

**PARENT-PERCEIVED CHALLENGES RELATED TO THE
PAEDIATRIC COCHLEAR IMPLANTATION PROCESS
AND SUPPORT SERVICES RECEIVED
IN SOUTH AFRICA**

by

AAQILAH BHAMJEE

A dissertation submitted in fulfilment of the requirements for the degree

MA AUDIOLOGY

In the Department of Speech-Language Pathology and Audiology

FACULTY OF HUMANITIES

UNIVERSITY OF PRETORIA

SUPERVISOR: Dr Talita le Roux

CO-SUPERVISORS: Dr Kurt Schlemmer

Prof Bart Vinck

November 2018

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Aaqilah Bhamjee

Department of Speech-Language Pathology and Audiology

University of Pretoria

bhamjeeaaqilah@gmail.com

ACKNOWLEDGEMENTS

I praise and glorify the ALMIGHTY for allowing me the privilege and ability to complete this research study. I am eternally grateful to HIM for this opportunity and for HIS continuous guidance. As Muslims we are encouraged to seek knowledge from the cradle to the grave and to be an asset to our fellow beings. I hope to accomplish just that.

To Dr Talita le Roux, my supervisor and mentor, I cannot thank you enough for your invaluable and continuous support, guidance and input throughout the last two years. Thank you for making this research project a possibility and for the privilege to have shared this amazing experience with you. Thank you for always being available when I needed assistance and for your thoroughness when reviewing my work. Thank you for believing in me and encouraging me to confidently present at conferences. You are a distinguished inspiration to me and I could not have imagined having a better advisor and mentor for my study.

To Dr Kurt Schlemmer, your support, dedication and special attention to detail is much appreciated. Thank you for your contributions to my study and for sharing your specialized knowledge with me.

To Professor Bart Vinck, thank you for your wisdom and guidance throughout this study.

To Mr Andries Masenge, thank you for your valuable support and assistance with the data analysis.

To the participating cochlear implant teams, thank you for affording me the opportunity to conduct research and for your assistance with the retrospective data collection.

Nobody has been more important to me in the pursuit of this project than the members of my family. I would like to thank my parents whose love and guidance are with me in whatever I pursue. Mum and Dad, thank you for always encouraging me to study further and expand my knowledge. No amount of words can express my profound gratitude for all the sacrifices that you've made in ensuring that I receive the best possible education. Mum, thank you for all of your prayers and for always believing in me, I dedicate this master's study to you.

To my mother-in-law Rayhana, thank you for supporting me and for always taking such great care of my daughters whilst I'm away at work and throughout my studies. I sincerely appreciate and value all that you do for us.

To my husband Idrees and beautiful daughters Aleeyah and Nuhaa, thank you for your unending inspiration and love. You have been so patient and selfless with me and I am forever grateful to have been blessed with such an incredible family. I love you all so much.

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RESEARCH OUTPUTS

Parts of this thesis have been presented at the following conferences:

1. **Bhamjee, A;** le Roux, T; Schlemmer, K & Vinck, B. (2018). Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa. Paper presented at the *34th World Congress of Audiology, Cape Town, South Africa* (28-31 October 2018).
2. **Bhamjee, A;** le Roux, T; Schlemmer, K & Vinck, B. (2018). Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa. Paper presented at the *4th World Congress on Cochlear Implants in Emerging Countries, Cape Town, South Africa* (31 October – 2 November 2018).

ABSTRACT

The aim of this study was to determine parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa (SA).

This multicenter survey study involved six cochlear implant (CI) programs throughout SA. The study sample included 82 parents of paediatric (≤ 18 years) CI recipients. A questionnaire was developed to explore parental challenges regarding the CI process, educational aspects and support services received.

The financial implications of cochlear implantation, including CI device maintenance, was identified by parents as the most prominent challenge. Financing issues were the highest scoring reason that attributed to the delay between hearing loss diagnosis 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 deliver intervention services to children with CIs. The presence of one/ more additional developmental conditions and grade repetition were significantly associated with more pronounced parent-perceived educational challenges. The three support services that parents considered as most critical for their implanted children to achieve optimal outcomes were speech-language therapy, tutoring in the school system and counselling. Parent guidance, financial support and

guidance to discipline the child with a CI(s) were the three support services deemed most critical for parents of paediatric CI recipients.

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

KEYWORDS

Cochlear implant

Paediatric cochlear implantation

South Africa

Questionnaire

Parents

Perceptions

Challenges

Cochlear implant process

Education

Support services

ABBREVIATIONS

BCIP	Bloemfontein Cochlear Implant Program
CCIPP	Children with Cochlear Implants: Parental Perspectives
CHBAH-CIP	Chris Hani Baragwanath Academic Hospital-Cochlear Implant Program
CI	Cochlear Implant
DCIP	Durban Cochlear Implant Program
DeafSA	Deaf Federation of South Africa
EHDI	Early Hearing Detection and Intervention
JCIC	Johannesburg Cochlear Implant Centre
NHS	Newborn Hearing Screening
PCIU	Pretoria Cochlear Implant Unit
PECIU	Port Elizabeth Cochlear Implant Unit
SA	South Africa
SACIG	South African Cochlear Implant Group
SNHL	Sensorineural Hearing Loss
TH-SU-CIU	Tygerberg Hospital–Stellenbosch University-Cochlear Implant Unit

1. INTRODUCTION

1.1. Background

Cochlear implantation is recognized as an established intervention for individuals with severe-profound sensorineural hearing loss (SNHL) who derive insufficient benefit from acoustic amplification. Over 300 000 deaf individuals worldwide, of which more than 80 000 are children, have received access to sound through cochlear implantation (Kral & O'Donoghue, 2011; O'Donoghue, 2013). The benefits of early cochlear implantation for speech and language development are well documented (Manrique, Cervera-paz, & Huarte, 2004; May-mederake, 2012; Svirsky, Teoh, & Neuburger, 2004; Zwolan et al., 2004). Recent evidence also indicates that some prelingually deaf children implanted within the first year of life can achieve speech and language skills comparable to normal hearing children (Ching et al., 2009; Niparko et al., 2010; Wie, 2010). Not only does cochlear implantation have a positive impact on communication, but also on broader psychosocial and educational outcomes (Sach & Whynes, 2005). Understandably, parental expectations for paediatric cochlear implantation are high (Birman, Elliott, & Gibson, 2012).

1.2. Outcomes of paediatric cochlear implantation

In spite of high expectations, outcomes following implantation vary (Bat-Chava, Martin, & Kosciw, 2005; Sach & Whynes, 2005) and are neither definitively guaranteed nor instantaneous (Geers, 2004). Paediatric cochlear implantation

outcomes are influenced by numerous internal and external factors. Some of the proven prognostic factors in paediatric cochlear implantation include age at implantation, the presence of middle-ear malformations, occurrence of meningitis, Connexin 26 GJB2 gene-related deafness, the presence of additional disabilities, bilateral implantation and parental involvement in the rehabilitation process (Black, Hickson, Black, & Khan, 2014; Black, Hickson, Black, & Perry, 2011; le Roux et al., 2016). Many of these factors have the potential to affect clinical outcomes, and as a result, numerous paediatric CI recipients present with sub-optimal outcomes (le Roux et al., 2016).

Varying outcomes of paediatric cochlear implantation not only initiates parental anxiety but also affects the parenting role (Zaidman-Zait, 2008). Furthermore, post implantation, parents of implanted children are also required to commit to early intervention and ongoing audiological monitoring, managing the associated financial costs for cochlear implantation, as well as lifelong maintenance of the device (Incesulu, Vural, & Erkam, 2003; Sach & Whynes, 2005; Spencer, 2004). These parental responsibilities should be recognized by CI teams, since the level of parental commitment towards the implantation and (re)habilitation process affects the outcomes achieved (Boons et al., 2012; Sarant, Holt, Dowell, Rickards, & Blamey, 2009; Spencer, 2004). The overall satisfaction of parents with their children's improvements in hearing, awareness of environmental sounds, their expressive and receptive language development and their improved confidence and independence levels following cochlear implantation have been reported (Archbold, Sach, O'Neill, Lutman, & Gregory, 2008; Chundu, Manchaiah, Stephens, & Kumar, 2013). In spite of these positive experiences, parents do recognise the long-term

nature of CI (re)habilitation and as a result parental stress does not necessarily decrease over time (Weisel, Most, & Michael, 2007).

1.3. Early cochlear implantation

As a result of technological advances and universal newborn hearing screening, some CI programs are implanting children as young as six months of age and in some instances even earlier (Birman, 2009; Dettman, Pinder, Briggs, Dowell, & Leigh, 2007; Holt & Svirsky, 2008; Hyde, Punch, & Komesaroff, 2010; Lesinski-Schidat, Illg, Heermann, Bertram, & Lenarz, 2004; Valencia, Rimell, Friedman, Oblander, & Helmbrecht, 2008). The rationale behind early implantation is to ensure that a child gains maximal auditory experience thereby increasing the likelihood of speech-language development best suited to his/ her age (Ching et al., 2013; Leigh, Dettman, Dowell, & Briggs, 2013; Sharma, Dorman, & Spahr, 2002). Early implantation also increases the probability of early enrolment into a mainstream educational setting and the prospect of the child acquiring an education level matching his/ her normal-hearing counterparts (le Roux et al., 2016; Lester, Dawson, Gantz, & Hansen, 2011). Furthermore, early implantation has been proven to be cost effective for society and to enhance quality of life, confidence and inclusion into a normal-hearing society (Armstrong et al., 2013; Lester et al., 2011). In view of the benefits of early implantation, parents are required to make decisions about cochlear implantation and/ or other intervention services very early in their child's life, and many parents find this decision-making process difficult and stressful (Hyde et al., 2010). In general, parents are also aware of the possibility of the implantation altering the life pattern of their child and escalating their parenting demands (Incesulu et al., 2003; Zaidman-Zait, 2008). Thus parents are faced with the

challenge of assessing the risks, challenges and benefits of implantation prior to making a decision regarding the implantation (Huttunen & Välimaa, 2012).

International CI research predominantly focuses on the medical aspects of implantation and the speech and language outcomes post implantation; however it is equally important that the challenges and stressors experienced by parents are recognized as it is evident that parents encounter ongoing stressors and numerous challenges related to cochlear implantation (Huttunen & Välimaa, 2012; Zaidman-Zait, Curle, Jamieson, Chia, & Kozak, 2015). This will ensure that professionals can better assist parents during the challenging decision making process (Zaidman-Zait et al., 2015).

1.4. Financial costs associated with cochlear implantation

In SA, there is limited public funding available for CIs which are considered as an intervention for the privileged. Thus, the availability of financial support to parents of children requiring CIs should be addressed. Studies conducted in the United Kingdom by Sach, Whynes, Archbold and O'Donoghue (2005) and in SA by Kerr, Tuomi and Muller (2012) relating to the costs incurred during the CI process, reported that the extensive financial costs which parents encounter throughout the CI process are burdening, more so within the first two years of the cochlear implantation procedure. Financial (direct and indirect medical costs) as well as incorporeal costs (time dedicated towards the CI process and subsequent intervention) are encountered, thereby warranting the need for financial assistance (Sach et al., 2005). In the majority of the developed countries, direct CI medical costs are not incurred by the parents and are instead covered by a national health system (Kerr et al., 2012). However, for most developing countries, the funding of CIs and the

subsequent (re)habilitation thereafter remains the onus of the parents (Khan, Mukhtar, Saeed, & Ramsden, 2007). The majority (85%) of the South African population are reliant on public healthcare services (Blecher & Harrison, 2006) and whilst rehabilitative services such as CIs are vital, they are not highly prioritized in the public sector when compared to life-threatening conditions such as HIV/AIDS and Tuberculosis (Kerr et al., 2012). Consequently, there are currently only four active, public sector/ government funded CI programs in SA and due to funding constraints, only a limited number of individuals with severe to profound degrees of SNHL receive CIs within SAs public health sector (le Roux, 2016; South African Cochlear Implant Group, 2017). As a result, most parents of children requiring CIs have to have access to a private medical aid or sufficient finances to access cochlear implantation (Kerr et al., 2012). In 2010, on estimate, the average costs for a child five and ten years succeeding cochlear implantation was 298 961 ZAR and 455 225 ZAR respectively (Kerr et al., 2012). The financial costs incurred by parents are however not only limited to the implantation costs itself as costs are also incurred both pre-operatively and post-operatively (Kerr et al., 2012; Sach et al., 2005). Pre-operatively, parents require adequate finances to cover the consultation fees and necessary assessments conducted by the professionals on the CI team as well as the costs of the hearing aid trial and the necessary intervention thereafter (Kerr et al., 2012; Sach et al., 2005). Surgically, parents are required to cover the costs of the implant itself, as well as the costs pertaining to the CT scan, surgeon's labor, the facility and operation room, anesthesia and the postoperative medication (Emmett et al., 2015). Post-operatively, parents are faced with the financial responsibility related to the life-long maintenance of the device including the costs relating to the purchasing of batteries, spare parts, upgrades required for the speech processor and

external repairs done and the lifetime CI mapping sessions that are required (Emmett et al., 2015; Kerr et al., 2012). A case report study on two children with acquired SNHL from a lower income status in the developing country of Nigeria reported that the families of these children found the costs of batteries and the attendance of rehabilitation sessions to be financially challenging (Suleiman et al., 2014). Additionally, parents are also faced with the financial responsibility of covering the expenses related to the support services which their child requires (required (re)habilitation) and the educational support required (educational placement specific to their child's needs) post-operatively (Emmett et al., 2015; Kerr et al., 2012; Sach et al., 2005). Throughout the CI process, parents also encounter travelling expenses when commuting back and forth to the CI center and some parents also incur accommodation expenses (Emmett et al., 2015; Kerr et al., 2012; Sach et al., 2005). Moreover, optional costs involved include insurance costs for the CI device(s), frequency modulation (FM) system costs and in the case of a bilateral hearing loss and unilateral cochlear implantation, the costs for a hearing aid in the non-implanted ear (Emmett et al., 2015; Kerr et al., 2012). In addition, parents also encounter indirect costs which refer to the time which they dedicate towards the entire and ongoing CI process (Sach et al., 2005). 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 to bear.

1.5. Delayed cochlear implantation

In spite of the known benefits of early cochlear implantation, a substantial number of children from developing and developed world regions still undergo implantation at a late age (Fitzpatrick, Ham, & Whittingham, 2015; le Roux, Swanepoel, Louw, Vinck,

& Tshifularo, 2015). At present, delayed implantation is considered as implantation performed more than twelve months succeeding the hearing loss diagnosis (Fitzpatrick et al., 2015). Possible factors contributing towards delayed implantation include the presence of a progressive or delayed-onset hearing loss, the presence of clinical issues such as medical concerns or additional disabilities, the family's geographical location or family indecision or uncertainty (Fitzpatrick et al., 2015). A study conducted in the United States confirmed a strong association between public insurance and delayed implantation as opposed to private insurance (Yang, Reilly, & Preciado, 2018). Dev, Lohith, Pascal, Dutt and Dutt (2018) categorized the delay in obtaining audiological services in terms of three stages, namely the delay in hearing loss diagnosis, the delay in the use of hearing aids and the delay in proceeding with cochlear implantation. Results indicated that limited parental knowledge regarding hearing loss and its intervention, parental refusal to accept their child's hearing loss, doubt in the benefit of hearing aids and concern over the stigma around hearing loss were contributing towards the delay in the first two stages (Dev et al., 2018). Only once parents decided to proceed with a CI for their child, finances were the highest scoring reason that attributed to the delay in implantation (Dev et al., 2018). Besides the impact of delayed implantation on speech and language outcomes, delayed implantation also increases the probability of non-mainstream school placement (le Roux et al., 2016). Within a developing country such as SA, le Roux et al. (2015) reported that the average age of implantation for children with congenital/ early onset hearing loss exceeded three and a half years of age and indicated an average delay of two years or more from the time of hearing loss diagnosis to cochlear implantation. These results suggest that paediatric CI candidates in SA often miss out on early auditory stimulation during the period of optimal neural plasticity that is

required for age appropriate speech and language skills (Ching et al., 2013; le Roux et al., 2016; Leigh et al., 2013; Sharma et al., 2002). Within sub-Saharan Africa where resources are limited, commencement of early intervention services for children with hearing loss are often delayed as a result of extensive poverty, poor health infrastructure and the scarcity of audiological services (Joint Committee on Infant Hearing (JCIH), 2007; Olusanya, 2012; Swanepoel & Storbeck, 2008; Van der Spuy & Pottas, 2008). It has been estimated that less than 10% of more than one million infants born in SA annually have the prospect of having their hearing screened (Meyer, Swanepoel, le Roux, & van der Linde, 2012; Theunissen & Swanepoel, 2008), thereby averaging the age of hearing loss diagnosis to be between 23 to 44.5 months (Butler et al., 2013; Swanepoel, Johl, & Pienaar, 2013; Van der Spuy & Pottas, 2008) as opposed to the suggested age of 3 months (Joint Committee on Infant Hearing Screening (JCIH), 2007). A delay in diagnosis results in delays in initial hearing aid fitting, the commencing of early intervention and subsequent cochlear implantation (le Roux, 2016). Thus additional factors contributing towards delayed implantation within a South African context include funding constraints due to limited financial support from the South African government or medical aids, administrative restraints such as delays in referrals to specialized CI programs, the incurrence of additional costs for family's required to travel long distances to a CI unit, the presence of healthcare inequalities for cutting-edge interventions such as CIs and an overall inequality in healthcare across ethnicities in SA (Kerr et al., 2012; le Roux et al., 2015).

1.6. Bilateral cochlear implantation

The benefits of bilateral implantation as opposed to unilateral implantation in children are well documented (Lovett, Kitterick, Hewitt, & Summerfield, 2010; Scherf et al., 2007; Sparreboom et al., 2010; Van Deun, Van Wieringen, & Wouters, 2010; Zeitler et al., 2008) and in developed countries bilateral implantation has become the norm for the management of children with severe to profound hearing loss (Sarant, Harris, Bennet, & Bant, 2014; Tait et al., 2010). Additionally, bilateral implantation performed simultaneously or sequentially with a small time lapse between the two implantations as opposed to a prolonged time lapse between the two implantations are more favorable for optimal cortical brain activity (Gordon, Wong, & Papsin, 2010). However, within the South African context, implanted children do not share equivalent prospects of obtaining second implants (le Roux et al., 2016). It is only the families who have access to adequate financial resources who are able to make provisions for bilateral implantations for their hearing impaired children (le Roux et al., 2016).

1.7. Education

Succeeding paediatric cochlear implantation, the issue of education is a significant concern for families of children with CIs as they often encounter altercations with the education authorities (Sach & Whynes, 2005). Children with CIs require educational placement appropriate to each of their specific needs and requirements (Jachova & Kovacevic, 2010; le Roux et al., 2016). As a result, parents need to decide on which educational setting would best suit their child succeeding the implantation, however, finding such a school is a concern and challenge encountered by many parents (Christiansen & Leigh, 2004; Moroe & Kathrada, 2016; Sorkin & Zwolan, 2004;

Wheeler, Archbold, Hardie, & Watson, 2009). Also, obtaining specialized support services in schools is a challenge experienced by many families in developing countries such as SA (Department of Education, 2015; Moroe & Kathrada, 2016) as well as in developed countries such as the United States (Sach & Whynes, 2005) and the United Kingdom (Sorkin & Zwolan, 2004). Moreover, many children with CIs encounter numerous challenges in school (Jachova & Kovacevic, 2010; Punch & Hyde, 2010). Since hearing loss is not a visible disability, teachers do not always recognize this disability and modify their teaching methods accordingly (Jachova & Kovacevic, 2010). Additionally, parents and teachers often seek support from the CI team regarding educational issues since numerous education systems lack the necessary resources required for providing an ideal learning environment for paediatric CI recipients (Zwolan & Sorkin, 2004). Furthermore, for many parents, a primary motive behind the decision to have their child implanted is for their child to be mainstreamed (Sorkin & Zwolan, 2004). The placement of children with hearing loss alongside normal hearing children within a mainstream classroom setting not only lessens social isolation but also results in improved speech intelligibility for the students with hearing loss (Jachova & Kovacevic, 2010; Sorkin & Zwolan, 2004). The aim of an inclusive educational setting is for students with disabilities (such as hearing loss) to receive education in a mainstream setting along with specialized support services to help them cope within an inclusive setting (Jachova & Kovacevic, 2010). Within SA, the current educational policy aims to develop an inclusive education system, including children with severe-to-profound hearing losses (Department of Education, 2001). The advancement towards an inclusive education system is, however, encumbered by tenacious challenges such as the disproportionate resourcing of inclusive education across the country's provinces or

limitations in the availability of specialist support services in public ordinary schools (Department of Education, 2015). In a recent South African study including only a small sample of five parents of paediatric CI recipients (3-8 years of age), parents indicated that available remedial schools are either insufficiently equipped or are inconsistent in how they provide access to children with CIs (Moroe & Kathrada, 2016). Furthermore, these parents reported that the private remedial schools which are able to effectively accommodate children with CIs are costly (Moroe & Kathrada, 2016). Thus, accessing schools that adequately accommodate for the specific needs of each child with a CI(s) is a persistent challenge encountered by many parents and the educational costs involved and the lack of resources within the education system further exacerbate this challenge (Cheng et al., 2000; Christiansen & Leigh, 2004; Sach & Whynes, 2005; Wheeler et al., 2009). Consequently, the provision of inadequate educational support for children with CIs and their parents may exacerbate parental anxiety (Huttunen & Välimaa, 2012).

