = 13/79).

### *3.5 Associations between demographical variables and cochlear implant process and educational challenges*

Spearman correlation coefficients revealed no statistically significant ( $p < 0.05$ ) correlations between continuous variables (*age at study, age at diagnosis of hearing loss, age at implantation, duration of CI use, time-lapse between first and second implantation, duration of deafness and delay from diagnosis to implantation*) and *CI process* and *educational challenges*.

Pearson's chi-squared test was performed to determine possible associations between the independent categorical variables and the two dependent outcome variables (*CI process* and *educational challenges*). Twelve independent categorical variables were included in this analysis, namely *gender* (male/ female), *health sector* (private health care/ public health care), *presence of one or more additional developmental conditions* (one or more/ none), *onset of hearing loss* (congenital/ post-natal), *type of amplification* (unilateral/ bilateral), *communication*

*mode* (oral/ non-oral), *educational setting* (mainstream/ non-mainstream), *public versus private educational setting* (public/ private), *grade repetition* (yes/ no), *parents' marital status* (married/ not married), *relationship to the pediatric CI recipient* (mother/ father) and *highest qualification level obtained by parent* (high school/ tertiary qualification). No significant associations were observed between the independent categorical variables and the *CI process challenges* dependent variable. However, significant associations ( $p < 0.05$ ) were obtained between two of the twelve categorical variables (*presence of one or more additional developmental conditions* and *grade repetition*) and the *educational challenges* dependent variable. Consequently, a general linear model was constructed to test the effect of these two significant independent variables on *educational challenges*.

*Presence of one or more additional developmental conditions* ( $p = 0.0191$ ) and *grade repetition* ( $p = 0.0026$ ) were significantly associated with *educational challenges* (Table 5). Parents of children who had one or more additional developmental conditions on average perceive their child's education to be more challenging (mean = 2.78; 0.74 SD) compared to parents of children without additional developmental conditions (mean = 2.37; 0.78 SD). Also, parents whose children repeated a grade/ multiple grades on average perceive their child's education to be more challenging (mean = 2.88; 0.80 SD) compared to parents whose children did not repeat any grades (mean=2.33; 0.72 SD).

**Table 5**  
Associations between significant categorical independent variables and educational challenges (n = 70).

Outcome variable	Categorical independent variable	Pr > F (p-value)	Categories	Mean score (SD)
<b>Education</b>	Presence of one or more additional developmental conditions	0.0191*	None (n = 48)	2.37 (SD: 0.78)
			One or more (n = 22)	2.78 (SD: 0.74)
	Grade repetition	0.0026*	No (n = 48)	2.33 (SD: 0.72)
			Yes (n = 22)	2.88 (SD: 0.80)

\*p < 0.05.

### 3.6 Thematic analysis of parent-perceived challenges

In an open-ended question, parents were asked to substantiate their responses with qualitative descriptions on what they considered as the greatest challenges of being a parent of a child with a CI. The most prominent central themes and illustrative quotes from parents for this question are summarized (Table 6).

**Table 6**  
Central themes, percentages and illustrative quotes from parental reports of challenges perceived (n = 80).

Central theme	% (n)	Illustrative quotes
<b>Financial problems</b>	41.25% (33/80)	<i>'Having to go through so much of stress of funding the implants'</i> <i>'Often the cost of maintenance and replacement of parts are a concern as this is not covered by medical aid'</i> <i>'Financially it is very hard even after the implant, it is the maintenance costs and insurance etc.'</i>
<b>Demands of the CI process and (re)habilitation on the parenting role</b>	22.50% (18/80)	<i>'The non-stop therapy'</i> <i>'Constant support that the child requires'</i> <i>'Intensive attention and assistance towards school work/social skills/emotional well-being etc.'</i>
<b>Parental concerns and stresses surrounding their implanted child</b>	20.00% (16/80)	<i>'The stress of a young minor having the responsibility of dealing with an expensive device'</i> <i>'Worry that she would not be able to integrate into society'</i> <i>'I worry about the future and the financial burden I will be passing onto my child'</i>

## 4 Discussion

A comprehensive range of parent-perceived challenges related to the pediatric CI process and support services received in SA were identified.

The average ages for diagnosis of hearing loss and age at implantation for children with congenital/ early onset hearing loss in this study were 16.40 (13.31 SD) months and 35.08 (20.45 SD) months respectively, with a 19.34 (14.81 SD) months delay on average between hearing loss diagnosis and cochlear implantation. Since delayed implantation is considered as more than 12 months after diagnosis of hearing loss [39,40], on average, pediatric CI recipients in this study received their CIs late. Therefore, it is not surprising that the majority of parents (46.34%) felt that the timing between diagnosis of hearing loss and eventual cochlear implantation was

delayed for their child. Financial costs and obtaining the required funding for the implant procedure was the highest scoring reason for this delay. Similarly, a recent survey study conducted in India revealed that 80% of the parents of pediatric CI recipients perceived a delay in their child's hearing loss diagnosis and 83.30% perceived a delay in implantation, also indicating financial difficulties as the highest scoring reason for the delay in cochlear implantation [41].