1.8. Parental experiences and challenges post cochlear implantation

Knowledge concerning parents' experiences and challenges succeeding paediatric implantation is critical in ensuring that adequate guidance and support is provided in obtaining the best possible (re)habilitation outcomes (Huttunen & Välimaa, 2012). Ultimately parents are critical partners in the (re)habilitation process and understanding and addressing the challenges they experience post implantation is vital (Zaidman-Zait et al., 2015). Also, parents are the primary decision makers for cochlear implantation and when confronted with such a decision, knowledge regarding the perceptions of other parents who already experienced the CI process could be beneficial to them (Hyde et al., 2010; Nunes, Pretzlik, & Ilicak, 2005). These

experienced parents can also assist in keeping CI centres and policy makers well informed regarding their perceived challenges and experiences with the CI process (Nunes et al., 2005). Thus, it is critical that involved professionals have the required knowledge and a thorough understanding of parental perceptions and experiences of cochlear implantation in their children.

1.9. Cochlear implantation in South Africa

Currently, SA is the only country in sub-Saharan Africa with an established national CI platform as well as existing infrastructure for cochlear implantation (Emmett et al., 2015). The first multichannel cochlear implantation took place in SA in 1986 and since then more than 2654 individuals (including 1005 paediatric cases) have been implanted countrywide (Kerr et al., 2012; SACIG, 2017). Presently, there are four active public sector/ government funded CI programs in SA, namely Tygerberg Hospital-Stellenbosch University-Cochlear Implant Unit (TH-SU-CIU), Chris Hani Baragwanath Academic Hospital-Cochlear Implant Program (CHBAH-CIP), Groote Schuur Hospital Cochlear Implant Program and Mthata Cochlear Implant Program (Nelson Mandela Academic Hospital) (SACIG, 2017). Additionally, there are six private sector CI programs in SA, namely the Bloemfontein Cochlear Implant Program (BCIP), Durban Cochlear Implant Program (DCIP), Ear Institute Cochlear Implant Program, Johannesburg Cochlear Implant Centre (JCIC), Port Elizabeth Cochlear Implant Unit (PECIU) and Pretoria Cochlear Implant Unit (PCIU) (SACIG, 2017).

1.10. Problem statement and rationale

At present there is a dearth of published data on cochlear implantation in SA and only recently national outcome data was published (le Roux et al., 2015; le Roux et al., 2016; le Roux et al., 2017). Moreover, 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 (Most & Zaidman-Zait, 2003). Thus, contextual data are required for the implementation of evidence-based pre-operative counselling, as well as CI intervention and (re)habilitation services post implantation. Furthermore, it is necessary to obtain context-specific CI data in SA, since current literature primarily focus on the experiences of parents of paediatric CI recipients in middle to high-income countries. With the emphasis of international research being predominantly on the medical aspects of implantation and the speech and language outcomes of paediatric CI recipients (Huttunen & Välimaa, 2012), available data on parents' perceived challenges regarding the CI process and support services received are limited (Zaidman-Zait et al., 2015).

Given the importance of parents' experiences of and challenges related to cochlear implantation, the aim of the current study was to determine parent-perceived challenges related to the paediatric cochlear implantation process and support services received.

The research question is therefore: *What are the parent-perceived challenges related to the paediatric CI process and support services that they received?*

2. METHODOLOGY

2.1. Research aim

The main aim of this study was to determine parent-perceived challenges related to the paediatric cochlear implantation process and support services received.

2.2. Research design

A descriptive research design was employed for this study. Descriptive research describes and explains various characteristics within a participant group (Leedy & Ormrod, 2013) and can involve the asking of questions and the tabulation of responses to gain information concerning participants' attitudes or opinions in a clinical or natural setting (Leedy & Ormrod, 2005; Maxwell & Satake, 2006) without altering the situation under study (Leedy & Ormrod, 2013). Data for this research study was collected at a single point in time (Babbie & Mouton, 2001). Furthermore, this research project was a survey study and since its purpose was to explain and predict, quantitative data was primarily collected (Leedy & Ormrod, 2010). A qualitative component was embedded into the study as well since open-ended questions were included in the data collection tool. Qualitative studies allow for a comprehensive description and understanding of the process under investigation (Babbie & Mouton, 2001).

2.3. Ethical considerations

The following ethical principles were adhered to in this study with the intent of protecting the rights and welfare of the participants involved (Leedy & Ormrod, 2013):

2.3.1. Informed Consent

Preceding the commencement of data collection, ethical clearance was obtained from the *Research Ethics Committee* of the Faculty of Humanities, University of Pretoria (Appendix A). At the time of data collection there were nine independent CI programs in SA and all nine programs were approached to participate in this study. The nine CI programs included BCIP, CHBAH-CIP, DCIP, Ear Institute Cochlear Implant Program, JCIC, PECIU, PCIU, Steve Biko Academic Hospital-Cochlear Implant Program and TH-SU-CIU. The CI team coordinator of each CI program received an information letter detailing the nature of the study and what would be expected of them (Appendix B). Permission to conduct this study and to access patient records was obtained from the CI team coordinators of six of the nine CI programs in SA (Appendix B). Participating CI programs included BCIP, CHBAH-CIP, DCIP, PECIU, PCIU and TH-SU-CIU.

Potential participants that complied with the inclusion criteria for this study were approached to participate in this research by sending them an information letter detailing the nature of the study and their levels of involvement (Appendix C) (Leedy & Ormrod, 2013). Prior to data-collection, each prospective participant was required to give consent to partake in this research project (Appendix D). All participants were made aware that their participation was voluntary and should they opt to withdraw,

they could do so at any given time without encountering any negative consequences (Leedy & Ormrod, 2013).

2.3.2. Right to privacy

No identifying information was utilized for the purposes of this study as patient privacy should be maintained at all times (Leedy & Ormrod, 2013). Therefore, a unique alphanumeric research code was assigned to each participant and documents were labelled with that number thereby ensuring confidentiality (Leedy & Ormrod, 2013). Thus all identifiable information was omitted from the study and data was presented anonymously for data analysis. Participants' identity was only known to the researcher. The right to privacy was also confirmed in the parent participants' information letter which was provided to all participants (Appendix C).

2.3.3. Protection from harm

Research participants should not be exposed to unnecessary physical or psychological harm and the risk involved in participating in a research study should not surpass the risks encountered in normal daily living (Leedy & Ormrod, 2013). Since data was collected through means of a questionnaire, there was no physical contact or testing involved and the research participants were not harmed in any way, physically or psychologically (Leedy & Ormrod, 2013).

2.3.4. Plagiarism

This research report reflects the researcher's own work and the utilization of any secondary material was accurately cited and referenced in accordance with the

University of Pretoria's requirements. The declaration regarding plagiarism and originality was signed by the researcher (Appendix E).

2.3.5. Storage of data

On completion of the study, data will be stored in both digital and hard copy at the Department of Speech-Language Pathology and Audiology, University of Pretoria for a period of at least 15 years. A declaration for the storage of research data and/ or documents was obtained from this research study's supervisor (Appendix F).

2.3.6. Release of findings

A research article was compiled, ensuring that the research is available to the scientific community and a research dissertation was completed and will be made available online and in hard copy in the University of Pretoria's library.

2.3.7. Co-authorship of manuscripts to be submitted for publication

One representative from each CI team will act as a co-author for the publication for this research study. Co-authors were expected to give input to the manuscript drafts and oversee the data-collection procedure at their respective CI program for the purposes of this study.

2.4. Research participants

2.4.1. Participants selection criteria

There were nine independent CI programs in SA at the time of data collection. All nine CI programs were approached to participate in this multicentre study. Six programs had consented to participation. Thus, parents of paediatric CI recipients from these six programs were considered as participants for this study. A nonprobability purposive sampling method was used when selecting participants for this study as the sample aimed to be representative of parents of CI recipients in SA. Hence, this sampling technique allowed for the selection of these participants for the research study.

The following inclusion criteria were specified for participants:

- Participants should be parents/ primary caregivers of CI recipients with a unilateral or bilateral CI.
- Parents/ primary caregivers of paediatric (≤ 18 years of age) CI recipients who were active users of their CI(s) and had at least 12 months of CI experience. Twelve months CI experience was deemed crucial in order to ensure that parents/ primary caregivers gained sufficient experience with the CI process and support services prior to completing the questionnaire as this would allow for more insightful responses.
- Participants should be proficient in English as the data collection tool was only available in English.
- Participants should be literate and able to either complete the questionnaire electronically (online) or in writing (hard-copy) should they have preferred this method of completion.

For the purpose of this study there was no case selection or any exclusion other than parents/ primary caregivers of paediatric CI recipients who were non-users of their CIs. Therefore, parents/ primary caregivers of CI recipients from the complete range of educational and communication environments in SA were included. The study sample was however biased as it did not include parents whose children were not approved for cochlear implantation, as well as parents of implanted children who became non-users of their CI devices.

2.4.2. Study population

The website link was emailed to approximately 290 potential participants who adhered to the inclusion criteria of this study. Of these 290 potential participants, only 60 completed the online questionnaire. The approximate response rate was thus 20.69%. According to Leedy and Ormrod (2010), a low response rate can be expected from a survey study (Leedy & Ormrod, 2010). In an attempt to improve the response rate however, during the data collection period, questionnaires were handed out to participants in hard-copy whilst they attended consultations at their various CI programs. This improved the approximate response rate to 28.28%.

This multicentre study included a total sample of 82 parents of paediatric (≤ 18 years) CI recipients in SA. The representative number of participants from each CI program were as follows: BCIP: 1, CHBAH-CIP: 1, DCIP: 9, PCIU: 25, PECIU: 5 and TH-SU-CIU: 41.

From the 82 participants, 78.05% (n=64/82) were mothers and 21.95% (n=18/82) were fathers. Most participants were married (78.05%, n=64/82) and held some form of tertiary qualification (67.07%, n=55/82).

Demographical and clinical characteristics of 82 paediatric CI recipients are presented in Table 1. At the time of data collection, the average age of the paediatric CI recipients was 10.15 years (range: 2.81-17.27 years; SD 3.97; n=82) and the average duration of CI use was 6.91 years (range: 1.01-15.58 years; 4.17 SD; n=82). More than half of the children (57.32%, n=47/82) were implanted bilaterally. Bilateral implantation was done sequentially for 39 (82.98%) of the cases, while only eight cases (17.02%) were implanted simultaneously (n=47). The mean interval between the first and second implant for those implanted sequentially ranged from 0.1 to 7.9 years (mean = 1.69 years; 1.57 SD; n=39). All paediatric CI recipients in this sample were active users of their implants.

The presence of one or more additional developmental conditions was reported for 34.15% (n=28/82) of the children, with the most frequent additional developmental condition being attention deficit hyperactivity disorder/ attention deficit disorder (42.86%, n=12/28). Participants reported newborn hearing screening (NHS) to be conducted in only 39.02% (n=32/82) of the paediatric CI recipients.

Table 1. Characteristics of paediatric cochlear implant recipients

Demographics	% (n)	Hearing loss and cochlear implant characteristics	% (n)
Age at study (years) (n=82)		Newborn hearing screening	
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)
Gender		Onset of hearing loss (n=82)	
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)
Health sector		Age at diagnosis of hearing loss (months) (n=62) *	
Private	74.39 (61/82)	Mean (SD)	16.40 (13.31)
Public	25.61 (21/82)	Range	1.00 - 48.00
Communication mode		Mode of amplification	
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)		
Current educational setting		Age at implantation (months) (n=70) *	
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)		

Special nursery school or pre-school for children with hearing loss: oral approach (spoken language)	10.98 (9/82)	Duration of deafness (time of deafness before implantation) (months) (n=82) Mean (SD) 36.04 (21.25) Range 5.95-101.50 Delay from diagnosis to implantation (months) (n=73) Mean (SD) 19.34 (14.81) Range 2.07-79.30
Full mainstream nursery school or pre-school	7.32 (6/82)	
School for the Deaf: Sign Language or Total Communication approach	7.32 (6/82)	
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)	
Presence of one or more additional developmental conditions (n=28)	34.15 (28/82)	Age at second implantation (sequential bilateral implantation) (years)(n=39) Mean (SD) 4.40 (2.54) Range 0.83-10.67 Time-lapse between first and second implantation (sequential bilateral implantation) (years)(n=39) Mean (SD) 1.69 (1.57) Range 0.10-7.90 Duration of cochlear implant use (years) Mean (SD) 6.91 (4.17) Range 1.01-15.58
Attention Deficit Hyperactivity Disorder/ Attention Deficit Disorder	42.86 (12/28)	
Visual impairment	14.29 (4/28)	
Developmental cognitive delay	10.71 (3/28)	
Apraxia	7.14 (2/28)	
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)	

**Only children with congenital/ early onset hearing loss were considered*

2.5. Data collection materials

2.5.1. Cochlear implant questionnaire for parents

Data was collected using a self-administered electronic questionnaire specifically developed for this study (Appendix G). Hard-copies of the questionnaire were made available to participants who preferred to complete the questionnaire in writing. The questionnaire was only available in English. A statistician assisted with the coding of each question to ensure that participants' responses could be categorized into answer categories for the purpose of data analysis.

The questionnaire was compiled according to the research study's aim and it incorporated a variety of sources. To ensure content validity, published articles, questionnaires and protocols in the field of early intervention for children with hearing loss (Muñoz et al., 2015; Summers et al., 2007) and paediatric cochlear implantation (Archbold et al., 2015; Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Damen, Krabbe, Archbold, & Mylanus, 2007; Fitzpatrick et al., 2015; Huttunen et al., 2009; Most & Zaidman-Zait, 2003; O'Neill, Lutman, Archbold, Gregory, & Nikolopoulos, 2004; Zaidman-Zait, 2008; Zaidman-Zait et al., 2015; Zaidman-Zait & Most, 2005; Zaidman-Zait & Young, 2008) were reviewed. These articles and questionnaires were reviewed prior to developing the questionnaire and consequently influenced the development of each question eventually included in the questionnaire.

The questionnaire was used to obtain demographic and background information as well as information pertaining to participants' perceived challenges relating to the CI process and support services received. It comprised of five sections and included a

total number of 36 questions. The information obtained from these questions allowed for the data to be statistically analysed in terms of measures of central tendency and measures of correlation (Leedy & Ormrod, 2013) thereby enabling the data to be compared against the data from similar international studies.

Sections A and B tapped questions concerning demographical information relating to the parents of the paediatric CI recipients and the paediatric CI recipients respectively. The aim of these sections was to obtain information relating to both the parent/ primary caregiver and the child's demographical profile.

Sections C (information about the CI process), D (information about the education of the child with a CI(s) and E (information on the support services received) of the questionnaire tapped questions concerning parents' perceived challenges related to the CI process and support services received. These sections were aimed at gaining more information on the types of challenges that the participants encountered.

Section C consisted of five close-ended and three open-ended questions whilst Sections D and E consisted of three close-ended and five close-ended questions respectively. The use of close-ended questions allows participants to complete questionnaires timeously whilst still allowing the researcher to collect increasing amounts of information as participants tend to understand these questions better than open-ended questions (Neuman, 2012). Additionally, they provide for more consistency in the responses obtained and are more easily analysed (Babbie & Mouton, 2001). A variety of close-ended question categories were used in the questionnaire such as multiple choice single/ multiple response questions, contingency questions, matrix questions and ordering questions. Contrastingly,

open-ended questions enable the researcher to obtain supplementary information not necessarily prompted by the close-ended questions (De Vos, Strydom, Fouche, & Delport, 2011) and are an effective means of identifying the challenges most prominent to parents of deaf children with CI(s) (Zaidman-Zait, 2008). The number of open-ended questions utilized in this questionnaire were however minimal as they're more time consuming to answer, they can potentially cause participants to opt to withdraw and not complete the questionnaire and their statistical analysis is more challenging (De Vos et al., 2011). Thus, open-ended questions were utilized only when additional information from participants were required.

Additionally, eight questions included in the questionnaire were adapted from the *Children with Cochlear Implants: Parental Perspectives (CCIPP)* questionnaire (Archbold et al., 2008). The CCIPP questionnaire is an established and validated parent-proxy health-related quality of life assessment for children with CIs, covering two main domains of the cochlear implantation process namely decision-making and outcomes of implantation (Archbold et al., 2008; Damen et al., 2007).

In addition to questionnaire data, supplementary retrospective data was captured from patient files/ clinical records and included demographical, hearing loss and CI-related data (Appendix H).

An outline of the sections and type of questions contained in the CI questionnaire for parents is provided below in Table 2.

Table 2. Outline of cochlear implant questionnaire for parents used for data collection

Section	Theme	Type of questions asked (with numbering as indicated in questionnaire)	Number of questions contained in sub-section
A	Demographic information: parent/ primary caregiver	Multiple choice single response questions: <ul style="list-style-type: none"> Relationship to the child with a cochlear implant(s) (1) Highest qualification level obtained (2) Marital status (3) 	3
B	Demographic information: child with cochlear implant(s)	<p>Comment response question:</p> <ul style="list-style-type: none"> Name of child (4) <p>Date/ time question:</p> <ul style="list-style-type: none"> Date of birth (5) <p>Multiple choice single response questions:</p> <ul style="list-style-type: none"> Gender (6) Whether the child's hearing was screened shortly after birth (7) Health sector (8) Current cochlear implant program (9) Funding of the first cochlear implant (10) Funding of the second cochlear implant (if applicable) (11) Type of fitting (bilateral cochlear implant; unilateral cochlear implant with a hearing aid or unilateral cochlear implant with no hearing aid) (12) Communication mode (13) Current educational setting (14) Nature of formal educational setting i.e. public or private (15) 	17

		<ul style="list-style-type: none"> ○ Repetition of one/ multiple grades in school (16) ○ Whether the child was electively held back during a grade or enrolled into school at a later age (17) ○ Presence of a genetic syndrome (18) ○ Comment response question: specification of the genetic syndrome present if applicable (19) ○ Multiple choice multiple response question: presence of one/ more additional developmental conditions/ needs (20) 	
C	Cochlear implant process	<p>Five close-ended questions and three open-ended questions</p> <ul style="list-style-type: none"> ○ Five-point Likert scale (21). Scale: strongly agree (1), agree (2), neither agree nor disagree (3), disagree (4), strongly disagree (5) Six statements/ items were included in the five-point Likert Scale: <ol style="list-style-type: none"> 1. It was a difficult time waiting for the results of the cochlear implant assessment before implantation* 2. It was a problem getting someone to look after the family when we had to go to the cochlear implant centre* 3. The costs of travel to the cochlear implant centre were a problem* 4. It was hard to take time off work for the appointments at the cochlear implant centre* 5. As a family, we were financially prepared to meet the financial demands of the cochlear implantation process 6. We are currently financially able to meet the long-term and continuous financial demands following cochlear implantation (costs relating to habilitation, device maintenance etc.) ○ Multiple choice single response contingency question: participant's opinion on whether the timing between the diagnosis of the hearing loss and the eventual cochlear implantation was delayed (22) 	8

		<ul style="list-style-type: none"> ○ Follow-up to the contingency question – matrix single select question: possible reason(s) for the delay (if applicable). Participants had to select possible reason(s) from a list provided (23) ○ Multiple choice single response contingency question: if the child has one cochlear implant, whether the participant would want the child to receive a second cochlear implant (24) ○ Follow-up to the contingency question - matrix single select question: possible barriers preventing the child from obtaining a second implant (if applicable). Participants had to select possible reason(s) from a list provided (25) ○ Follow-up open-ended question to the previous contingency question: participants had to list possible reasons for not wanting the child to receive a second implant (if applicable) (26) ○ Open-ended question: the greatest challenge(s) of being a parent/ primary caregiver of a child with a cochlear implant (s) (27) ○ Open-ended question: the greatest challenge(s) that the child experiences as a result of his/ her cochlear implant(s) (28) 	
D	Education	<p>Three close-ended questions</p> <ul style="list-style-type: none"> ○ Six-point Likert scale. Scale: strongly agree (1), agree (2), neither agree nor disagree (3), disagree (4), strongly disagree (5), not applicable (6) <p>Eight statements/ items were included in the six-point Likert Scale (29):</p> <ol style="list-style-type: none"> 1. Finding an adequate educational setting for my child has been a challenge 2. I am happy about my child's progress at school currently * 3. My child is keeping up well with other children (normal hearing) his/ her age in school * 4. My child is able to follow/ keep up with the pace at which the teacher presents information 5. My child is able to cope academically in a mainstream school setting * 6. The local school and its support services adequately meet all our needs concerning the use of my child's implant at school * 	3

		<ul style="list-style-type: none"> 7. My child's current school placement is appropriate for his/ her specific needs 8. There is a shortage of appropriately trained teachers to deliver intervention services, specifically for children with cochlear implants ○ Multiple choice multiple response question: the professional(s) who assisted the participant in obtaining a school for the child (30) ○ Matrix single select question: whether the child encounters any of the challenges listed below in his/ her current educational setting. Participants had to select either yes, no or N/A for each challenge listed (31) <ul style="list-style-type: none"> 1. The number of children in the classroom is too big 2. The classroom environment is too noisy 3. No/ little consideration is given for our child's unique language needs 4. No/ little support from school for additional services (we must pay for private tutors, remedial therapy etc.) 5. Teachers and therapists often unsure of how to support our child's individual needs 6. Bullying as a result of his/ her cochlear implant is an issue 7. As parents, we don't always have adequate finances to pay for all the additional academic support services our child needs 8. Teachers have unrealistic expectations of parents 9. We do not receive accurate feedback from the teachers (for e.g. they'll report that our child is coping and in another instance report that he/ she is not coping) 10. Teachers have limited patience with our child and don't have the capacity to go the extra mile in assisting him/ her 	
E	Support services received	Five close-ended questions	5

- Multiple choice single response question: the professional on the cochlear implant team who provided the most continued support from the time of implantation to present. Participants had to select a professional from the list of professionals (32)
- Rating scale. Rating of six support services that the child with a CI(s) received since his/ her (first) implant (33)
 Scale: support service not available (1); received limited support (2); received adequate support (3); received exceptional support (4) and not applicable (5)
 Support services:
 Speech and language therapy; occupational therapy; behaviour support; counselling; tutoring in school system; Sign Language instruction; other (specification required)
- Rating scale. Rating of nine support services that the parent/ primary caregiver has received since the child's (first) implant (34)
 Scale: support service not available (1); received limited support (2); received adequate support (3); received exceptional support (4) and not applicable (5)
 Support services:
 Parent guidance; counselling; guidance for educational placement; parent support group; financial support; tele-intervention; technical support for device maintenance; support and guidance to discipline my child with a cochlear implant(s); counselling and support for the siblings of my child with a cochlear implant(s); other (specification required)
- Matrix single select ordering question: participants had to select three support services from a list of six support services that they considered as critical for a child with a cochlear implant(s) to ensure optimal outcomes (35).
 Participants needed to select the three services in order of importance: most important (1); second important (2) and third important (3)

- Matrix single select ordering question: participants had to select three support services from a list of ten support services that they considered as critical for the parent/ primary caregiver of a child with a cochlear implant(s) to ensure optimal outcomes (36)
Participants needed to select the three services in order of importance: most important (1); second important (2) and third important (3)

**Questions adapted from 'CCIPP' questionnaire by Archbold et al.,2008*

2.5.2. Pilot study

As the data collection questionnaire was newly developed, its preliminary validity and reliability needed to be ascertained and therefore a pilot study was first conducted. A pilot study was used to identify possible weaknesses in the CI questionnaire for parents and to amend them accordingly (Leedy & Ormrod, 2013). This ensures meticulousness in the research method and accuracy in the data that is obtained (De Vos, Strydom, Fouché, & Delport, 2005). The purpose of this pilot study was to determine whether the questionnaire was designed in a manner that was unambiguous, easily understandable and addressed the issues relevant to the aim of the study. Also, this pilot study aimed to clarify and modify the wording of all the questions included in the questionnaire.

Three parents of paediatric CI recipients fitting the inclusion criteria for this study (as outlined in sub-section 2.4) participated in the pilot study. These three pilot study participants were not included as participants in the actual study in order to avoid data contamination (van Teijlingen & Hundley, 2002).

Furthermore, input from professionals with expertise in working with parents of paediatric CI recipients was sought to ensure face validity. These experienced professionals who participated in the pilot study included one special needs educator, one audiologist, one auditory-verbal therapist and two speech-language therapists.

The pilot study participants were provided with the parent information letter (Appendix C) and the purpose and procedures for the study were explained to them

as well as the areas of evaluation (question content; question structure, order and length; appropriateness of questions and clarity) requiring their input. All the participants had provided feedback within one month of sending out the questionnaire. The audiologist and one speech-language therapist provided detailed feedback in written format whilst the three parents of paediatric CI recipients, special needs educator, auditory-verbal therapist and one of the speech-language therapists provided verbal feedback to the researcher (either telephonically or face-to-face). Based on the parents and professionals' feedback, the questionnaire was reviewed and modified for clarity.

A summary of the feedback received from the pilot study participants based on the aspects/ areas they were asked to review and the adaptations that were consequently made to the questionnaire is provided in Table 3.

Table 3: Findings from the pilot study

Aspects considered	Comments	Adaptation
Question content	<ul style="list-style-type: none"> Section B, questions 10 and 11: “How was your child’s (first) cochlear implant funded?” “How was your child’s (second) cochlear implant funded?” <i>Make additions to the option lists for these two questions and add in the option of a sponsor(s)</i> Section C, question 23: “What do you think possible reason(s) for the delay between the diagnosis of your child’s hearing loss and the eventual cochlear implantation could be?” <i>Make additions to the option list and add in the option of cultural beliefs: seeking alternative/ traditional treatment</i> Section C, question 25: “If yes, what do you think are the barriers preventing your child from obtaining the second implant? Please select possible reasons (more than one reason can be selected)” <i>Make additions to the option list and add in: “not recommended by the cochlear implant team”</i> Section C, question 27: “What would you consider as the greatest challenge(s) of being a PARENT of a child with a cochlear implant(s)?” <i>Add in Primary caregiver</i> 	<p>Option lists for questions 10 and 11 were modified and the option of a sponsor(s) was added to both questions option lists</p> <p>Option list for question 23 was modified and this option was added in</p> <p>Option list for question 25 was modified and this option was added in</p> <p>Question modified to: “What would you consider as the greatest challenge(s) of being a PARENT/ PRIMARY CAREGIVER of a child with a cochlear implant(s)?”</p>

	<ul style="list-style-type: none"> Section D, question 29, bullet 3: “My child is keeping up well with other children his/ her age in school” <i>Elaborate whether this statement is comparing the child to normal hearing children or hearing-impaired children</i> 	<p>Question modified to: “My child is keeping up well with other children (normal hearing) his/ her age in school”</p>
Question structure, order and length	<ul style="list-style-type: none"> <i>Questionnaire is slightly lengthy</i> Section C, questions 27 and 28: <i>Provide more space for parents to answer</i> Section E, questions 35 and 36: “In your opinion, which of the following support services would you consider as critical for <u>A CHILD</u> with a cochlear implant(s) to ensure optimal outcomes? Please select <u>THREE</u> support services (from the table below) that you deem most important and rate their importance (on a scale from 1 to 3, 1 being a highly critical support service, 2 a moderately critical support service and 3 a mildly critical support service)” “In your opinion, which of the following support services would you consider as critical for <u>THE PARENTS/ PRIMARY CAREGIVERS</u> of a child with a cochlear implant(s) to ensure optimal outcomes? Please select <u>THREE</u> support services (from the table below) that you deem most important and rate their importance (on a scale from 1 to 3, 1 being a highly critical support service, 2 a moderately critical support service and 3 a mildly critical support service)” <i>Questions are a bit confusing. Change structure</i> 	<p>Two questions from Section E were omitted from the final questionnaire.</p> <p>More answering space (lines) were provided</p> <p>Structures were changed, and questions were simplified to: “In your opinion, which of the following support services would you consider as critical for <u>A CHILD</u> with a cochlear implant(s) to ensure optimal outcomes? Please select <u>THREE</u> support services (from the table below) that you deem most important.” Participant to select three support services in order of importance (most important, second important and third important) “In your opinion, which of the following support services would you consider as critical for <u>THE</u></p>

		<p><u>PARENTS/ PRIMARY CAREGIVERS</u> of a child with a cochlear implant(s) to ensure optimal outcomes?</p> <p>Please select <u>THREE</u> support services (from the table below) that you deem most important.”</p> <p>Participant to select three support services in order of importance (most important, second important and third important)</p>
Appropriateness of questions	None	None
Clarity	<ul style="list-style-type: none"> Section D, question 29, bullet 4: “My child is able to manage the pace at which the teacher follows” <i>Re-phrase for clarity purposes</i> Section D, question 29, bullet 5: “My child is able to cope in a mainstream school setting” <i>Clarify whether the question is addressing if the child is able to cope academically, socially or emotionally</i> Section D, question 31, bullet 4: “No/ little support from school (we must pay for private tutors, remedial therapy etc.)” <i>Further elaborate and clarify on this statement. Add in “for extra services”</i> 	<p>Question changed to: “My child is able to follow/ keep up with the pace at which the teacher presents information”</p> <p>Question modified to: “My child is able to cope academically in a mainstream school setting”</p> <p>Question modified to: “No/ little support from school for additional services (we must pay for private tutors, remedial therapy etc.)”</p>

2.6. Data collection procedures

Permission was obtained from the CI team coordinators of the six participating CI programs to access patient data and contact details of eligible parents of paediatric CI recipients from their respective CI programs (Appendix B). Patient registers were reviewed at the participating CI programs and prospective participants fitting the inclusion criteria for this study were identified.

The CI team coordinators emailed the parents of these eligible paediatric CI recipients and invited them to participate in the study. The information letter detailing the nature of the study and the participants' levels of involvement (Appendix C) was attached to this email along with the website link to the online survey tool used for this study (SurveyMonkey) so that the questionnaire could be accessed by potential participants. The website link first opened into a website page requesting informed consent from participants for this study. This website page allowed the researcher to obtain informed consent as participants' responding with a virtual "click to accept" key served as an indication of their consent to participate (Leedy & Ormrod, 2013). Data collection only commenced once consent was obtained from the participants as access to the questionnaire was only made possible once consent had been provided. Potential participants were then required to complete an online, self-administered questionnaire. The participants were requested to complete the questionnaire within seven working days of receiving the website link.

A computer database was created to keep track of all the participants who responded and those who had not as this assisted in identifying participants who needed a reminder to complete the questionnaire (Leedy & Ormrod, 2013).

Two weeks after the questionnaire had been sent, follow-up emails were sent to participants by the CI team coordinators to serve as reminders for them to complete the questionnaire if they hadn't already done so. Follow-up electronic messages are an efficient means of improving the return rates in mail questionnaires (Babbie & Mouton, 2001).

Participants were also given the option of completing the questionnaire in writing (hard copy) (Appendix G), if this method of completion was preferred. In these instances, written consent as opposed to electronic consent was first obtained prior to the completion of the questionnaire (Appendix D). In order to increase the response rate, those participants who attended regular device programming sessions at the respective CI programs were requested to complete the questionnaire in hard copy. They were provided with the information letter (Appendix C), informed consent form (Appendix D) and a hard copy of the questionnaire (Appendix G).

Once the questionnaire data was collected and captured onto an excel spreadsheet, the CI team coordinators were contacted to inform them that the supplementary retrospective data was required. This information was only required for the paediatric patients whose parents completed the questionnaire. Permission from the CI team

coordinators to make this data from the patient files available to the researcher was obtained at the commencement of the study (Appendix B) and permission to access and capture this data for the purpose of this research study and for publication in scientific literature was also obtained from all participating parents prior to them completing the questionnaire (Appendix D).

An excel spreadsheet containing the names and required retrospective data fields of the paediatric CI recipients (children of participants who completed the questionnaire from each participating CI program) was compiled and consequently emailed to the respective CI team coordinators. CI team coordinators of the participating CI programs were requested to capture the required data retrospectively from the patient/ clinical files. This retrospective data included the patients' date of birth, date of implantation (first and second CI – if applicable), date of initial activation (first and second CI if applicable), age at identification of hearing loss, hearing loss onset/ etiology, age at deafness, whether the implantations were done sequentially or simultaneously in the case of bilateral implantations and the presence of auditory neuropathy spectrum disorder (Appendix H).

Once the six CI team coordinators captured the required retrospective data, this data was merged onto the excel spreadsheet created to capture the questionnaire data. This ensured that all the quantitative data obtained was captured onto a single excel spreadsheet for the purpose of data analysis.

2.7. Data processing and analysis

Obtained data were analyzed using a commercially available statistical software package (SAS version 9.4). The participants' 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 the two open-ended questions in the questionnaire (questions 27 and 28) were systematized and transcribed for the purpose of thematic analysis.

The quantitative data obtained were predominantly analyzed using descriptive statistical measures. Frequency tables and descriptive statistics were used to define the implanted children of parent participants in terms of demographical, CI and hearing loss characteristics. Measures of central tendency and variability (means, medians and standard deviations) were calculated for all demographic, hearing loss and CI related data (Table 1). Descriptive statistical measures and frequency tables were also utilized to describe questionnaire data in terms of the 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) consisted

of 6 statements and participants rated their responses on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). Question 29 consisted of 8 statements and participants also rated their responses on a 5-point Likert ranging from 1 (strongly agree) to 5 (strongly disagree), with an additional “not applicable” option. 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.

Prior to regression modelling, bivariate data analyses (Pearson chi-square test) were conducted to determine the presence of possible associations between the independent categorical variables (*gender, health sector, presence of one or more additional developmental conditions, onset of hearing loss, type of amplification, communication mode, educational setting, public vs private educational setting, grade repetition, parents’ marital status, relationship to the paediatric CI recipient and highest qualification level obtained*) and the dependent outcome variables (*CI process 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 (*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 the dependent outcome variables (*CI process and educational challenges*). For the *age at diagnosis of hearing loss* and the *age at implantation*, 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 (EHDI) services in SA.

General linear models were constructed to test the effect of all significant independent variables identified through the Pearson-chi square test simultaneously on the dependent outcome variables. Statistical significance was considered as $p < 0.05$.

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).

The qualitative data obtained from the open-ended questions were analysed using thematic content analysis. All responses attained from the open-ended questions were coded into central themes to ensure that common emerging trends amongst participants' responses were identified (Leedy & Ormrod, 2013).

Cronbach's Alpha test was used to calculate internal consistency for the scales utilized in the questionnaire (question 21 addressing the challenges related to the CI process and question 29 addressing the challenges related to the education of a child with a CI).

A higher alpha corresponds with a higher internal consistency reliability (Damen et al., 2007). Additionally, a Cronbach's alpha exceeding 0.70 is indicative of good reliability (Nunes et al., 2005). The Cronbach's alpha for question 21 and 29 was 0.74 and 0.83 respectively. Thus, both scales have a good reliability. Furthermore, this suggests that all of the items within question 21 and 29's rating scales are reliable determining aspects of the same fundamental theme i.e. challenges related to the CI process (question 21) and challenges related to the education of a child with a CI (question 29).

2.8. Reliability and validity

A research measurement must be both reliable and valid as this will impact the degree to which a researcher gains insight into the situation under investigation, the possibility of gaining statistical significance during the analysis of the data obtained and the degree to which the researcher is able to make meaningful inferences from the data (Leedy & Ormrod, 2013).

Reliability refers to the consistency with which a measurement method yields a certain, constant result whilst the validity of a measurement method refers to the extent that the research study measures that which it is purported to measure (Leedy & Ormrod, 2013).

Reliability and validity was ensured in the following ways:

Face validity refers to the degree whereby a measuring instrument appears to measure that which it is designed to measure and it is particularly valuable for ensuring the participation of the individuals partaking in the research study (Leedy & Ormrod, 2013).

The face validity of the questionnaire was ensured by conducting a pilot study to confirm the question content, question structure, order and length, appropriateness of questions and the clarity of the questionnaire. Based on the input received from the pilot study participants, the questionnaire was revised and modified prior to data collection.

Content validity refers to the degree whereby the content of a measuring instrument represents the domain being measured (Leedy & Ormrod, 2013). Content validity was required to ensure that the questionnaire addressed and included all of the domains pertinent to the research topic (De Vos et al., 2011). Published articles and protocols were reviewed prior to the development of the questionnaire to ensure that content validity was obtained.

Construct validity refers to the degree whereby a measuring instrument measures a characteristic that cannot be directly observed but is presumed to exist based on patterns in people's behaviour (Leedy & Ormrod, 2013). In an attempt to avoid threats to the construct validity of the research study, the questionnaire included only the questions relevant to the current research study's aim and any potentially ambiguous, biased or misleading questions were adapted or excluded from the questionnaire. This was done through the use of a pilot study which allowed for the revision and modification of the questionnaire prior to data collection.

Additionally, the use of a questionnaire as a means of obtaining data enabled participants to provide carefully thought-through responses thereby enhancing the reliability and validity of their responses (De Vos et al., 2011).

As the questionnaire utilized Likert scales in two of the five sections, the Cronbach's alpha coefficient was calculated following data collection. This was done in order to calculate the internal consistency reliability of the set of items used in the Likert scales with the objective of determining the extent whereby the participants' response to those items yielded consistent results (Leedy & Ormrod, 2013). Results from the Cronbach's alpha indicated that both Likert scales utilized in the questionnaire (question 21 and 29) have a good internal consistency reliability.

3. RESULTS

3.1. Process of cochlear implantation

The average age at diagnosis of hearing loss for paediatric CI recipients in this sample was 16.40 months (13.31 SD; range=1.00-48.00 months; n=62) and the average age at implantation was 35.08 months (20.45 SD; range=6.03-85.30 months; n=70). On average, the delay from diagnosis of hearing loss to cochlear implantation was 19.34 months (14.81 SD; range= 2.07-79.30 months; n=73). Furthermore, for those children with bilateral CIs who were sequentially implanted, the average age at the time of the second implant was 4.40 years (2.54 SD; range=0.83-10.67 years) and the average time-lapse between the first and second implant was 1.69 years (1.57 SD; range=0.10-7.90 years; n=39).

Participants were asked to indicate how their child's first and second CI (applicable to bilaterally implanted recipients) were funded by choosing a possible funding option on a list of 10 items. The majority of the participants (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 complete, 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 participants in this sample indicated that their child's first CI was funded through public (government) funding and 4.88% (n=4/82) of participants obtained 'other' means of funding such as a combination of public (government) funding and private

funding (sponsors and donations). Almost a third of the participants (29.27%, $n=24/82$) indicated that their child's first CI was funded through a combination of medical aid contribution and private funding. All 47 bilaterally implanted recipient's parents indicated that the second CI was funded privately. More than a third of these participants of children with bilateral CIs (42.55%, $n=20/47$) indicated that the second CI was funded through a combination of medical aid contribution and private funding. Thus, no participants 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 participants to rate six statements on a 5-point Likert scale that ranged from strongly agree (1) to strongly disagree (5). Table 4 summarizes the parental ratings of the statements on challenges encountered during the CI process.

Table 4. Parental responses on challenges related to the cochlear implant process

Statements	Agree**	Neutral**	Disagree**
	%(n)	%(n)	%(n)
It was a difficult time waiting for the results of the cochlear implant assessment before implantation (n=81)*	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)*	23.17 (19)	10.98 (9)	65.85 (54)
The costs of travel to the cochlear implant centre were a problem (n=82)*	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)*	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)

*Questions adapted from 'CCIPP' questionnaire by Archbold et al., 2008

**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

The majority of the participants either agreed or strongly agreed (74.07%, n=60/81) that it was a difficult time waiting for the results of the CI assessment before implantation.

The responses for taking time off work for appointments at the CI centre was equally balanced, 35 participants agreed that this was difficult (42.68%, n=35/82), whilst 35 participants maintained that this was not difficult (42.68%, n=35/82), and 12 participants remained neutral (14.63%, n=12/82). For 23.17% (n=19/82) of the participants, it was a problem getting someone to look after their family when they had to go to the CI centre and the travelling costs to the CI centre were a problem for 32.93% (n=27/82).

Additionally, most participants 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 (costs relating to habilitation, device maintenance etc.) (45.12%, n=37/82).

An average mean rating of 2.85 (SD=0.85, range=1.00-4.67) was obtained for parent-perceived challenges that relate to the CI process. This indicates that in general, participants on average perceive the CI process to be more challenging rather than less challenging.

Participants were asked if they think that the timing between the diagnosis of their child's hearing loss diagnosis and eventual cochlear implantation was delayed. Almost half of the participants (46.34%, n=38/82) indicated that they felt the timing between diagnosis of hearing loss and eventual cochlear implantation was delayed. Table 5 summarizes parent-perceived reasons for the delay between diagnosis and implantation. 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), while the second highest scoring reason was a lack of prompt referral to specialized CI services (39.47%, n=15/38). The third highest scoring reason for this delay was difficulty in taking off from work to attend appointments at the CI centre (31.58%, n=12/38).

Parents of children implanted unilaterally were asked if they would like their child to have a second implant. Two thirds of the participants (68%, n=24/35) reported that they would like their child to receive a second implant whilst 31.43% (n=11/35) participants did not see the need for a second CI. For the participants who reported a desire for a

second implant for their child, the most frequently reported barriers preventing bilateral implantation were financial costs and funding of the second implant procedure (91.67%, n=22/24), financial costs and funding of the device maintenance (75%, n=18/24) and uncertainty as to whether their child would benefit from a second implant (41.67%, n=10/24). Table 5 shows parental responses in terms of perceived barriers for bilateral implantation.

Table 5. Reasons for perceived delay between diagnosis and implantation and barriers to bilateral 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)		

Of the 8 participants (72.73%, n=8/11) who provided reasons as to why they did not want their child to receive a second CI, the highest scoring reason against bilateral implantation was due to feeling that a second implant was not required (50%, n=4/8). Not meeting the criteria for a second implant was the reason provided by 25% (n=2/8) of the participants whilst 12.50% (n=1/8) of the participants reasoned that there is no

perceived benefit from the CI and another 12.50% (n=1/8) of the participants mentioned that due to funding and financial constraints, it would be too costly to afford and maintain two CIs (n=8). Parental responses against bilateral implantation can be found in Appendix I.

3.2. Educational aspects

Most of the paediatric 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. A grade/ multiple grades were repeated by almost a third (31.43%, n=22/70) of the paediatric CI recipients in this sample. Furthermore, 18.99% (n=15/79) of the paediatric CI recipients were electively (non-compulsory) held back during a grade, 11.39% (n=9/79) started school at a late age and 5.06% (n=4/79) started school at a late age and were electively (non-compulsory) held back during a grade(s).