On average, the time-lapse between the first and second CI for children who were implanted sequentially in this study was more than a year and a half (1.69 years; 1.57 SD). Since a critical time period for central binaural auditory development exists [42], bilateral implantation performed simultaneously or sequentially with a minimal delay between the two implantations as opposed to a prolonged time lapse between the two implantations are more favorable for optimal cortical brain activity [43]. Consequently, a prolonged delay between the first and second implant could potentially hinder or compromise the development of binaural processing [44]. Whilst bilateral implantation is customary in developed countries for individuals with severe to profound hearing loss [45,46], in developing countries such as SA, funding of the second implant remains the onus of the parents [47]. Consequently, this results in unequitable accessibility towards bilateral implantation whereby only financially-able parents are able to afford a second implant for their child [47]. Hence, funding the second implant was done so privately by all the parents in this study and none of the parents received public sector/ government funding for the procedure. More than two thirds (68.57%) of the parents of unilaterally implanted pediatric CI recipients in this study indicated that they wanted their child to receive a second implant, but that

the financial costs and funding of the second implant procedure (91.67%) and the costs and funding of the device maintenance (75%) prevented their child from obtaining a second implant.

The most prominent challenges reported by parents regarding the CI process centered around financial difficulties relating to the costs of the implant procedure (medical costs), costs for the device (internal and external components) and costs related to the maintenance of the device (long-term costs). Due to minimal financial support received in SA for cochlear implantation [21,47], finances were a challenge for most of the parents in the current study, with 53.66% of parents reporting that they were not able to meet the financial demands of the CI process or the long-term and continuous financial demands following implantation (45.12%). This finding is in agreement with the findings by Moroe and Kathrada [29] and Kerr et al. [21] who reported that South African parents of pediatric CI recipients are not fully equipped to meet the continuous financial demands post cochlear implantation. Khan et al. [23] also reported that cost is the biggest limiting factor for cochlear implantation in developing countries, while Chundu et al. [17] confirmed that the greatest challenge reported by parents of implanted children in Southeast Asia was attributed to the costs and maintenance of the CI device. These findings demonstrate that the level of financial support provided by a country's government system impacts a family significantly. In developing countries such as SA, India and Southeast Asia, where financial support is minimal, parents are financially more stressed as opposed to parents in Finland whereby the Finnish government system makes provisions for the implantation and habilitation costs [21,33,41,47]. In between are developed countries like Canada and the United Kingdom, where the costs of pediatric implantation are covered by the government, however parents continue to experience financial concerns post CI due to the habilitation costs [7,11,22].

In SA, the current educational policy aims to advance towards inclusive educational settings whereby even children with severe to profound hearing impairments are included in such settings [48]. However, challenges such as the disproportionate resourcing of inclusive education across the country's provinces, limitations in the availability of specialist support services in public ordinary schools and a lack of resources for children with CIs in the available remedial schools are currently hindering this advancement towards inclusive education [32]. An additional challenge in SA is the exorbitant costing for well-equipped private remedial schools [29], as indicated in the current study as well. Finding an educational setting for their implanted children (55%) and a shortage of appropriately trained teachers to deliver intervention services specifically for children with CIs (68.83%) were perceived challenges reported by most parents in this study. Finding an appropriate educational setting best suited to their child's needs was a concern for parents in other studies as well [28–31]. Ultimately, decisions on educational placement for pediatric CI recipients should be made based on the appropriateness of a setting for to each child's specific needs [47].

Within this study sample, the *presence of one or more additional developmental conditions* and *grade repetition* were associated with more pronounced educational challenges. Since the parental responsibilities of parents of deaf children with concomitant problems are higher than parents of deaf children with no additional developmental conditions [34], increased understanding by professionals on the experiences and challenges that these families face is required in order to improve service provision. Repeating a grade would elevate parental anxiety and increase their perceived negativity towards the educational system, more so if parents fail to obtain the educational support which their implanted child requires. Most pediatric CI recipients

require intervention and support services throughout their schooling years from specialized teachers and/ or hearing-related specialists [49,50] and therefore continuous training of professionals working in educational settings is required so that they can be better equipped to assist implanted children who are struggling academically.

An alarming 28.21% of parents in this study reported that they did not receive assistance from any professional to obtain a suitable educational placement for their child. A lack of educational support for pediatric CI recipients and their parents may intensify parental anxiety [33]. These educational challenges reported by parents of pediatric CI recipients in this study highlights the urgent need for educational support to both pediatric CI recipients and their parents as well as ongoing support to professionals working in educational settings.