A 5-point Likert scale was used to obtain parental ratings of possible challenges that relate to their child's education. The scale consisted of eight statements and participants rated their responses on a scale ranging from strongly agree (1) to strongly disagree (5), with an additional "not applicable" option applying to children not yet in an educational setting. Table 6 displays the responses from parents to the statements about education in general.

Table 6. Parent responses on general challenges encountered with education

Statements	Agree** %(n)	Neutral** %(n)	Disagree** %(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)*	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)*	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)*	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)*	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)

**Questions adapted from 'CCIPP' questionnaire by Archbold et al.,2008*

***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 participants agreed that finding an adequate educational setting for their child was a challenge (55%, n=44/80) and that there is a current shortage of appropriately trained teachers to deliver intervention services, specifically for children with CIs (68.83%, n=53/77).

An average mean rating of 2.63 (SD=0.86; range=1.13-5.00) was obtained for parent-perceived educational challenges. With a higher rating corresponding to a greater degree of perceived challenges, participants on average perceive their child's education to be more challenging rather than less challenging.

An additional question (matrix single select question) was utilized whereby participants had to select either 'yes', 'no' or 'not applicable' in response to ten statements pertaining to possible challenges encountered within their child's current educational setting. Table 7 displays the responses from the parents to the statements about their child's current educational setting.

Table 7. Parental responses on challenges encountered with their child's current educational setting

Statements	Yes %(n)	No %(n)
As parents, we don't always have adequate finances to pay for all the additional academic support services our child needs (n=71)	63.38 (45)	36.62 (26)
Teachers and therapists often unsure of how to support our child's individual needs (n=76)	40.79 (31)	59.21 (45)
The classroom environment is too noisy (n=78)	38.46 (30)	61.54 (48)
No/ little support from school for additional services (we must pay for private tutors, remedial therapy etc.) (n=69)	36.23 (25)	63.77 (44)
We do not receive accurate feedback from the teachers (for e.g. they'll report that our child is coping and in another instance report that he/ she is not coping) (n=72)	25.00 (18)	75.00 (54)
Teachers have unrealistic expectations of parents (n=71)	19.72 (14)	80.28 (57)
The number of children in the classroom is too big (n=75)	14.67 (11)	85.33 (64)
No/ little consideration is given for our child's unique language needs (n=72)	15.28 (11)	84.72 (61)
Bullying as a result of his/ her cochlear implant is an issue (n=71)	15.49 (11)	84.51 (60)
Teachers have limited patience with our child and don't have the capacity to go the extra mile in assisting him/her (n=72)	15.28 (11)	84.72 (61)

With regards to the specific educational challenges encountered within their child's current educational setting, almost two thirds of the participants (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. More than a third of the participants

agreed that teachers and therapists are often unsure of how to support their child's individual needs (40.79%, n=31/76) and that their child's classroom environment is too noisy (38.46%, n=30/78).

When asked which professional(s) assisted parents in obtaining a school for their child, most participants indicated that the audiologist (44.87%, n=35/78) assisted them and some participants indicated that the speech-language therapists (15.38%, n=12/78) also assisted them. However, 28.21% (n=22/78) of the participants reported that they did not receive assistance from any professional to obtain a school for their child.

3.3. Support services received

When participants 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 participants 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.

Participants 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 shows parental rankings for each of the support services their child received.

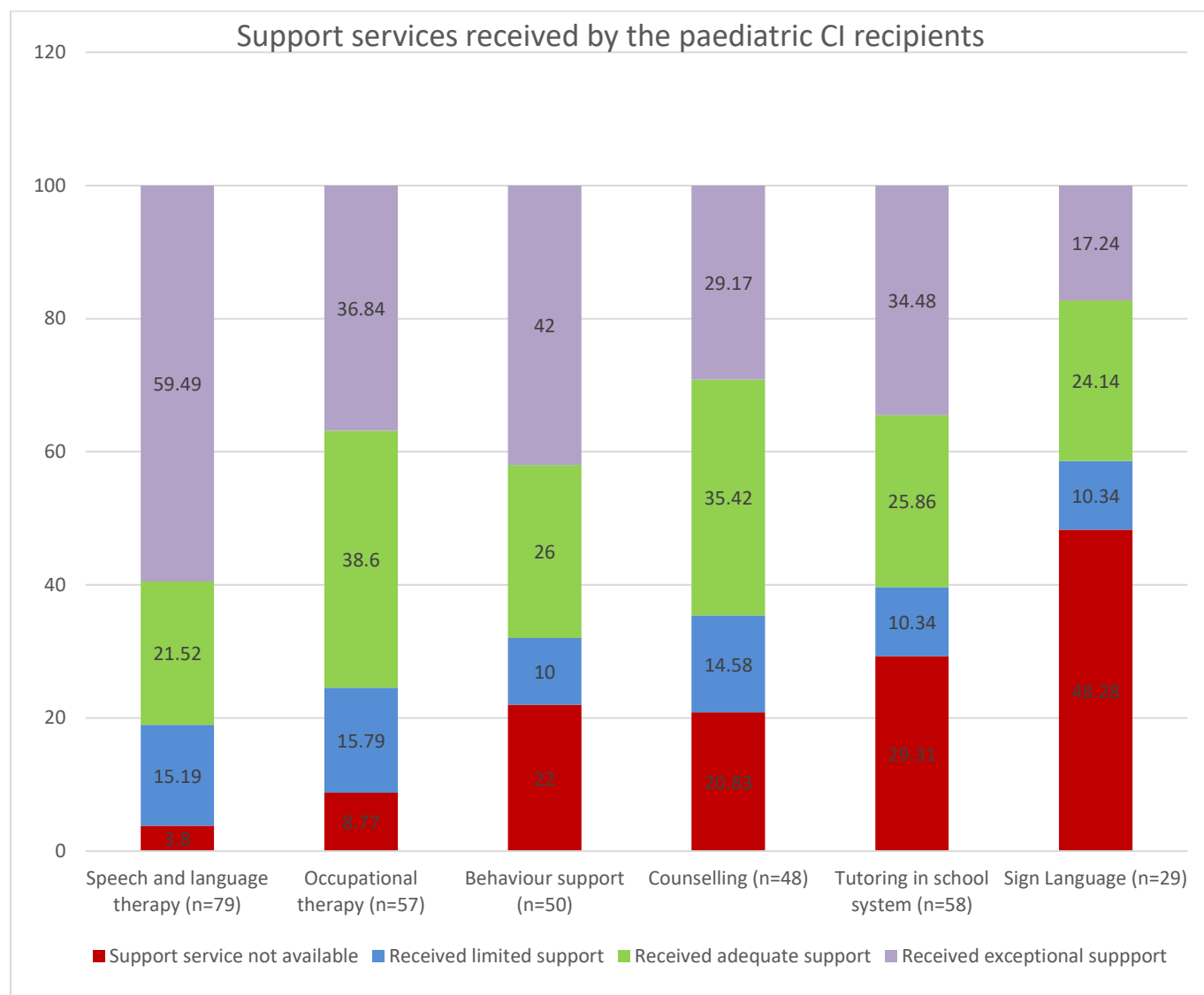


Figure 1. Support services received by the paediatric CI recipients. *The x-axis illustrates the support services and the total number of responses for each support service (speech and language therapy, occupational therapy, behavior support, counselling, tutoring in school system and Sign Language instruction). 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). Additionally, the majority of the participants scored occupational therapy support received as either 'adequate' (38.60%, n=22/57) or 'exceptional' (36.84%, n=21/57), behavior support received as 'exceptional' (42%, n=21/50), and counselling support received as 'adequate' (35.42%, n=17/48). Interestingly, 34.48% (n=20/58) of the participants indicated that their child received 'exceptional' support in terms of tutoring in the school system whilst 29.31% (n=17/58) reported that this tutoring service was not available to them.

Participants were also asked to rate the support services received by them as parents of a child with a CI(s) since their child's first implantation. Ratings ranged from 'support service not available' (for parents 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 parents not requiring/ receiving a particular support service. Figure 2 shows parental rankings for each of the support services received.

Support services received by the parents of paediatric CI recipients

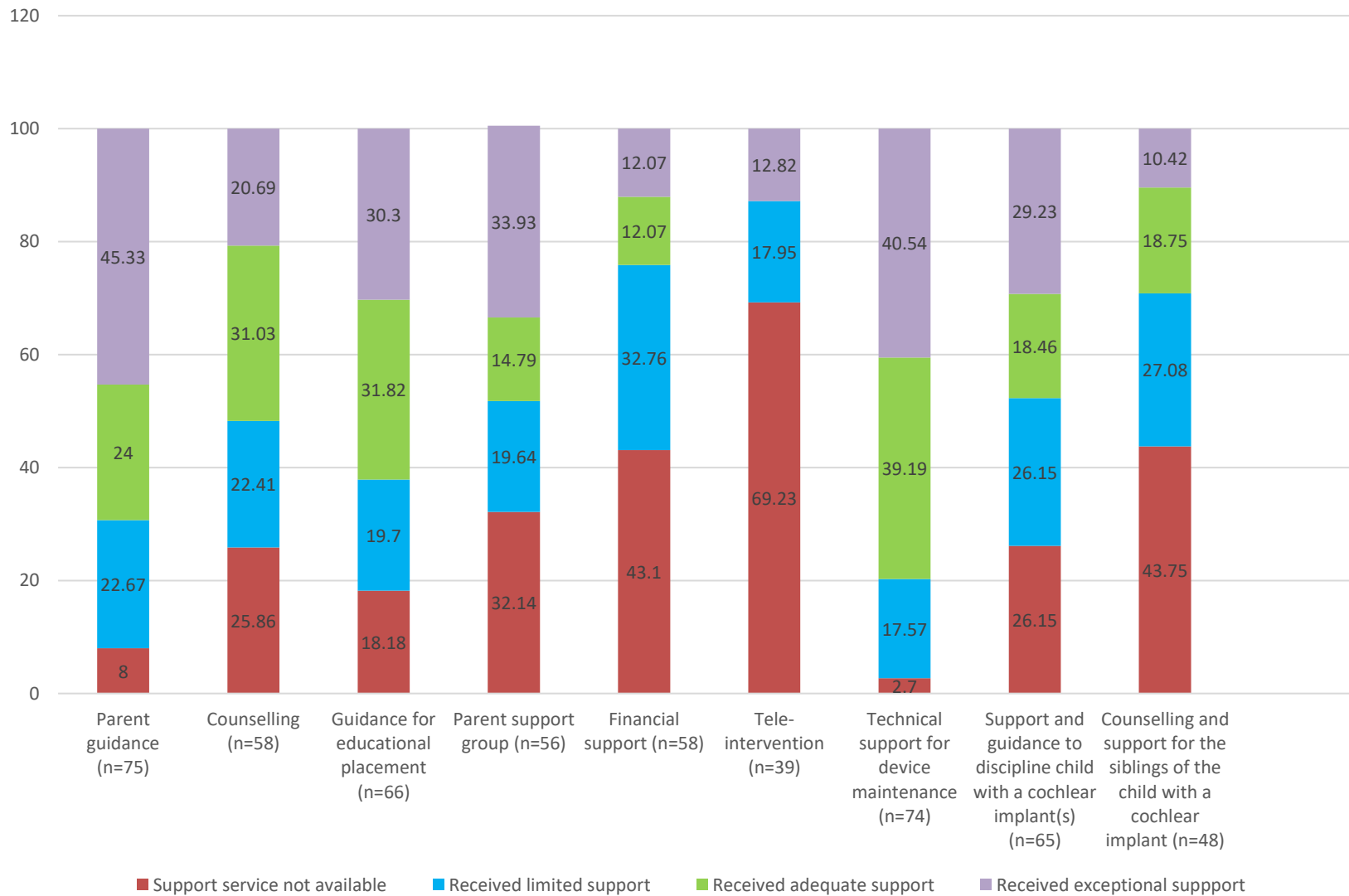


Figure 2. Support services received by the parents of the paediatric CI recipients. *The x-axis illustrates the support services and the total number of responses for each support service (parent guidance, counseling, guidance for educational placement, parent support group, financial support, tele-intervention, technical support for device maintenance, support and guidance to discipline child with a CI(s), counseling 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) and the second highest was *technical support for device maintenance* (40.54%, n=30/74). In contrast, the highest-ranking support service not available to participants requiring that particular service was *tele-intervention* (69.23%, n=27/39) followed by *counselling and support for the siblings of children with a CI(s)* (43.75%, n=21/48) and *financial support* (43.10%, n=25/58). Additionally, the majority of the participants scored *counselling support* received as 'adequate' (31.03%, n=18/58) and *guidance for educational placement* received as either 'adequate' (31.82%, n=21/66) or 'exceptional' (30.30%, n=20/66). Interestingly, *parent support group* 33.93% (n=19/56) and *support and guidance to discipline their child with a CI(s)* (29.23%, n=19/65) were both ranked as 'exceptional' whilst an almost equal percentage of participants rated these same two support services as not available to them (*parent support group*: 32.14%, n=18/56 and *support and guidance to discipline child with a CI(s)*: 26.15%, n=17/65).

Consequently, participants were asked to select 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) to receive in order to ensure optimal outcomes for their child.

Participants were requested to choose from the following paediatric CI recipient support

services: *speech and language therapy, occupational therapy, behavior support, counseling, tutoring in school system and Sign Language instruction*. The options for parent support services that participants were requested to choose from were *parent guidance, counseling, guidance for educational placement, parent support group, financial support, tele-intervention, technical support for device maintenance, support and guidance to discipline their child with a CI(s), counseling, support for the siblings of their child with a CI(s) and Sign Language instruction*. For both these questions, participants also had the opportunity to add additional support services not necessarily indicated as an option to choose from.

Regarding the services for children with a CI(s), *speech and language therapy* was deemed as the most important service by participants (88.6%, n=70/79) whilst 11.39% (n=9/79) selected other support services options, the second most important service was *tutoring in a school system* (26.6%, n=21/79) whilst the rest selected other options (73.42%, n=58/79) and the third most important support service was *counseling* (25.6%, n=20/78) and the rest selected other options (82.86%, n=58/70). Regarding services for parents of children with a CI(s), *parent guidance* was deemed as the most important service (44.9%, n=35/78) whilst 55.13% (n=43/78) selected other support services options, the second most important support service was *financial support* (24.4%, n=19/78) whilst the rest selected other options (75.64%, n=59/78) and the third most important support service was *support and guidance to discipline their child with a CI(s)* (16.5%, n=13/79) and the rest selected other options (83.54%, n=66/79).

3.4. Associations between demographical variables and cochlear implant process and educational challenges

Spearman correlation coefficients were computed to assess associations between independent continuous variables and the dependent outcome variables (*CI process challenges* and *educational challenges*). Seven continuous variables were included in the analysis, namely *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*. Spearman correlation coefficients revealed no statistically significant ($p < 0.05$) correlations between continuous variables and CI process challenges and educational challenges (Table 8). However, this analysis shows marginal evidence towards a positive correlation between *delay from diagnosis to implantation* and *educational challenges* ($r = 0.21$, $p = 0.0588$) implying that parents of children who had a longer delay between hearing loss diagnosis and cochlear implantation reported educational challenges to be more challenging compared to parents of children who had a shorter delay between hearing loss diagnosis and cochlear implantation. However, this finding did not reach statistical significance and can be attributed to chance.

Table 8. Associations between continuous demographical variables and cochlear implant process and educational challenges

Challenges	Age at study (n=82)	Age at diagnosis of hearing loss (n=62) *	Age at implantation (n=70) *	Duration of cochlear implant use (n=82)	Time-lapse between first and second implantation (n=39)	Duration of deafness (n=82)	Delay from hearing loss diagnosis to implantation (n=82)
Cochlear implant process	-0.02 0.8346	-0.06 0.6639	-0.20 0.0996	0.00 0.9694	0.19859 0.2255	-0.17 0.1273	-0.08 0.4641
Education	0.08 0.4622	0.02 0.8858	0.15 0.2129	0.01 0.9623	-0.09 0.5731	0.20 0.0770	0.21 0.0588

*Only congenital/ early onset hearing loss were considered.
Spearman correlation coefficient, (with $p < 0.05$)

Linear regression analyses were used to determine possible associations between independent categorical variables and the outcome variables. Pearson's chi-squared test was performed to determine possible associations between the independent categorical variables and the two dependent outcome variables (*CI process challenges* 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 vs private educational setting (public/ private)*, *grade repetition (yes/ no)*, *parents' marital status (married/ not married)*, *relationship to the paediatric CI recipient (mother/ father)* and *highest qualification level obtained (high school/ tertiary qualification)*. No significant associations were observed between the independent categorical variables and the *CI process challenges* dependent variable. Significant associations ($p < 0.05$) however 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*. Table 9 and Figure 3 present the general linear regression analysis results in terms of the educational challenges outcome variable that yielded significant ($p<0.05$) associations with the categorical variables.

Table 9. Associations between significant categorical independent variables and educational challenges

Outcome variable	Categorical independent variable	Pr>F (p-value)	Categories	Mean score (SD)
Education	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)

* $p<0.05$

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

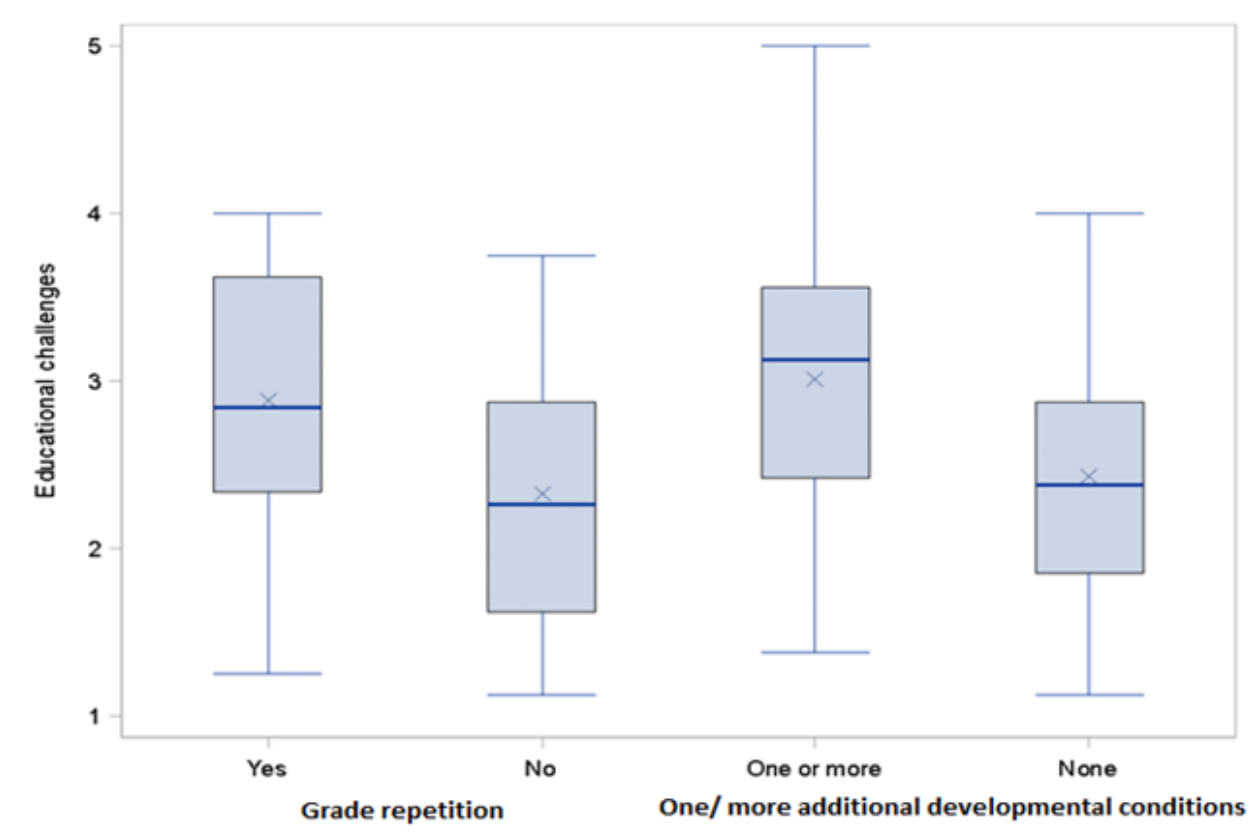


Figure 3. Significant associations between *categorical independent variables* and *educational challenges* (n=70). The x-axis illustrates the two independent categorical values (presence of one or more additional developmental conditions and grade repetition). The y-axis display parental ratings on a scale from 1 to 5, with 5 being the most negative. The box plot represents parent ratings on a scale from 1 to 5, lower quartile, median (bold line), mean (x) and upper quartile.

3.5. Thematic analysis of parent-perceived challenges

In two open-ended questions, participants were asked to substantiate their responses with qualitative descriptions on what they consider as the greatest challenges of being a parent of a child with a CI and what they consider as the greatest challenges that their child experiences as a result of his/ her CI. The central themes for these two questions, together with frequency counts, descriptions and illustrative quotes from participants are

summarized in Table 10. A comprehensive excel sheet documenting the qualitative parental responses in detail is available in Appendix J.

Regarding parental challenges, the most prominent themes – in order of importance (based on the percentage of mentions for each theme) were: *financial problems* (41.25%, n=33/80), *demands of the CI process and re(habilitation) on the parenting role* (22.50%, n=18/80), *parental concerns and stresses surrounding their implanted child* (20%, n=16/80), *education/ academic challenges* (15%, n=12/80), *emotional challenges* (15%, n=12/80), *communication difficulties* (13.75%, n=11/80), *support services* (12.50%, n=10/80) and *implant technology* (12.50%, n=10/80).

Regarding challenges experienced by the paediatric CI recipients as perceived by their parents, the most prominent themes – in order of importance (based on the percentage of mentions for each theme) were: *CI device, use and maintenance* (21.25%, n=17/80), *social issues* (17.50%, n=14/80) and *audition (hearing ability)* (17.50%, n=14/80).

Table 10. Central themes, and illustrative quotes from parental reports of challenges perceived (n=80)

Central theme	%(n)	Description of challenge	Illustrative quotes
Challenges experienced by parents of paediatric CI recipients			
Financial problems	41.25% (33/80)	Costs related to funding the CI technology and the surgical procedure; the continuous financial costs associated with CI device maintenance (including replacement and repairs) and costs for insurance, (re)habilitation services and travelling.	<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> <i>'Saving money so that there's money to buy things for the device that is needed e.g. battery's cable'</i>
Demands of the CI process and (re)habilitation on the parenting role	22.50% (18/80)	The ongoing commitments and responsibilities parents encounter following implantation	<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> <i>'Inability to spend time away from the child to follow personal goals'</i>
Parental concerns and stresses surrounding their implanted child	20.00% (16/80)	Parental concerns centered around the device; their child's education; social integration; speech and language development; general health and future.	<i>'Should she lose her device(s), I have no insurance on them'</i> <i>'Worrying whether all will be okay when he is away from home, example camping with school'</i> <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>
Educational/ academic challenges	15.00% (12/80)	Challenges in accessing equitable, affordable, good quality education in schools that are equipped to accommodate the individual needs of hearing-impaired children; limited support received in the educational setting and mistreatment from teachers and fellow students.	<i>'Finding the right school that caters for these kids, private schools are very expensive'</i> <i>'My greatest challenge as a parent of a deaf child is accessing sustainable equal education'</i> <i>'The fact that the schooling system failed due to bullying and teacher abuse'</i> <i>'More mainstream schools should be equipped to think out of the box and be prepared to assist these children. Support from the cochlear unit to the school with information about how the cochlear implant works and how they can improve communication and learning would be appreciated'</i>
Emotional challenges	15.00% (12/80)	Parental emotions experienced pre and post-implantation and dealing with their child's emotions post-implantation	<i>'The emotional management of everybody in the family, including the CI recipient'</i> <i>'Emotional exhaustion due to worries or developmental obstacles etc.'</i>

			<p><i>'As with any disability, it is the loss of what then you thought life would be. It is very emotionally challenging on the parents as you feel unprepared and uncertain of what lies ahead.'</i></p> <p><i>'Psychological and emotional journey and helping my child with being different'</i></p>
Communication difficulties	13.75% (11/80)	Communicative failures experienced during interactions between parent and child and also communication challenges associated with delayed speech and language development.	<p><i>'Communicating effectively with child'</i></p> <p><i>'The communication between parent and child'</i></p> <p><i>'Initially trying to understand my child's needs and wants. I could not communicate with him fully. It was very stressful for me as he is my second child and I could communicate with my older child and not fully with my younger'</i></p> <p><i>'Development of speech and language after implant at over two years of age'</i></p>
Support services	12.50% (10/80)	Dearth of support services and accessibility of services required. Negative encounters with health professionals.	<p><i>'Lack of speech therapists trained in the field'</i></p> <p><i>'Lack of quality audiologists when they're critically needed during the acceptance phase with the device'</i></p> <p><i>'Lack of parent guidance or support'</i></p> <p><i>'Lack of service centre for emergency repairs'</i></p> <p><i>'Dealing with health professionals and service providers: having to fight to receive good and fair services'</i></p>
Implant technology	12.50% (10/80)	CI device problems, failures, repairs and maintenance	<p><i>'The greatest challenges – implant drawbacks including breakdowns and failures'</i></p> <p><i>'Managing the technology'</i></p> <p><i>'That the processors work 100%'</i></p> <p><i>'You must check every day that the CI is working and that the batteries are full all of the time'</i></p>
Social challenges	7.50% (6/80)	Dealing with social integration, adaptation and stigmatization	<p><i>'People staring at her. She is almost like a normal child'</i></p> <p><i>'Getting her to fit in with normal hearing friends'</i></p> <p><i>'The social implications and the challenge to ensure that her self-image is such that she can withstand any questions, rejections'</i></p> <p><i>'To be sure that she can handle herself in certain situations'</i></p>
Impact on the family	5.00% (4/80)	Family adaptations and impact of CI process on parents' marriage, on the siblings and on the family as a whole. Having to balance the needs of the implanted child with the needs of the siblings.	<p><i>'The constant travelling to the centre which has a huge impact on the family as a whole and on normal life and work'</i></p> <p><i>'Tremendous stress on marriage, resulting in divorce'</i></p> <p><i>'The other children can also feel a bit neglected'</i></p> <p><i>'Giving siblings equal attention'</i></p>
Retention of CI device	5.00% (4/80)	Child's unwillingness to keep the CI device on, failure of device to stay in place and the presence of additional disabilities.	<p><i>'My child is also autistic and has sensory issues which we were not aware of prior to implantation. To get her to keep her CI processors on has always been a challenge. Due to the ASD she is difficult to test and map'</i></p> <p><i>'My daughter used to take it off and stick the magnet to anything she could find, such a trampoline, jungle gym etc.'</i></p>

Educating others about the CI	3.75% (3/80)	Explaining to others the functioning and purpose of a CI and ensuring the child is regarded as "normal"	<i>'Making sure that they are being seen as normal as they are like normal children just with CIs'</i> <i>'Teaching other family members who come into contact with her about the CI'</i>
Discipline	1.25% (1/80)	Disciplining a child with a CI	<i>'Trying to discipline her'</i>

Challenges experienced by paediatric CI recipients

CI device use and maintenance	21.25% (17/80)	Responsibility of wearing, caring for and maintenance of the CI device; CI device problems and breakdowns and discomfort/irritation caused by the device	<i>'Getting used to the device and being more responsible about it has been a challenge'</i> <i>'Not being able to wear a helmet or hat'</i> <i>'When it's faulty she cannot go to school as she cannot hear, and I have to also stay with her at home until a solution comes'</i> <i>'She hates when the coil does not sit properly on her head and moves or falls whilst she is doing sports at school'</i> <i>'Incidence of flat batteries exclude her from communication'</i>
Social issues	17.50% (14/80)	Issues with social inclusion and integration, and interaction with and acceptance by individuals with normal hearing	<i>'Fitting into and functioning in society'</i> <i>'Social interaction is a challenge'</i> <i>'Children staring and keep asking what is that'</i> <i>'In his younger years at a mainstream school, making friends was the hardest. Now as he gets older and is a teenager, when people look at him oddly because of his implants it is beginning to bother him more'</i> <i>'Rejection from peers due to wearing the devices'</i>
Audition (hearing ability)	17.50% (14/80)	Difficulty hearing in different situations, auditory/ hearing fatigue or sound intolerance	<i>'She does not enjoy the sound that much and prefers the silence'</i> <i>'Hearing fatigue – she battles to do her homework late in the afternoons due to exhaustion'</i> <i>'Struggling to hear in social situations'</i> <i>'Not being able to hear all sounds'</i> <i>'Listening in noisy environments'</i>
Academic challenges	16.25% (13/80)	Limited support received in the educational setting	<i>'Had to change schools after hearing loss diagnosis. He had to go to a special school instead of mainstream school and had to repeat grade three due to hearing loss'</i> <i>'Kids making fun of her at school'</i> <i>'No support is offered in schools – you as a parent have the full responsibility for your child's well-being'</i> <i>'Very minimal understanding from teachers'</i> <i>'Functioning and coping in a mainstream school environment because the challenges are many and there isn't a suitable alternative'</i>

Communication difficulties	15.00% (12/80)	Difficulty when communicating with others due to speech/ language delays and impairments	<i>'He gets frustrated because he cannot express himself in words since his vocabulary is limited because of hearing sounds very late in life for the first time'</i> <i>'Having to push harder to make sure that spoken words are understood'</i> <i>'Speech is a challenge'</i> <i>'Catching up on language delay'</i> <i>'Closing the learning gap and language gap. She is learning English in school, it's difficult for her to understand or speak her home language'</i>
Physical and sport restrictions	15.00% (12/80)	Inability to participate in some sports or limitations during sporting activities as well as physical limitations as a result of the CI device	<i>'Keeping them safe when playing sport and the limitation of some sport activities'</i> <i>'Not being allowed certain contact sports'</i> <i>'Unable to do sports easily'</i> <i>'Lack of spontaneity – she can't just jump or be pushed into a pool or river'</i> <i>'Not being able to play freely – constantly check and worry about the CI /processor'</i>
Self-esteem and acceptance of hearing loss/ CI	13.75% (11/80)	Issues with self-esteem and self-acceptance	<i>'As a teenager they are more self-conscious of the CIs, they are more accepting when they're younger'</i> <i>'The challenge of developing a positive self-image despite the "things on her head" making her look different'</i> <i>'Feeling that she is abnormal or different'</i> <i>'Her desire to hear without implants'</i> <i>'Accepting that she's deaf and it's not necessarily a bad thing'</i>
Presence of additional disabilities/ challenges	5.00% (4/80)	Additional challenges encountered due to the presence of other disabilities in addition to the hearing loss	<i>'Being on the autism spectrum, she lacks the organizational skill to "order" her world so this becomes problematic in her case'</i> <i>'He has a Mondini deformity, so he doesn't get full benefit from his CIs'</i> <i>'Not being mobile has been a great challenge also as the implant keeps coming off'</i>
Educating others about the CI	3.75% (3/80)	Answering questions and explaining to others the functioning and purpose of a CI	<i>'Having to continuously explain what is on her ears'</i> <i>'Having to answer the same questions from new people/ children about what is on her head'</i> <i>'Explaining to other children what it is for when they ask. Children outside of school who are not familiar with it tend to ask about it but she has gotten more and more responsible in explaining.'</i>
CI (re)habilitation process	1.25% (1/80)	Ongoing (re)habilitation demands following implantation	<i>'Having to undergo and attend all of the numerous CI appointments'</i>
General health issues	1.25% (1/80)	Health challenges	<i>'The greatest challenge was sickness at first – headaches, ear infections. But as time goes on this has changed and his health has improved'</i>

4. DISCUSSION

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

4.1. Process of cochlear implantation

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 (SD=13.31) months and 35.08 (SD=20.45) months respectively. On average, there was a 19.34 (SD=14.81) months delay between hearing loss diagnosis and cochlear implantation for this study sample. Since delayed implantation is presently regarded as implantation performed more than 12 months after the diagnosis of hearing loss (Fitzpatrick et al., 2015), this allows one to conclude that on average, paediatric CI recipients in this study received their CIs late. Therefore, it is not surprising that the majority of participants (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 a developing country (India) revealed that 80% of the parents in their study perceived a delay in their child's hearing loss diagnosis and 83.30% of parents perceived a delay in implantation whereby financial difficulties was also the highest scoring reason for the delay in cochlear implantation (Dev et al., 2018).

The average time-lapse between the first and second CI in this study was 1.69 (SD=1.57) years. Whilst bilateral implantation is customary in developed countries for individuals with severe to profound hearing loss (Sarant et al., 2014; Tait et al., 2010), in developing countries such as SA, funding of the second implant remains the onus of the parents (le Roux et al., 2016). Consequently, this results in unequitable accessibility towards bilateral implantation whereby only financially able parents are able to afford a second implant for their child (le Roux et al., 2016). Hence, funding the second implant was done so privately by all of the participants in this study and none of the participants received public sector/ government funding for the procedure. More than two thirds (68.57%) of the parents of unilaterally implanted paediatric 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). Within the South African context, these challenges are understandable due to limitations in the availability of public sector/ government funded CI programs as there are presently only four active public sector/ government funded CI programs (SACIG, 2017). Therefore, the majority of the parents of paediatric CI recipients in this study (86.59%) privately funded the costs of their children's first CI (either through medical aids, private funding, combined medical aid and private funding, donations etc.) and less than

10% received public sector/ government funding for their child's CI. Consequently, the majority of South African parents need to have access to a medical aid or adequate funds in order to finance the CI procedure (Kerr et al., 2012) as only a limited number of children are able to access CIs through public sector/ government funding. Since direct CI device costs are covered by the national health system in most developed countries (Kerr et al., 2012), financial challenges may not be as profound in developed countries as they are in developing countries such as SA. In addition to funding the implant procedure (medical costs) and the device costs (internal and external components), parents encounter expenses both pre-operatively and post-operatively, including long-term maintenance of the CI device, CI mapping/ programming sessions, (re)habilitation and educational costs, optional costs such as insurance costs and FM systems, and travelling and accommodation expenses when commuting back and forth from the CI centers (Emmett et al., 2015; Kerr et al., 2012; Sach et al., 2005). Therefore, it is evident that the financial demands placed on South African parents of paediatric CI recipients are continuous and long-term. Hence it makes sense that most participants in the current study reported that they were not able to meet the financial demands of the CI process (53.66%) or the long-term and continuous financial demands following implantation (45.12%). This finding is in agreement with the findings by Moroe and Kathrada (2016) and Kerr et al. (2012) who reported that South African parents of paediatric CI recipients are not fully equipped to meet the continuous financial demands succeeding cochlear implantation either. Khan et al. (2007) also reported that cost is the biggest limiting factor for cochlear implantation in developing countries, while Chundu et al. (2013) confirmed that the greatest challenge reported by parents of

paediatric CI recipients in Southeast Asia was attributed to the costs and maintenance of the CI device.

Most of the participants in this study (74.07%) felt that it was a difficult time waiting for the results of the CI assessment before implantation. These findings support the findings of Archbold, Sach, O'Neill, Lutman and Gregory (2006) who also found that waiting for the results of the CI assessment before implantation was a difficult period for parents. Constant support to parents during this waiting period and sensitivity towards their opinions and views may contribute towards making this period less challenging for them (Archbold et al., 2006). Travelling costs (32.93%) and finding someone to look after their families when they had to attend appointments at the CI centers (23.17%) were less pronounced challenges whilst taking time off from work for appointments at the CI center was equally balanced in responses for participants who agreed and disagreed that this was a challenge. Clearly there are variations in parental-perceived challenges regarding the CI process. Because parental views vary, each family may require different types of support from CI team members and at different stages in the process. CI teams therefore need to be sensitive towards the individualized challenges which each family encounter (Archbold et al., 2006).

4.2. Educational aspects

Single/ multiple grades were repeated by almost a third (31.43%) of the paediatric CI recipients enrolled in formal educational settings in this study, whilst almost one out of five (18.99%) were electively held back during a grade(s). A smaller number of children started school at a late age (11.39%) and 5.06% both started school at a late age and were electively held back during a grade(s). These results support the

findings of Punch and Hyde (2010) who investigated the perceptions of teachers working with paediatric CI recipients (attending a range of educational settings) who indicated that some paediatric CI recipients struggle to keep up with the academic pace of their hearing peers and 70% of the paediatric CI recipients fell below their class averages in terms of academic performance (Punch & Hyde, 2010).

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 participants in the current study. Finding an appropriate educational setting best suited to their child's needs was a concern for parents in other studies as well (Christiansen & Leigh, 2004; Moroe & Kathrada, 2016; Sorkin & Zwolan, 2004; Wheeler et al., 2009). Also, 30% of parents in a study by Sorkin and Zwolan (2004) reported a lack of knowledge on the part of school employees regarding the needs of paediatric CI recipients. As indicated by le Roux et al. (2016), decisions on educational placement should be made based on the appropriateness of a setting to each child's specific needs.

Furthermore, regarding educational challenges encountered within the current educational setting, the greatest parental-perceived challenge (63.38%) was financial difficulties in paying for all the additional academic support services required by their implanted children. The second highest ranked challenge (40.79%) pertained to teachers and therapists often being unsure of how to support paediatric CI recipients' individual needs. Very seldom do professionals who work in educational settings receive training on hearing loss and cochlear implantation and CI teams should therefore strive towards increasing informational support to these

professionals in order to equip them to support the specific needs of paediatric CI recipients (Zwolan & Sorkin, 2004).

Audiologists (44.87%) were the professionals perceived to provide the most assistance to participants in obtaining a school for their child. However, an alarming 28.21% of participants 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 paediatric CI recipients and their parents may intensify parental anxiety (Huttunen & Välimaa, 2012). These educational challenges reported by parents of paediatric CI recipients in this study highlights the urgent need for educational support to both paediatric CI recipients and their parents as well as ongoing support to professionals working in educational settings.

4.3. Support services received

Regarding the support services received by paediatric CI recipients, 59.49% of participants indicated that they received exceptional support in terms of *speech-language therapy* services and less than 5% of participants reported that this service was not available to them. This is consistent with the findings by Summers et al. (2007) whereby majority of the parents of paediatric CI recipients in their study were most satisfied with the *speech/ language services* compared to all of the other services their children received. The speech-language therapist is a pivotal member of the CI team whose role extends from pre-operative communication assessments to post-operative rehabilitation (SACIG, 2011). According to the quality standards for cochlear implantation in SA as reported by the South African Cochlear Implant Group (SACIG), post-operative rehabilitation should include assessing and training

CI recipients in the following areas: sound detection, auditory training, voice quality, speech intelligibility, language comprehension and expression, social skills, lip reading, communication strategies, telephone training and music training (SACIG, 2011). Speech-language therapists are involved in majority of these areas and are therefore essential members of the CI team who strive to improve the speech, language and listening skills of CI recipients.

In contrast, *Sign Language support* was the highest ranked support service not available to paediatric CI recipients requiring this service in this study. With 12.20% of the paediatric CI recipients in the current study using mixed/ total communication and 3.66% using Sign Language as their mode of communication, the availability of Sign Language support to this population is vital. The Deaf Federation of South Africa (DeafSA) reported that approximately 3.5% of South Africans have varying degrees of hearing impairment of which on estimate, 500 000 of these individuals utilize Sign Language as their first language (Storbeck, 2010). The challenge in SA however, is that 66% of these individuals are illiterate, 70% of them are unemployed and typically an adult Deaf individual's general knowledge is on par with that of an eight-year-old hearing child (Storbeck, 2010). These challenges are in part a result of minimal support and academic services being offered to these individuals (Storbeck, 2010). Hence, increased support should be provided to South African Sign Language (SASL) users. Paediatric CI recipients who require Sign Language support should have access to SASL trainers and should also receive the necessary academic support required. CI teams should therefore ensure that diversified rehabilitative service options are available to paediatric CI recipients (including SASL support) in an attempt to improve their communicative competence (Bosco,

D'Agosta, Traisci, Nicastri, & Filipo, 2010). Ultimately the priority should be for each paediatric CI recipient to achieve adequate communicative skills and excel across other developmental areas as well (cognitive, socioemotional and academic development) (Bosco et al., 2010; Hall, 2017).

Regarding the support services received by parents of paediatric CI recipients, most participants (45.33%) indicated that they received exceptional support in terms of parent guidance. In contrast, most participants (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 (Swanepoel & Hall, 2010).

Therefore, improving upon the accessibility of tele-intervention services in SA is one of the ways in ensuring improved CI support service delivery. This will especially assist families residing in areas with an increased geographical distance from their CI centre and/ or where available support services/ interventionists in their geographical area are scarce (Havenga, Swanepoel, le Roux, & Schmid, 2017). This will in turn reduce travelling/ accommodation costs incurred by parents and lead to improvements in the availability of necessary support services required (including informational and technical support).

To obtain increased parental insight into CI related support services, participants were asked to select three support services deemed crucial (in order of importance) for paediatric CI recipients to receive as well as three support services which they felt they as parents of paediatric CI recipients should receive in order to promote optimal outcomes. In order of importance, *speech-language therapy, tutoring in a*

school system and *counseling* were support services deemed critical for paediatric CI recipients to receive in order to ensure optimal outcomes. Summers et al. (2007) and Zaidman-Zait et al. (2015) 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* were also the highest ranking service that parents in both studies indicated as necessary. 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 paediatric CI recipients to receive. Financial support was also the second most important support service deemed necessary by parents of paediatric CI recipients in the study by Summers et al. (2007).

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. Moreover, continued efforts should be made to increase and improve the accessibility to support services that are limited in SA. Accessibility to required support services will assist towards decreasing the level of challenges related to the paediatric CI process and support services received in SA. The *Developmental Systems Model for Early Intervention* will be a useful model of care to follow in supporting families of children with CIs. This model will allow CI teams to focus on the individual strengths and abilities of each paediatric CI recipient, their family patterns of interaction, and family resources whilst also

identifying potential stressors that will influence positive developmental outcomes for the paediatric CI recipients and their families (Guralnick, 2001).