*Speech-language therapy* (59.49%) was the highest ranked exceptional support service received by pediatric CI recipients as indicated by the parents. This is consistent with the findings by Summers et al. [51] whereby the majority of the parents of pediatric CI recipients were most satisfied with the *speech/ language services* compared to all of the other services their children received. In contrast, *Sign Language support* was the highest ranked support service not available to pediatric CI recipients requiring this service in this study. With 12.20% of the pediatric CI recipients in the current study using mixed/ total communication and 3.66% using South African Sign Language (SASL) as their mode of communication, the availability of SASL support to this population is vital. CI teams should therefore ensure that diversified rehabilitative service options are available to implanted children (including SASL support) in an attempt to improve their communicative competence [52]. Ultimately the priority should be for each

pediatric CI recipient to achieve adequate communicative skills and excel across other developmental areas as well (cognitive, socioemotional and academic development) [52,53].

*Parent-guidance* (45.33%) was the highest ranked exceptional support service received by parents of pediatric CI recipients in this study. Conversely, most parents (69.23%) who required support in terms of *tele-intervention* indicated that this service was not available to them. Using the internet as a medium for service delivery is an established means of ensuring that patients and professionals connect remotely [54]. Therefore, one of the ways in which improved CI support service delivery can be ensured is by improving upon the accessibility of tele-intervention services in SA.

In order of importance, parents reported that *speech-language therapy, tutoring in a school system* and *counselling* were support services deemed critical for pediatric CI recipients to receive in order to ensure optimal outcomes. Summers et al. [51] and Zaidman-Zait et al. [34] utilized the *Services Inventory* in their studies to evaluate parental perceptions of support services needed and the adequacy of each support service received. Consistent with the current study, *speech-language services* was also the highest ranking service that parents in both studies indicated as necessary [34,51]. Evidently, speech-language therapy is a vital support service in CI (re)habilitation. *Parent guidance, financial support* and *support and guidance to discipline their child with a CI(s)* were the three support services deemed most critical for parents of pediatric CI recipients to receive. Financial support was also the second most important support service deemed necessary by parents of pediatric CI recipients in the study by Summers et al. [51].

Parents place emphasis on different support services that they deem critical depending on the needs of their child, therefore it is important for CI teams to identify the specific support services that each family requires to ensure efficient and individualized family support. Furthermore, post implantation, parents of newly implanted children encounter new responsibilities and demands in addition to their existing parental responsibilities [7,12,13]. This could potentially escalate their stress levels if there are no coping mechanisms in place to facilitate these new-found demands. Adequate informational and emotional counselling from CI teams throughout the CI process may assist parents in managing and balancing their existing and new-found responsibilities in a constructive manner. Ultimately, the degree of parental commitment towards the implantation and (re)habilitation process impacts the outcomes achieved [13–15], thus ongoing parental guidance, assistance and support by CI teams is crucial.

With most of the parents' implanted children within this study sample representing the private health care sector (74.39%), this sample can be considered as representative of pediatric CI recipients in South Africa and reflects the current health care inequalities for advanced hearing health interventions such as CIs [26,47]. However, this research sample is not representative of the larger South African population, since 85% of the South African population receive public health care services [24]. Not all parents/ primary caregivers of pediatric CI recipients from all sites were included as participants, and this may have induced selection bias in the data. Hence, the generalizability of study results was decreased by the relatively small sample size, the low response rate (28%) and selection bias. Even though broad-spectrum input was obtained from parents with implanted children across a wide age range and from various communication and educational environments, parent perceptions were limited to the recruited study sample,

possibly excluding additional insights that could have been obtained from a larger sample of parent participants.

## **5 Conclusion**

On average, the diagnosis of hearing loss in this sample was delayed, resulting in deferred ages for cochlear implantation. The most prominent parental-perceived challenge encountered during the CI process pertains to financial difficulties in funding the implant procedure and managing the long-term and continuous financial demands post implantation. Regarding the education of children with CIs in SA, the greatest parental-perceived challenges stem from finding adequate educational settings for each implanted child appropriate to his/ her individualized needs and a current shortage in the availability of trained teachers able to deliver intervention services to children with CIs. Both the presence of one/ more additional developmental conditions and grade repetition were associated with a higher degree of perceived educational challenges encountered. Speech-language therapy for pediatric CI recipients and parent guidance support for parents of pediatric CI recipients were the support services deemed most critical by parents of implanted children in ensuring optimal outcomes.

Despite the study's limitations, this was the first multicenter study in SA to describe parental-perceived challenges related the CI process, the education of their implanted children and the support services received. This study provided insight into parental perceptions and contributed towards promoting optimal outcomes, evidence-based service delivery and on-going support to pediatric CI recipients and their families.

## **6 Conflicts of interest**

The author(s) have no conflicts of interest to declare.

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