4.4. Associations between demographical variables and cochlear implant process and educational challenges

Within this study sample, the *presence of one or more additional developmental conditions* was associated with more pronounced educational challenges, implying that participants whose children had one or more additional developmental conditions perceived educational challenges to be greater than participants whose children did not have any additional developmental conditions. Similarly, Huttunen et al. (2009) also reported that the more additional developmental conditions an implanted child presents with, the higher the parental dissatisfaction with their child's education. A study by Zaidman-Zait et al. (2015) on the parental perceptions of benefits, challenges and service provision in cochlear implantation among deaf children with additional disabilities revealed that 17.40% of participants raised academic concerns. Additionally, the parental responsibilities of parents of deaf children with concomitant problems are higher than parents of deaf children with no additional developmental conditions (Zaidman-Zait et al., 2015). Therefore, increased understanding by professionals on the experiences and challenges that these families face is required in order to improve service provision to these families. Educationally it would be beneficial for children with multiple disabilities to follow educational approaches specifically developed by educators specializing in the educational support of children with cognitive, attention or behavioural conditions (Spencer, 2004). This supports the notion that increased accessibility of specialized

support services are required for children with CIs (Sach & Whynes, 2005; Sorkin & Zwolan, 2004).

Grade repetition was also associated with educational challenges, implying that participants whose children repeated a grade/ multiple grades, perceived educational challenges to be more pronounced than those participants whose children did not repeat a grade/ multiple grades. A study by Punch and Hyde (2010) on the educational settings of children with CIs in Australia revealed that on average, the academic performance of children with normal hearing was better than the academic performance of their peers with CIs. Hence, it is understandable that some children with CIs are prone to repeating grades in school, especially if these children require additional educational support specific to their individual needs and are failing to receive such support. Reasonably, 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 paediatric CI recipients require intervention and support services throughout their schooling years from specialized teachers and/ or hearing-related specialists (Archbold & O'Donoghue, 2007; De Raeve, Baerts, Colleye, & Croux, 2012). Consequently, this highlights the need for increased educational support to paediatric CI recipients and their parents as well as increased support and training to professionals working in educational settings so that they can be better equipped to assist paediatric CI recipients who are struggling academically.

4.5. Thematic analysis of parent-perceived challenges

The purpose of adding two open-ended questions was to enable participants to express their challenges spontaneously without any restrictions which could have been present in the closed-ended questions. Participants provided comprehensive information regarding their perceived challenges as parents of children with CI(s) as well as the challenges which their children with CI(s) encounter.

4.5.1. Challenges experienced by parents of paediatric CI recipients

Concurring with the responses obtained from the closed-ended questions, the greatest challenge reported by 41.25% of participants were *financial problems*. As described by participants, financial challenges included funding of the CI technology and the surgical procedure, continuous costs incurred for the CI device maintenance (including replacement and repairs of parts) as well as costs relating to the insurance, (re)habilitation services and travelling back and forth to the CI centre. Due to minimal financial support received in SA for cochlear implantation (Kerr et al., 2012; le Roux et al., 2016), it is not surprising that finances were a challenge for most of the participants in the current study. In India, where there is also a lack of financial support from the government and where CIs are not covered by medical aid schemes, 26.70% of the parents of paediatric CI recipients in a survey reported financial concerns for implantation and subsequent habilitation costs (Dev et al., 2018). Likewise, minimal financial support from the Southeast Asian government was also reported in a study by Chundu et al. (2013) whereby the greatest challenge reported by parents in their study was also finances incurred due to the implant and subsequent maintenance thereof. Financial difficulties have also been reported in a similar study by Zaidman-Zait (2008) where parents of paediatric CI recipients in a

developed country (Canada) with access to medical aid to cover the implantation costs, cited financial challenges in covering the post-operative CI costs incurred. Likewise, Sach et al. (2005) reported that the post-implantation habilitation and care costs incurred by British parents are high. In contrast to all these findings, a Finnish study revealed that parents of paediatric CI recipients in Finland were not burdened by post-operative habilitation costs (Huttunen & Välimaa, 2012). 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 (Dev et al., 2018; Huttunen & Välimaa, 2012; Kerr et al., 2012; le Roux et al., 2016). In between, are developed countries like Canada and the United Kingdom, where the costs of paediatric implantation are covered by the government, however parents continue to experience financial concerns post CI due to the habilitation costs (Sach et al., 2005; Sach & Whynes, 2005; Zaidman-Zait, 2008).

Demands of the CI process and (re)habilitation on the parenting role was the second highest challenge reported by 22.50% of the participants and addresses the ongoing commitments and responsibilities parents encounter following implantation, including the long-term therapy required, as well as the constant support and attention required by the paediatric CI recipient. These issues were also prevalent in the findings of a similar study by Zaidman-Zait (2008) whereby a quarter of the parents of paediatric CI recipients were worried that they would lag behind in other important areas of their personal and family life due to the extensive demands of habilitation

post implantation. Similarly, Sach and Whynes (2005) reported that parents of paediatric CI recipients were alarmed at the efforts and demands that habilitation necessitated and Archbold et al. (2006) found that parents in the United Kingdom perceived the habilitation process following cochlear implantation to be more intrusive than anticipated. Post implantation, parents of newly implanted children encounter new responsibilities and demands in addition to their existing parental responsibilities (Incesulu et al., 2003; Sach & Whynes, 2005; Spencer, 2004). 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 (Boons et al., 2012; Sarant et al., 2009; Spencer, 2004), thus ongoing parental guidance and assistance by CI teams is crucial.

Parental concerns and stresses surrounding their implanted child were mentioned by 20% of the participants and relates to parental concerns centered around the CI device, their child's education, social integration, speech and language development, general health and the future ahead. Comparable concerns and stresses were also reported by parents in similar studies conducted (Incesulu et al., 2003; Sach & Whynes, 2005). In the study by Incesulu et al. (2003), parental concerns centered around the CI device and implant drawbacks, future education of their implanted children and their speech and language development whilst in the study by Sach and Whynes (2005), concerns with the educational placement and the future education of

paediatric CI recipients and concerns with their children's language/ grammar were reported. Parental concerns and stresses post implantation may not necessarily decrease over time or with improvements in their child's functional and developmental abilities (Zaidman-Zait, 2008). This could possibly be explained by the realization of parents that the CI habilitation and maintenance demands are continuous (Weisel et al., 2007) or that children encounter difficulties such as health-related and behavioral problems at different ages during different periods of time. Thus, parents face everyday problems and stresses related to their implanted child and intervention should therefore focus not only helping parents in coping with the clinical aspects related to their child's CI but also in coping with these everyday problems and stresses which they encounter (Zaidman-Zait, 2008).

Educational/ academic challenges were reported by 15% of the participants in this study and supports previous findings obtained from both international and local studies (Archbold et al., 2002; Dev et al., 2018; Huttunen & Välimaa, 2012; Moroe & Kathrada, 2016; Sach & Whynes, 2005; Zaidman-Zait, 2008). The parent-perceived educational/ academic challenges reported in this study centered around accessing equitable, affordable, good quality education in schools that are equipped to accommodate the individual needs of children with hearing loss; the limited support which is received in the educational setting and the mistreatment of paediatric CI recipients by teachers and fellow students. It is evident that paediatric CI recipients from both developed and developing countries encounter educational/ academic challenges. Within 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 (Department of Education, 2001).

Moreover, the country's *National Development Plan 2030* further promotes an acceleration towards inclusive education and the *White Paper 6 on Persons with Disabilities* stipulates that disabled individuals must have accessibility to inclusive learning opportunities in which they are able to learn alongside individuals with no disabilities in barrier-free settings (Department of Social Development, 2016). 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 (Department of Education, 2015). An additional challenge in SA is the exorbitant costing for well-equipped private remedial schools (Moroe & Kathrada, 2016). Therefore, it is understandable that educational/ academic challenges were reported by many participants in this study. These results intensify the need for the South African educational system to aid in ensuring that each child is placed within a general educational setting and receives the support required appropriate to his/ her individual and specific needs in order to ensure that effective education is received (Department of Social Development, 2016). Also, individuals with disabilities (such as hearing loss) should be empowered to learn life and social development skills as this will ensure their full and equal participation in inclusive educational settings (Department of Social Development, 2016).

Emotional challenges relating to parental emotions experienced pre and post-implantation and the need to deal with their child's emotions post-implantation were reported by 15% of the participants. Families are significantly impacted after having a deaf child, they may experience feelings of grief following their child's hearing loss

diagnosis and escalated levels of parenting stress and anxiety with having to make decisions about appropriate hearing intervention and obtaining suitable support services (Anagnostou, Graham, & Crocker, 2007; Sach & Whynes, 2005; Zaidman-Zait, 2007). Therefore, parental emotions should be considered and addressed throughout the CI process as well as the (re)habilitation process thereafter. Formal emotional and psychological support should be offered by CI teams (Roberts, Sands, Gannoni, & Marciano, 2015). Additionally, emotional support from family and friends can improve parents' coping abilities in parenting their hearing impaired children (Zaidman-Zait, 2007). Moreover, an increase in social support for parents of paediatric CI recipients has the potential to improve their coping mechanisms against challenges and stressors, promote improved parental adjustment and well-being and decrease their levels of parenting stress whilst increasing their levels of life satisfaction (Åsberg, Vogel, & Bowers, 2008; Dunst & Trivette, 1996; Hintermair, 2004, 2006; Zaidman-Zait, 2007). *Thrive* is a South African parent-only support group aimed at supporting parents whose children are deaf/ hard of hearing through the provision of parent mentorship, emotional support, hearing-related resources, accessibility to unbiased information and community outreach to parents residing in remote areas (Thrive SA, 2018). CI teams should therefore consider referring parents of paediatric CI recipients to initiatives such as *Thrive*, as parent-support groups have the potential to assist parents in coping more effectively with their children's hearing loss and CI journey.

Communication challenges such as communication breakdowns experienced during interactions between parent and child and also communication challenges associated with their children's delayed speech and language development were

issues reported by 13.75% of the participants and is reportedly a stressor for parents in other studies as well (Zaidman-Zait, 2008; Zaidman-Zait et al., 2015). Zaidman-Zait (2008) reported that communication difficulties such as communication breakdowns during parent-child conversations and paediatric CI recipients' poor speech perception and production competence, and language level was an everyday challenge reported by 40% of parents in the study. Similarly, Zaidman-Zait et al. (2015) studied parental perceptions of benefits, challenges and service provision of paediatric CI recipients with additional disabilities and reported that communication difficulties (60.9%) were the most frequently reported challenge by parents in their study. These communication difficulties can result in parental exasperation and communicative misinterpretations between parent and child (Zaidman-Zait, 2008).

Challenges related to the support services received were reported by 12.50% of the participants and pertains to the dearth of support services and accessibility of services required as well as negative encounters with health professionals. Likewise, Sach and Whynes (2005) and Zaidman-Zait (2008) reported that parents of paediatric CI recipients expressed difficulties in accessing support services for their children with CIs. This highlights a need for the provision of appropriate rehabilitative services for each child specific to his/ her needs and the necessity in ensuring that these services are accessible to families across all socio-economic backgrounds. This is to ensure that even paediatric CI recipients from lower-income families can access the required support services. Additionally, as proposed by Zaidman-Zait et al. (2015), assigning a case manager to each family can ensure a better coordination and integration of services and it can also assist in identifying and minimizing any challenges experienced with the support services received.

Implant technology (CI device problems, failures, repairs and maintenance) as a parental-perceived challenge was reported by 12.50% of the participants and has been reported as a challenge and concern by parents in other studies as well (Archbold et al., 2002; Chundu et al., 2013; Huttunen & Välimaa, 2012; Incesulu et al., 2003; Sach & Whynes, 2005; Zaidman-Zait, 2008). Drawbacks with the CI device was the highest scoring challenge reported by parents of paediatric CI recipients in a study by Zaidman-Zait (2008). Similarly, 34% of parents of paediatric CI recipients in a study by Sach and Whynes (2005) were astonished at the technical difficulties experienced with the CI(s). In a study by Dev et al. (2008), 13.30% of parents reported that their child's level of dependency on the CI made them anxious, as well as the challenges that surrounds maintenance of the CI device.

4.5.2. Challenges experienced by paediatric CI recipients

Regarding the greatest challenges which participants perceived their child with a CI(s) to experience, the most prominent challenges related to challenges with the CI, socialization and audition. The highest scoring challenge, as reported by 21.25% of participants related to *CI device use and maintenance*. This challenge pertains to the responsibility of wearing, caring for and maintaining the CI device in addition to CI device problems, breakdowns and discomfort. Similarly, Zaidman-Zait (2008) reported that paediatric CI recipients' lack of audition during periods of device malfunctioning/ breakdowns are a significant challenge for parents. Based on the responses obtained from the open-ended questions in this study, it can be concluded that CI technology challenges are encountered by both parents of paediatric CI recipients as well as the paediatric CI recipients themselves.

Social issues relating to challenges with social inclusion, integration and interaction with and acceptance by individuals with normal hearing were indicated as a challenge by 17.50% of the participants in this study. Even though it was the second highest scoring theme for parent-perceived challenges that the child with a CI experiences in the study, it accounts for less than one third of the participants who cited this challenge. Likewise, Zaidman-Zait (2008) reported that less than one third of parents in their study mentioned that socialization and their child's social competence and peer relationships were a perceived challenge. However, even though previous research confirmed improved socialization skills in children with hearing loss post implantation (Bat-Chava, 2001; Bat-Chava, Martin, & Kosciw, 2005; Bat-Chava & Martin, 2002), these improvements vary amongst children (Bat-Chava et al., 2005; Bat-Chava & Martin, 2002). As a result, some paediatric CI recipients will still present with poorer social skills long after receiving a CI (Bat-Chava et al., 2005).

Audition (hearing-related) challenges such as difficulty hearing in a variety of situations and experiencing auditory/ hearing fatigue or sound intolerance were indicated by 17.50% of the participants in this study. It is well-known that paediatric CI recipients continue to experience hearing difficulties post implantation (Zaidman-Zait, 2008). It is noteworthy however, that this challenge was reported by less than a third of the participants in the study (17.50%), thereby implying that almost two thirds of the participants may not perceive hearing difficulties as a challenge (possibly as a result of having been counselled well and/ or having realistic expectations as to what can be expected of their child in terms of hearing).

It is clear that the open-ended responses of the parental-perceived challenges reported in the current study are comparable to similar previous studies conducted in both developed and developing countries. However, a degree of variability is present in the magnitude of challenges reported based on each country's context-specific factors (for example, differences in CI funding and healthcare system, socio-economic status, educational settings, the availability and accessibility of support services received etc.).

5. CLINICAL IMPLICATIONS AND CONCLUSION

Since parents are critical partners in the paediatric CI process and (re)habilitation of their implanted children, knowledge on their experiences and challenges post implantation will assist professionals in providing evidence-based informational counseling (Huttunen & Valimaa, 2012). Evidence suggests that parents encounter ongoing stressors and challenges regarding cochlear implantation in their children (Huttunen & Valimaa, 2012; Zaidman-Zait et al., 2015). Whilst international CI research predominantly focuses on medical aspects and outcomes of implantation, it is equally important that challenges experienced by parents are recognized (Huttunen & Valimaa, 2012). Therefore, the aim of the study was to determine parent-perceived challenges related to the paediatric cochlear implantation process and support services received.

5.1. Overview of research findings

The financial implications of cochlear implantation, including CI device maintenance, was identified by participants as the most prominent challenge. Financing issues were the highest scoring reason that attributed to the delay between hearing loss diagnosis 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 deliver intervention services to children with CIs. The presence of one/ more additional developmental conditions and grade repetition were significantly associated with more pronounced parent-perceived educational

challenges. The three support services that participants considered as most critical for their implanted children to achieve optimal outcomes were speech-language therapy, tutoring in the school system and counselling. Parent guidance, financial support and guidance to discipline the child with a CI(s) were the three support services deemed most critical for parents of paediatric CI recipients.

5.2. Implications for clinical practice

- The average ages at diagnosis of hearing loss and implantation for children with congenital/ early onset hearing loss in this study were 16.40 and 35.08 months respectively, whilst the average delay between hearing loss diagnosis and cochlear implantation was 19.34 months. Moreover, the majority (52.44%) of children in this study did not receive NHS, reflecting the current EHDI status in SA where NHS services are offered in only a limited number of hospitals in both the public and private health care sectors (Meyer et al., 2012; Theunissen & Swanepoel, 2008). At present, delayed implantation is considered as implantation performed more than twelve months succeeding the hearing loss diagnosis (Fitzpatrick et al., 2015). Therefore, on average, the paediatric CI recipients in this study experienced a delay between their hearing loss diagnosis and eventual cochlear implantation. Parents of paediatric CI recipients in the current study provided possible reasons for the delays between their children's hearing loss diagnosis and eventual cochlear implantation. These parent-reported reasons should be addressed in an attempt to minimize the delay so that paediatric CI recipients can benefit from the optimal neural plasticity period and develop speech and language skills comparable to their normal-hearing counterparts (Ching.,et al., 2013; Leigh et

al., 2013; Sharma., et al., 2002). This will also assist in minimizing the communication challenges that exist between the paediatric CI recipients and their parents which were reported in this study. For example, since a lack of prompt referral to specialized CI services was the second highest parent-perceived reason for the delay in this study, CI programs should strive towards continuously educating referring audiologists (in both the public and private health care sectors) in SA on the referral criteria for paediatric cochlear implantation. In addition, this study's results highlight the need for improvement of the current status of NHS services in both the private and public health care sectors in SA.

- Based on both the qualitative and quantitative findings in this study, a prominent challenge reported was the exorbitant finances required for the CI procedure and follow-up (re)habilitation. This therefore implies a call for action regarding the financial support for paediatric CI recipients in SA.
- In keeping with the World Health Organization's action plan for the prevention of deafness and hearing loss, the following actions are needed on country level in order to address these paediatric CI-related issues (World Health Organization, 2016):

Raising awareness and building political commitment: increased awareness to relevant role-players and government officials regarding hearing loss prevalence, the subsequent social and economic impact, CIs as a cost-effective intervention for severe-to-profound hearing loss and the challenges

impeding cochlear implantation in SA (World Health Organization, 2016). In turn, this will assist in addressing the funding issues surrounding paediatric cochlear implantation in SA.

Implementing screening programs: hearing screening programs in addition to NHS programs should be implemented in both private and public health care sectors in SA. This should be done in an effort to ensure equitable access to hearing health care services to all South Africans and to improve the current EHDI status in SA.

Provide (early) access to CIs: The implementation of screening programs should be coupled with actions to provide hearing devices (such as hearing aids, CIs etc.) (World Health Organization, 2016). Therefore, SA needs to advance towards the development of maintainable policies and protocols for cochlear implantation and its subsequent maintenance as part of the country's universal health coverage.

- Finding an adequate educational setting appropriate to the individual needs of each paediatric CI recipient and the shortage of trained teachers able to deliver specialized intervention services to paediatric CI recipients were notable educational challenges reported in this study. Therefore, CI teams should provide increased and continued support to teachers and therapists working with paediatric CI recipients. Since 28.21% of the participants reported that they did not receive assistance from any professional in obtaining a school for their implanted children, increased support by CI teams

in obtaining appropriate schools for paediatric CI recipients is warranted. This will in turn improve the educational/ academic support services received by paediatric CI recipients and their parents. Overall, the study results also imply a call for action regarding the educational support for paediatric CI recipients in SA. A possible initial step would be for the SACIG to partner with the Department of Education to assess SAs educational settings and their potential to cater for the individual and specific educational needs of the paediatric CI recipients. A partnership between the SACIG and the Education Department could also create increased opportunities for CI teams to educate and provide ongoing support to teachers working with paediatric CI recipients and also increase the availability of professional support to parents in obtaining schools for their children.

- Parents of paediatric CI recipients in this study rated the support services received by themselves as well as their implanted children. This allowed for the identification of possible gaps in the support services provided to paediatric CI recipients and their families in SA. Study results indicated that on average, Sign Language instruction is not available to the majority of the paediatric CI recipients requiring this service and that tele-intervention is not available to majority of the parents of paediatric CI recipients requiring this support service. Parents of paediatric CI recipients requiring Sign Language instruction should be provided with information on where and how to access such support. Therefore, parents need to be made aware of the existing available structures offering this support such as DeafSA, 'Tiny Handz' training, 'eDeaf' etc. Parents should also be made aware of existing parent-

support group initiatives in SA (for e.g. *Thrive*). Furthermore, as some participants in this study found that the travel costs to the CI centre and finding individuals to look after the family during CI appointments were a problem, and that the CI process and (re)habilitation demands on the parenting role is often burdening, future research should investigate the feasibility of tele-intervention. Tele-intervention could potentially be a viable solution to some of parental challenges related to the accessibility of services reported in this study (Havenga et al., 2017). Whilst tele-intervention services are already available in SA, it is only utilized in a limited number of clinics. Thus, the prospect to expand and implement this in a greater variety of settings is important.

- Lastly, this study identified possible limitations in the support services received by paediatric CI recipients and their parents. To ensure an improved coordination and integration of support services received, case managers should be appointed to each family (Zaidman-Zait et al., 2015). According to the SACIG guidelines for quality standards for cochlear implantation in SA, each CI program should have a coordinator, whose responsibilities include (but are not limited to) ensuring the delivery of multidisciplinary services to CI recipients (SACIG, 2011). In an attempt to improve the coordination and integration of services to paediatric CI recipients, a possible solution would be for the coordinator of each program to allocate cases to each member on the respective CI teams to manage.

5.3. Critical evaluation

A critical evaluation of this study was conducted to identify its strengths and limitations.

5.3.1. Study strengths

- Parents of paediatric CI recipients (≤ 18 years) from the complete range of communication and educational environments were considered as potential participants. This ensured a broad spectrum of input from parents with implanted children across a wide age range and from various communication and educational environments.
- This was the first multicenter study in SA to describe parental-perceived challenges related the CI process, educational aspects and support services received. This study has therefore provided valuable contextual data in the field of paediatric cochlear implantation and can contribute towards the enhancement of evidence-based pre-operative informational counselling and CI intervention and re(habilitation) services to paediatric CI recipients and their families.
- Data obtained from this study can also be used to guide the development and modification of CI-related policies and protocols in SA such as CI funding and educational policies and protocols as well as the SACIGs '*Quality Standards for Cochlear Implantation in South Africa*' document.

5.3.2. Study limitations

- Even though there was no case selection and parents of implanted children from the complete range of communication and educational environments were included, the study sample was biased as it did not include parents whose children were not approved for the cochlear implantation procedure. Consequently, the inputs from these parents were not accounted for in this study. Knowledge on the perceived challenges of parents whose children were not approved for cochlear implantation would be valuable when counselling parents whose children were not approved for cochlear implantation.
- The CI questionnaire for parents was only available in English. Consequently, only literate parents of paediatric CI recipients who were proficient in English were able to participate in this study. As SA has 11 official languages (Statistics South Africa, 2011), a possible limitation was the questionnaire only being available in one of the 11 official languages.
- Even though six CI programs across SA participated in this multicentre study, most of the participants (74.39%) were representative of the private health care sector. Since 85% of the South African population receive public health care services (Blecher & Harrison, 2006), this research sample is not representative of the South African population and results can therefore not be generalized.

- Some of the participating CI programs were underrepresented in this study, due to the low response rate obtained from the parents of paediatric CI recipients from participating CI programs. Additionally, due to the relatively small sample size, the results of this study are not necessarily representative of the perceptions of all parents/ primary caregivers of paediatric CI recipients in SA. However, a low response rate can be expected from a survey study (Leedy & Ormrod, 2010). In an attempt to improve the response rate in future studies, more than one method of data collection should be utilized, for example self-administered surveys can be collected electronically as well as in hard-copy. Also, interviewer-administered surveys, either face-to-face or telephonically, can be utilized for participants with poor computer skills and/ or reading and writing skills (Fowler, 2012).

5.4. Suggestions for future research

This study has established a platform for further research in the field of paediatric cochlear implantation in SA. Similar multicenter studies should be conducted involving parents of paediatric CI recipients across all eleven CI programs in SA in order to obtain comprehensive insight into the parental-perceived challenges in the field of paediatric cochlear implantation. More elaborate information on parent-perceived challenges and experiences related to cochlear implantation can be obtained if the CI process, education of paediatric CI recipients and support services received are studied in separate studies. This will allow for rich and more detailed data in each of these three fields to be obtained. Furthermore, an increased understanding of parents' perceived challenges, needs and experiences will allow CI teams and service providers to develop a more comprehensive model of service

delivery that improves parental involvement and coping in addition to paediatric CI recipients' language and socio-emotional outcomes (Roberts et al., 2015).

The cost-effectiveness of cochlear implantation in SA should be further studied as this information can assist in motivating for increased public sector (government) funding for the cochlear implantation procedure and the maintenance of the device thereafter.

Future research should examine the educational settings in SA and their degree of suitability relative to the individual and specific educational needs of paediatric CI recipients. Additionally, future research should investigate the perspectives of professionals who are involved in the provision of academic services to paediatric CI recipients (Punch & Hyde, 2011). Increased knowledge on the challenges encountered by paediatric CI recipients in their educational settings, and the challenges encountered by professionals themselves who work with them can assist in modifying academic interventions to meet the needs of paediatric CI recipients and also ensure that the challenges experienced by these professionals are minimized and that they receive the necessary support required to meet the individual and specific academic needs of paediatric CI recipients. The perceptions of professionals may also enhance understanding by providing a more realistic depiction of functional outcomes in actual life situations as opposed to information obtained from standardized assessment measures (Fitzpatrick & Olds, 2015).

A comprehensive investigation into the support services required by paediatric CI recipients and their families should be conducted to gain increased insight as to

where each of the support services required are lacking. This will assist in increasing accessibility of the support services required.

Future research should also investigate the feasibility of tele-intervention and the prospect to expand and implement it in a greater variety of settings.

5.5. Conclusion

The most noticeable parent-perceived challenge encountered during the CI process pertains to financial difficulties in funding the CI 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. Regarding challenges in the current educational settings of paediatric CI recipients, a dearth of knowledge on the part of some teachers/ therapists in supporting the individualized needs specific to each implanted child and financial difficulties in funding the additional academic support services required by paediatric CI recipients were the most pronounced challenges reported. 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 paediatric CI recipients and parent guidance support for parents of paediatric CI recipients were the support services deemed most critical by parents of paediatric CI recipients in ensuring optimal outcomes.

This study provided valuable and comprehensive insight into parental-perceived challenges related to the CI process and support services received. This investigation of the perceived challenges associated with the CI process and support services received therefore contributes towards promoting optimal outcomes, evidence-based service delivery and on-going support to paediatric CI recipients and their families.

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APPENDICES

Appendix A: Ethics approval letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YENIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

2 October 2017

Dear Ms Bhamjee

Project: Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa
Researcher: A Bhamjee
Supervisor: Dr TE Le Roux and Prof BHME Vinck
Department: Speech –Language Pathology and Audiology
Reference number: 10067125 (GW20170912HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at a meeting held on 28 September 2017. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

CC: Dr TE Le Roux (Supervisor)
Prof BHME Vinck (Co-Supervisor)

Research Ethics Committee Members: Prof MAX Schoeman (Deputy Dean); Prof LG Langa; Prof L Ndlovu; Ms A nos Sotse; Dr R Freyell; Ms KT Govender; Dr E Jorissen; Dr C Kanyiro; Dr C Arogidi; Dr D Ray; Dr M Tshiki; Prof GA Spies; Prof E Tshabe; Ms B Tsebe; Dr E van der Kolk; Dr C Wolmarans; Ms D Masingo

Appendix B: Information letter and informed consent from cochlear implant team coordinators of participating programs

- BCIP
- CHBAH-CIP
- DCIP
- PECIU
- PCIU
- TH-SU-CIU

May 2017

Attention: Mr Deon Ceronio
Team coordinator: Bloemfontein Cochlear Implant Program

Dear Mr Ceronio,

RE: Permission to conduct a research study on parents of paediatric cochlear implant recipients from the Bloemfontein Cochlear Implant Program

I am a Master's degree student from the Department of Speech-Language Pathology and Audiology at the University of Pretoria. My research is in the field of cochlear implants (CIs). The aim of my study is to describe parent-perceived challenges related to the paediatric cochlear implantation process and support services received. This national multicentre study attempts to collect data from parents/primary caregivers of paediatric CI recipients across nine CI programs in South Africa.

Title: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*

Researcher: Aaqilah Bhamjee

Study leaders: Dr Talita le Roux, Dr Kurt Schlemmer and Prof Bart Vinck

Design and procedure:

A descriptive research design (collecting mainly quantitative data) will be used for this study. Research participants would be parents/primary caregivers of paediatric CI recipients ≤ 18 years of age. There will be no case selection and parents/primary caregivers of CI recipients from the complete range of educational and communication environments will be included. Participants should be competent in either English or Afrikaans since the data-collection tool will only be available in English and Afrikaans. It will be expected that one parent/primary caregiver of each paediatric CI recipient complete an online, self-administered electronic questionnaire.

Additional to questionnaire data, selected demographic and CI related information needs to be collected/verified from patient files/clinical records, including age at initial hearing loss diagnosis/deafness, onset of hearing loss, date of implantation and date of initial stimulation.

Confidentiality: Data obtained from the questionnaires and patient files/clinical records will be handled with strict confidentiality and all identifying information of participants will not be disclosed. An identifying code will be assigned to each participant, which will be used for data analysis. All participants will be guaranteed anonymity at all times.

Informed consent: Parents/primary caregivers will be provided with an information letter detailing the purpose and procedure of the study. Informed consent will be required from each participant prior to the collection of data. Participation is voluntary and all participants have the right to withdraw from the study at any time without encountering any negative consequences.

Risks: There are no risks related to this study.

Release of findings: This research study results will be published in both accredited academic journals and a summative research report.

Data storage: On completion of the study, data will be stored in both digital and hard copy at the Department of Speech-Language Pathology and Audiology, University of Pretoria for a period of at least 15 years.

Co-authorship of manuscripts to be submitted for publication:

One representative from each CI team will act as a co-author for subsequent publications for this research study. Co-authors will be expected to give input to the manuscript drafts and oversee the data-collection procedure at their respective CI program for the purposes of this study.

Procedure for participation:

In order to conduct this study, the Bloemfontein CI Program will be required to provide us with the contact details of parents/primary caregivers of paediatric CI recipients (≤ 18 years of age) from Bloemfontein CI Program. Additionally, data on age at initial hearing loss diagnosis/deafness, onset of hearing loss, date of implantation and date of initial stimulation should be made available to the researcher for each participant from Bloemfontein CI Program who gave consent to participate in this study.

If permission for this is granted by you as team coordinator of the Bloemfontein CI Program, you are requested to copy and paste the consent slip (found at the bottom page of this letter) onto the Bloemfontein CI Program's official letterhead, sign it and return it to the researcher as an indication of your consent.

Should you require any furthermore information, please feel free to contact us. Thank you in advance for your time and co-operation.

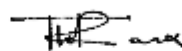
Yours sincerely,



Mrs Aaqilah Bhamjee
Researcher/ student



Prof Bart Vinck
Supervisor
HoD: Dept Speech-Language Pathology and Audiology
Director: University of Pretoria Cochlear Implant Unit



Dr Talita le Roux
Supervisor



Dr Kurt Schlemmer
Supervisor



PERMISSION FOR PARTICIPATION AND USE OF INFORMATION
OF PAEDIATRIC COCHLEAR IMPLANT RECIPIENTS OF BLOEMFONTEIN CI PROGRAM

Herewith I, **Mr Deon Ceronio**, give permission that the contact details of parents/ primary caregivers of paediatric CI recipients (< 18 years of age) from the Bloemfontein CI Program may be provided to the researcher for the purposes of this study. Furthermore, required demographic/ CI related information from patient files/ clinical records will be provided to the researcher and may be used for this research project titled: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*.

The representative from Bloemfontein CI Program who will act as co-author for subsequent publications for this research study will be:

Gideon Pieter Ceronio (Deon Ceronio)

I have received the required information about this study. I do understand what is expected from me as team coordinator of the Bloemfontein CI Program and had the opportunity to ask questions regarding this project.

Mr Deon Ceronio

Team coordinator: Bloemfontein Cochlear Implant Program

Date: 20/09/2017

Program Co-ordinator: Deon Ceronio (Mapping Audiologist) | Dr. Johannes Claassen (ENT Surgeon) | Marianna van Heerden (Mapping Audiologist)
Louise le Roux (Auditory Verbal Therapist) | Julia Jensen (Otolologist)



GAUTENG PROVINCE

REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 9 Feb 2018

TITLE OF PROJECT: Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa

UNIVERSITY: Pretoria

Principal Investigator: A Bhamjee

Department: Department of Speech-Language Pathology and Audiology

Supervisor (if relevant): T Le Roux

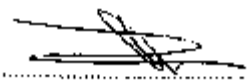
Permission Head Department (where research conducted): Yes

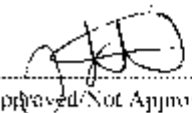
Date of start of proposed study: Feb 2018

Date of completion of data collection: Dec 2019

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.


Recommended
(On behalf of the MAC)
Date: 09 February 2018


Approved/Not Approved
Hospital Management

Date: 13/02/18



**PERMISSION FOR PARTICIPATION AND USE OF INFORMATION
OF PAEDIATRIC COCHLEAR IMPLANT RECIPIENTS OF DCIP**

Herewith I, Dr Kurt Schlemmer, give permission that the contact details of parents/ primary caregivers of paediatric CI recipients (≤ 18 years of age) from the Durban Cochlear Implant Program (DCIP) may be provided to the researcher for the purposes of this study. Furthermore, required demographic/ CI related information from patient files/ clinical records will be provided to the researcher and may be used for this research project titled: Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa.

The representative from DCIP who will act as co-author for subsequent publications for this research study will be:

Dr Kurt Schlemmer

I have received the required information about this study. I do understand what is expected from me as team coordinator of the DCIP and had the opportunity to ask questions regarding this project.

Dr Kurt Schlemmer
Team coordinator: Durban Cochlear Implant Program

Date: 2017/07/27

**PERMISSION FOR PARTICIPATION AND USE OF INFORMATION
OF PAEDIATRIC COCHLEAR IMPLANT RECIPIENTS OF PE CI Program**

Herewith I, **Ms Kelly Schroeder**, give permission that the contact details of parents/ primary caregivers of paediatric CI recipients (≤ 18 years of age) from the PE CI Program may be provided to the researcher for the purposes of this study. Furthermore, required demographic/ CI related information from patient files/ clinical records will be provided to the researcher and may be used for this research project titled: *Parent perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*.

The representative from PE CI Program who will act as co-author for subsequent publications for this research study will be:

Kelly Schroeder

I have received the required information about this study. I do understand what is expected from me as team coordinator of the PE CI Program and had the opportunity to ask questions regarding this project.

K Schroeder
Ms Kelly Schroeder
Team Coordinator: Port Elizabeth Cochlear Implant Program

Date: 17 August 2017

**PERMISSION FOR PARTICIPATION AND USE OF INFORMATION
OF PAEDIATRIC COCHLEAR IMPLANT RECIPIENTS OF PCIU**

Herewith I, **Ms Nicolize Cass**, give permission that the contact details of parents/ primary caregivers of paediatric CI recipients (≤ 18 years of age) from the Pretoria Cochlear Implant Unit (PCIU) may be provided to the researcher for the purposes of this study. Furthermore, required demographic/ CI related information from patient files/ clinical records will be provided to the researcher and may be used for this research project titled: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*.

The representative from PCIU who will act as co-author for subsequent publications for this research study will be:

I have received the required information about this study. I do understand what is expected from me as team coordinator of the PCIU and had the opportunity to ask questions regarding this project.



PRETORIA COCHLEAR
IMPLANT UNIT
NPC 2015/24147/08

Ms Nicolize Cass
Team coordinator: Pretoria Cochlear Implant Unit

Date: 2017/6/18



**PERMISSION FOR PARTICIPATION AND USE OF INFORMATION
OF PAEDIATRIC COCHLEAR IMPLANT RECIPIENTS OF TH-SU-CIU**

Herewith I, **Ms Jenny Perold**, give permission that the contact details of parents/ primary caregivers of paediatric CI recipients (≤ 18 years of age) from the Tygerberg Hospital-Stellenbosch University Cochlear Implant Unit (TH-SU-CIU) may be provided to the researcher for the purposes of this study. Furthermore, required demographic/ CI related information from patient files/ clinical records will be provided to the researcher and may be used for this research project titled: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*.

The representative from TH-SU-CIU who will act as co-author for subsequent publications for this research study will be:

_____**Jenny Perold**_____

I have received the required information about this study. I do understand what is expected from me as team coordinator of the TH-SU-CIU and had the opportunity to ask questions regarding this project.

Ms Jenny Perold

Team coordinator: Tygerberg Hospital Stellenbosch University Cochlear Implant Unit

Date: 8 January 2018



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: Dr GG
Marinus
TELEPHONE: 021 938 5752

Folio Reference: **10067125 [GW20170912H5]**

TITLE: Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa.

Dear Ms Bhamjee

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).


DR GG MARINUS
MANAGER: MEDICAL SERVICES


DR D ERASMUS
CHIEF EXECUTIVE OFFICER

Date: 6 January 2018

Administration Building, Francis van Zyl Avenue, Parow 7600
Tel: +27 21 938 6267 Fax: +27 21 938 4893

Private Bag 24, Tygerberg, 7505
www.capegateway.gov.za

Appendix C: Information letter



Faculty of Humanities
Department of Speech-Language Pathology and Audiology

July 2017

Dear parent/primary caregiver of cochlear implant recipient,

RE: Permission to take part in a research study on parent-perceived challenges related to the paediatric cochlear implantation process and support services received

I am a Master's degree student from the Department of Speech-Language Pathology and Audiology at the University of Pretoria. My research is in the field of cochlear implants (CIs). The aim of my study is to describe parent-perceived challenges related to the paediatric cochlear implantation process and support services received. This national multicentre study attempts to collect data from parents of paediatric CI recipients across nine CI programs in South Africa.

Title: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa*

Researcher: Aaqilah Bhamjee

Study leaders: Dr Talita le Roux, Dr Kurt Schlemmer and Prof Bart Vinck

Design and procedure:

A descriptive research design (collecting mainly quantitative data) will be used for this study. Research participants would be parents/ primary caregivers of paediatric CI recipients ≤ 18 years of age with at least 12 months experience with their CI(s). There will be no case selection and parents/ primary caregivers of CI recipients from the complete range of educational and communication environments will be included. Participants should be competent in English since the data-collection tool will only be available in English. It will be expected that one parent/primary caregiver of each paediatric CI recipient complete an online, self-administered electronic questionnaire.

Additional to questionnaire data, selected demographic and CI related information needs to be collected/ verified from patient files/ clinical records, including age at initial hearing loss diagnosis/ deafness, onset of hearing loss, date of implantation and date of initial stimulation.

Confidentiality: Data obtained from the questionnaire and the patient files/ clinical records will be handled with confidentiality and identifying data of all participants will not be disclosed. An identifying code will be assigned to each participant, which will be used for data analysis. All participants will be guaranteed anonymity at all times.

Fakulteit Geesteswetenskappe
Departement Sprek- en Taalpatologie en Oudleële
Lefapha la Bomotheo
Kgona ya Phatholotši ya Poloko-Melomo le Go kwe

talita.leroux@up.ac.za

Informed consent: In this information letter the purpose and procedure of the study is provided to the parents/primary caregivers. Informed consent, given freely, from parents/primary caregivers is required. Participation is voluntary and all participants have the right to withdraw from the study at any time without encountering any negative consequences.

Risks: There are no risks related to this study.

Release of findings: This research study results will be published in both accredited academic journals as well in a summative research report.

Data storage: On completion of the study, data will be stored in both digital and hard copy at the Department of Speech-Language Pathology and Audiology, University of Pretoria for a period of at least 15 years.

The abovementioned information will appear on the website page of the questionnaire and should you agree to participate in this study, you will be required to accept that you clearly understand this information and agree to participate in this research study. Access to the questionnaire will only be granted once consent has been obtained from you.

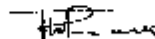
Should you require more information please feel free to contact us.

Thank you in advance for your time and co-operation.

Yours sincerely,



Mrs Aaqilah Bhamjee
Researcher



Dr Talita le Roux
Supervisor



Prof Bart Vinck
Supervisor
HoD: Dept Speech-Language Pathology and Audiology
Director: University of Pretoria Cochlear Implant Unit



Dr Kurt Schlemmer
Supervisor

Faculty of Humanities
Department of Speech-Language Pathology and Audiology
Fakulteit Geesteswetenskappe
Departement Spraak-Taalpatologie en Audiologie
Lefapha la Bomotheo
Kgona ya Phatholosi ya Palela-Malomo le Go koka

Appendix D: Informed consent form

PERMISSION FOR PARENT/ PRIMARY CAREGIVER TO TAKE PART IN THIS RESEARCH STUDY

I freely agree to participate in the research study entitled: *Parent-perceived challenges related to the paediatric cochlear implantation process and support services received in South Africa.*

I hereby give permission to the researcher to have access to my child's patient file/ clinical records. This information may be used for the purpose of this research study and for publication in scientific literature.

I am aware that patient confidentiality will be maintained at all times. Written consent should again be obtained should the data obtained for the purpose of this study be used in further clinical studies.

I acknowledge that I have received the necessary information about this study and have had the opportunity to ask questions regarding this project.

☐ YES, I clearly understand and accept the above-mentioned information and freely agree to proceed with the questionnaire.

☐ NO, I do not accept the above-mentioned information and do not want to participate in this research study.

Name of parent/primary caregiver: _____ Date: _____

Signature: _____

Fakulteit Geesteswetenskappe
Departement Spreek-Taalpatologie en Audiologie
Lefapha la Bomotheo
Kgona ya Phatholosi ya Polelo-Melame le Go-kgos

talita.jeroux@up.ac.za

Appendix E: Declaration of originality

DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department ofSpeech-Language Pathology and Audiology..... places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

While academic staff teach you about referencing techniques and how to avoid plagiarism, you too have a responsibility in this regard. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (eg a book, an article or a website) without acknowledging the source and pass it off as your own. In effect you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work with the intention of passing it off as his/her work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department ofSpeech-Language Pathology and Audiology..... No written work will be accepted unless the declaration has been completed and attached.

Full names of student: Aaqilah Bhamjee

Student number: 10067125

Topic of work: Parent-perceived challenges related to the paediatric cochlear implantation process
and support services received in South Africa

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that thisThesis..... (eg essay, report, project, assignment, dissertation, thesis, etc) is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE



Appendix F: Principal investigator(s) declaration for the storage of research data
and/or documents



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

FACULTY OF HUMANITIES
RESEARCH ETHICS COMMITTEE

Declaration for the storage of research data and/or documents

I/ We, the principal researcher(s) **Aaqilah Bhamjee**

and supervisor(s) **Dr Talita le Roux, Dr Kurt Schlemmer and Prof Bart H.M.E Vinck**

of the following study, titled: *Parent-perceived challenges related to the cochlear implantation process and support services received in South Africa*

will be storing all the research data and/or documents referring to the above-mentioned study in the following

department: **Department of Speech-Language Pathology and Audiology**

We understand that the storage of the mentioned data and/or documents must be maintained for a minimum of 15 years from the commencement of this study.

Start date of study: **31 July 2017**

Anticipated end date of study: **30 June 2018**

Year until which data will be stored: **30 June 2033**

Name of Principal Researcher(s)	Signature	Date
Aaqilah Bhamjee		2017/07/28

Name of Supervisor(s)	Signature	Date
Dr Talita le Roux		2017/07/28
Dr Kurt Schlemmer		2017/07/28
Prof Bart H.M.E Vinck		2017/07/28

Name of Head of Department	Signature	Date
Prof Bart H.M.E Vinck		2017/07/28

Appendix G: Cochlear Implant questionnaire for parents

Cochlear Implant Questionnaire for Parents

In the first two sections, we would like to learn more about you, the parent/primary caregiver as well as your child with a cochlear implant(s)

Section A: Information about you as a parent/primary caregiver of a child with a cochlear implant(s)

1. What is your relationship to the child with a cochlear implant(s)?

Mother	1
Father	2
Primary caregiver (grandparent, foster parent, stepparent)	3
Other (please specify)	4
.....	

2. Your highest qualification level obtained can best be described as:

Primary/ high school (< Grade 12)	1
Secondary education (Grade 12/matric) completed	2
Tertiary qualification (University)	3
Tertiary qualification (other)	4

3. Marital status:

Married	1
Partner (not married)	2
Divorced/ separated	3
Previously divorced, now remarried	4
Single	5
Widowed	6

Section B: Information about your child with a cochlear implant(s)

4. Child's name: _____

(Please note that your child's name is needed for data tracking purposes and will be omitted during data analysis)

5. Date of birth of your child: _____

(dd/mm/yyyy)

6. Gender of your child:

Male	1
Female	2

7. Did your child receive Newborn Hearing Screening (was his/her hearing screened shortly after birth/within the first 4-6 weeks after birth)?

Yes	1
No	2
Unsure	3

8. Current health care sector of your child:

Private health care	1
Public health care	2

9. At which Cochlear Implant Centre/ Program does your child currently receive cochlear implant services from?

Bloemfontein Cochlear Implant Program	1
Chris Hani Baragwanath Academic Hospital Cochlear Implant Program	2
Durban Cochlear Implant Program	3
Johannesburg Cochlear Implant Centre	4
Port Elizabeth Cochlear Implant Program	5
Pretoria Cochlear Implant Unit	6
Tygerberg Hospital-Stellenbosch University Cochlear Implant Unit	7

10. How was your child's (first) cochlear implant funded?

Private funding (no medical aid)	1
Medical aid complete	2
Medical aid and private funding	3
Donations only	4
Sponsor(s)	5
Donations and medical aid	6
Donations and private funding	7
Donations, medical aid and private funding	8
Public: government funding	9
Other (please specify)	10
.....	

11. If your child uses two cochlear implants, how was the second cochlear implant funded?

Private funding (no medical aid)	1
Medical aid complete	2
Medical aid and private funding	3
Donations only	4
Sponsor(s)	5
Donations and medical aid	6
Donations and private funding	7
Donations, medical aid and private funding	8
Public: government funding	9
Other (please specify)	10
.....	

12. Your child currently uses:

Two cochlear implants	1
One cochlear implant and a hearing aid in the non-implanted ear	2
One cochlear implant without a hearing aid in the non-implanted ear	3

13. How does your child currently communicate?

Spoken language only	1
Sign Language only	2
Spoken language and Sign Language (mixed/total communication)	3
Manual communication (informal gestures)	4
Alternative Augmentative Communication (AAC) device	5
Other (please specify)	6
.....	

14. Your child's current educational setting can best be described as:

Not yet in school (too young)	1
Full mainstream nursery school or pre-school	2
Special nursery school or pre-school for children with hearing loss: oral approach (spoken language)	3
Special nursery school or pre-school for children with hearing loss: Sign Language or Total Communication approach	4
Mainstream school	5
School for the Deaf: Sign Language or Total Communication approach	6
School for children who are hard-of-hearing: oral (spoken language) approach	7
Special needs school: mainstream syllabus	8
Special needs school: special syllabus	9
Home school	10
Doesn't go to school (even though at a school-age)	11
Other (please specify)	12
.....	

15. If your child is enrolled in a formal educational setting, is this setting a public or private institution?

Public	1
Private	2
N/A	3

16. Has your child repeated a grade/multiple grades in school?

Yes	1
No	2
N/A	3

17. Did you choose to hold your child back during a grade(s) or enroll him/her in school at a later age?

Child was electively (non-compulsory) held back during a grade	1
Child started school at a later age	2
Child started school at a later age and was electively (non-compulsory) held back during a grade(s)	3
N/A	4

18. Has your child been diagnosed with a genetic syndrome? (e.g. Down Syndrome, Ushers Syndrome, Waardenberg Syndrome etc.)

	Yes	No
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19. If yes, please specify

20. Does your child present with one or more of the following additional developmental condition(s)/needs?

Attention Deficit Hyperactivity Disorder (ADHD)/Attention Deficit Disorder (ADD)	1
Apraxia	2
Autism/ Autism Spectrum Disorder (ASD)	3
Cleft lip and/or palate	4
Cerebral Palsy	5
Developmental cognitive delay	6
Developmental behavioural delay	7
Developmental motor delay	8
Diagnosed learning disability (e.g. dyslexia)	9
Epilepsy	10
Feeding and/or swallowing disabilities	11
Mobility impaired	12
Visual impairment	13
Other (Please specify)	14
.....	

Section C: Information about the process to obtain a cochlear implant(s)

21. Please rate the following statements as best you can:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
<ul style="list-style-type: none"> * It was a difficult time waiting for the results of the cochlear implant assessment before implantation 	1	2	3	4	5
<ul style="list-style-type: none"> * It was a problem getting someone to look after the family when we had to go to the Cochlear Implant Centre 	1	2	3	4	5
<ul style="list-style-type: none"> * The costs of travel to the Cochlear Implant Centre were a problem 	1	2	3	4	5
<ul style="list-style-type: none"> * It was hard to take time off work for the appointments at the Cochlear Implant Centre 	1	2	3	4	5
<ul style="list-style-type: none"> As a family, we were financially prepared to meet the financial demands of the cochlear implantation process 	1	2	3	4	5
<ul style="list-style-type: none"> We are currently financially able to meet the long-term and continuous financial demands following cochlear implantation (costs relating to habilitation, device maintenance etc.)? 	1	2	3	4	5

22. In your opinion, do you think that the timing between the diagnosis of your child's hearing loss and eventual cochlear implantation was delayed?

Yes	No
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23. If yes, what do you think possible reason(s) for this delay could be? Please select possible reasons (more than one reason can be selected)

• Progressive hearing loss (my child did not meet the audiologic criteria for cochlear implant candidacy and later showed a deterioration in his/her hearing levels)	1	2
• Clinical issues: Medical or presence of additional developmental conditions	1	2
• Difficulty in taking off from work to attend appointments at the Cochlear Implant Centre	1	2
• Difficulty in finding someone to look after the family when we go to the Cochlear Implant Centre	1	2
• Family indecision/uncertainty	1	2
• Family's geographical location/ travelling distance to the Cochlear Implant Centre	1	2
• Family's geographical location/ travelling costs to the Cochlear Implant Centre	1	2
• Financial costs and obtaining the required funding for the implant procedure	1	2
• Lack of information/support from the Cochlear Implant Centre	1	2
• Stress of surgery to my child (stress of having my child undergo anesthesia, drilling into the skull etc.)	1	2
• Lack of prompt referral to specialized Cochlear Implant services	1	2
• Opted for a second opinion	1	2
• Cultural/religious beliefs: seeking alternative/traditional treatment	1	2
• Other (please specify)	1	2

24. If your child currently has one cochlear implant, would you like him/her to receive a second implant?

Yes	No	N/A
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25. If yes, what do you think are the barriers preventing your child from obtaining the second implant? Please select possible reasons (more than one reason can be selected)

• Family indecision/uncertainty	1	2
• Financial costs and funding of the second implant procedure	1	2
• Financial costs and funding of the device maintenance	1	2
• Lack of information/support from the Cochlear Implant Centre	1	2
• Stress of having my child undergo a second surgery (surgical anxiety)	1	2
• Uncertainty of the benefits of a second implant for my child	1	2
• Concerned about the disadvantage of destroying any residual hearing	1	2
• Not recommended by the Cochlear Implant Team	1 ^a	2
• Other (please specify)	1	2

26. If no, please list possible reasons for this decision

27. What would you consider as the greatest challenge(s) of being a PARENT/PRIMARY CAREGIVER of a child with a cochlear implant(s)?

28. In your opinion, what would you consider as the greatest challenge(s) that your CHILD experiences as a result of his/ her cochlear implant(s)?

Section D: Information about the education of your child with a cochlear implant(s)

29. Please rate the following statements as best you can

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	N/A
• Finding an adequate educational setting for my child has been a challenge	1	2	3	4	5	6
• * I am happy about my child's progress at school currently	1	2	3	4	5	6
• * My child is keeping up well with other children (normal hearing) his/her age in school	1	2	3	4	5	6
• My child is able to follow/keep up with the pace at which the teacher presents information	1	2	3	4	5	6
• * My child is able to cope academically in a mainstream school setting	1	2	3	4	5	6
• * The local school and its support services adequately meet all our needs concerning the use of my child's implant at school	1	2	3	4	5	6
• My child's current school placement is appropriate for his/her specific needs	1	2	3	4	5	6
• There is a shortage of appropriately trained teachers to deliver intervention services, specifically for children with cochlear implants	1	2	3	4	5	6

30. Which professional(s) assisted you in obtaining a school for your child? (indicate all applicable options)

Audiologist	1
Speech-Language Therapist	2
Educational Psychologist	3
Parent-Guidance Therapist	4
Auditory-Verbal Therapist	5
Did not receive assistance from any professional	6
N/A	7

31. Does your child encounter any of the following challenges in his/her current educational setting (more than one option may be selected)?

	Yes	No	N/A
• The number of children in the classroom is too big	1	2	3
• The classroom environment is too noisy	1	2	3
• No/little consideration is given for our child's unique language needs	1	2	3
• No/little support from school for additional services (we must pay for private tutors, remedial therapy etc.)	1	2	3
• Teachers and therapists often unsure of HOW to support our child's individual needs	1	2	3
• Bullying as a result of his/her cochlear implant is an issue	1	2	3
• As parents, we don't always have adequate finances to pay for all the additional academic support services our child needs	1	2	3
• Teachers have unrealistic expectations of parents	1	2	3
• We do not receive accurate feedback from the teachers (for e.g. they'll report that our child is coping and in another instance report that he/she is not coping)	1	2	3
• Teachers have limited patience with our child and don't have the capacity to go the extra mile in assisting him/her	1	2	3

Section E: Information on support services

32. The professional on the cochlear implant team who provided the most continued support from the time of implantation up until now is:

Audiologist	1
Ear, Nose and Throat Surgeon	2
Parent-Guidance Therapist	3
Psychologist	4
Speech-Language Therapist	5
Other (Please specify)	6

33. Please rate the support services your CHILD with a cochlear implant(s) has received since his/her (first) implant:

Support service	Support service not available	Received limited support	Received adequate support	Received exceptional support	Not applicable
Speech and language therapy	1	2	3	4	5
Occupational therapy	1	2	3	4	5
Behavior support	1	2	3	4	5
Counseling	1	2	3	4	5
Tutoring in school system	1	2	3	4	5
Sign Language instruction	1	2	3	4	5
Other (Please specify)	1	2	3	4	5

34. Please rate the support services you as a PARENT/ PRIMARY CAREGIVER has received since your child's (first) implant:

Support service	Support service not available	Received limited support	Received adequate support	Received exceptional support	Not applicable
Parent guidance	1	2	3	4	5
Counseling	1	2	3	4	5
Guidance for educational placement	1	2	3	4	5
Parent support group	1	2	3	4	5
Financial support	1	2	3	4	5
Tele-intervention	1	2	3	4	5
Technical support for device maintenance	1	2	3	4	5
Support and guidance to discipline my child with cochlear implant(s)	1	2	3	4	5
Counseling and support for the siblings of my child with a cochlear implant(s)	1	2	3	4	5
Other (Please specify)	1	2	3	4	5

35. In your opinion, which of the following support services would you consider as critical for A CHILD with a cochlear implant(s) to ensure optimal outcomes?

Please select THREE support services (from the table below) that you deem most important.

Support service	Most Important	Second Important	Third Important
Speech and language therapy	1	1	1
Occupational therapy	2	2	2
Behavior support	3	3	3
Counseling	4	4	4
Tutoring in school system	5	5	5
Sign Language instruction	6	6	6
Other (Please specify)	7	7	7

36. In your opinion, which of the following support services would you consider as critical for **THE PARENTS/PRIMARY CAREGIVERS** of a child with a cochlear implant(s) to ensure optimal outcomes?

Please select **THREE** support services (from the table below) that you deem most important.

Support service	Most Important	Second Important	Third Important
Parent guidance	1	1	1
Counseling	2	2	2
Guidance for educational placement	3	3	3
Parent support group	4	4	4
Financial support	5	5	5
Tele-intervention	6	6	6
Technical support for device maintenance	7	7	7
Support and guidance to discipline my child with cochlear implant(s)	8	8	8
Counseling and support for the siblings of my child with a cochlear implant(s)	9	9	9
Sign Language instruction	10	10	10
Other (Please specify)	11	11	11

THANK YOU for taking the time to answer these questions

**Questions adapted from the 'Children with cochlear implants: Parental perspectives' questionnaire by (Archbold et al., 2008)*

Appendix H: Excel data sheet for retrospective data collection

Name & surname:	Date of birth	1st CI surgery date:	1st CI switch on date:	2nd CI surgery date:	2nd CI switch on date:	Age at diag of HL (months):	Onset/etiology of HL:	Age deafness (months):	at	If bilateral implantation, was it sequential or simultaneous?	Diagnosed with ANSD?

Appendix I: Parental responses against bilateral implantation (question 26)

	Open-ended responses: question 26
Part No.	Question 26
9	She can hear a bit in the other ear
18	Not required
44	Presence of medical complications
50	Did not help him - he doesn't communicate verbally
59	Doesn't qualify for a second implant
67	She is responding well with one CI
74	I am struggling to pay for the repairs for 1 CI. I won't be able to afford 2 - it's too expensive
76	She is doing well with one, so no need for extra costs

Appendix J: Parental responses for questions 27 and 28

Open-ended responses: questions 27-28

Part No.	Question 27	Question 28
1	Stress about any head injuries/ falls etc. Maintenance costs. Doing Sports is stressful	Had to change schools after hearing loss diagnosis. He had to go to a special school instead of mainstream school and had to repeat grade 3 due to hearing loss. He doesn't see himself as normal anymore. Challenge with mood swings and acceptance
2	The quality education that the child received at a school for the deaf and their insistence that she should only sign. More mainstream schools should be equipped to think out of the box and prepare to assist these children. A good example of a school working with me as a parent for the greater good of the child is Hillcrest Remedial School. They have gone out of their way, even allowing me to attend school with my child when the need arises. Remedial units can play an important part in this regard. Support from the cochlear unit to the school with information about how the cochlear implant works and how they can improve communication and learning would be appreciated. Sign Language support should be signed English, which is currently not available to cochlear implanted children within the school system. Often the cost to maintain and replace cochlear implant parts are a concern as this is not covered by medical aid	Keeping them safe when playing sport and the limitation of some sport activities
3	Lack of cochlear support in Botswana and lack of speech therapists trained in the field	Swimming time is challenging for us
4	The emotional management of everybody in the family, including the Cochlear Implant recipient	The fact that her emotions developed later than those of her peers
5	Loving your child	To do good
6	People staring at her. She is almost like a normal child	Kids making fun of her at school
7	Worrying whether all will be okay when he is away from home, e.g. Camping with school etc.	Difficulty hearing in noisy environments (e.g. In the school hall) and in other places where somebody is talking over a microphone
8	On-going time off work in the initial stages	As a teenager, they are more self-conscious of the cochlear implants, they are more accepting when they're younger
9	The fact that the schooling system failed Saniya - due to bullying and teacher abuse	She does not enjoy the sound that much and prefers the silence
10	I am forced to be a working mom, due to the fact that we need the medical aid in order to pay for CI upgrades etc., and because I work, I am not able to give her as much as attention as possible to help her with her homework. It's a catch 22 situation	Hearing fatigue: She battles to do her homework late in the afternoons due to exhaustion. The aftercare at her school is an extremely noisy environment and leaves her with headaches more often than not
11	Financial constraints of CI technology	The fact that she has to change and 'accessorize' frequently, being on the autism spectrum, she lacks the organizational skill to 'order' her world, so this becomes problematic in her case
12	Getting her to fit in with normal hearing friends	Fitting in
13	Development of speech and language after implant at over 2 years of age	None
14	My child is also autistic and has sensory issues which we were not aware of prior to implantation. To get her to keep her cochlear implant processors on has always been a challenge (for the first 4 years). But as of last year, she will usually happily wear one side (left). She will not however, wear the right side and we are unsure if this is due to sensory overload or if there is a problem with the right side (internal) parts. Due to the ASD she is difficult to map and test	Sensory overload. Initially she also battled with pressure sores
15	Finding an affordable and the right school for him. Maintenance of the cochlear implant	Unsure

16	Costs involved in maintenance of cochlear implant device e.g. battery cost is R3100.00 and is not funded by medical aid	To place our child in a special needs school
17	Communicating effectively with child	He has a Mondini deformity, so he doesn't get full benefit from his Cis
18	Dealing with health professionals and service providers: having to fight to receive good and fair services	Unable to do sports easily
19	Lack of local support - at the time (2005) the implants were done in Pretoria, and we lived in Pietermaritzburg (KZN) - we did a whole lot of travelling up to Pretoria in the first 2 years after her implants were done. The people in Pretoria were amazing - kept me sane in those initial 2 years. The financial side of the implants - and the continuous financial implications. I struggle financially now and put every cent I had into getting the implants done - but it was worth it a hundred times over. I worry about the future and the financial burden I will be passing onto Nadine	Very difficult to answer. She was 2 1/2 when she got her first implant, so she does not remember life any differently - her cochlear implant is normal to her. She does not consider herself to be very different from other children. Her challenges come from being hearing impaired - such as hearing in the classroom - and not necessarily the cochlear device itself. Her biggest challenge relating directly to the cochlear implant is probably the responsibility of having them with her at all times - she cannot just put them anywhere or leave them with anyone if she is not wearing them. Also, going away with friends on school outings has always been stressful because of the worry of the cochlear device
20	The financial side is a big problem and I would also say the amount of time I need to spend with him for his homework and learning as he is far behind in his speech and understanding	He gets frustrated because he cannot express himself in words since his vocabulary is limited because of hearing sounds very late in life for the first time
21	Different challenges at different ages - in the beginning it was the devastation of the news and thinking there is no future for your child, and NO proper support available offered at the Centre except for a half an hour talk to a social worker which had no value at all. Then, the terrible financial implications. Then, the exhausting and anxiety-packed tasks for the first few years to ensure that your child learns language and gets the correct and sufficient input. The constant travelling to the Centre which has a huge impact on the family as a whole and on any normal life and work. The fear that something might happen to your child and the implant gets damaged. Later, the social implications and the challenge to ensure that her self-image is such that she can withstand any questions, rejections and the greatest challenge was having NO support and no one to turn to for support for yourself as a mother to assist and guide you into working through the trauma of having a deaf child and then dealing with the best way of helping your child to make the best of her life with a CI. It is a life trauma	I think that upon becoming a teenager, the challenge of developing a positive self-image despite the 'things of her head' making her look different if her hair does not cover them, accepting herself in the peer group as being a bit different and struggling to hear in social situations. NO support is offered in schools - you as a parent has the full responsibility for your child's well-being. And if children don't have parents who are lucky enough to be able to give that support, what happens to them?
22	Constant support that the child requires	Technical aspects related to the CI
23	Making sure that they are being seen as normal as they are like normal children just with CIs. I have two children with CIs	Being told that they are deaf by other children but handling it well. They want to hear with their own ears
24	Financial resources of obtaining and maintaining the CIs. Psychological and emotional journey and helping my child deal with being different	Being different from others. He wants to know why him. The challenge of having to wear the CIs constantly. Big battle not wanting to swim with friends because he cannot partake in games, even with aqua. Not being allowed certain contact sports. Not being able to wear a helmet or a hat
25	Not understanding/being able to relate how it is in everyday life to be deaf	Big crowds
26	Financial impact on the family. Time consumed going to the hospital. General health of the child. Inability to spend time away from the child to follow personal goals	Other children making fun of external part on the ear. Having to continuously explain what is on her ears. Feeling that she is abnormal or different. Not hearing 100%. Having to push harder to make sure that spoken words are understood. Not being able to hear without hearing devices
27	To stay in contact with the need of the child - meaning communication because of lack of quality audiologists when they're critically needed during the acceptance phase with the device. Lack of service Centre for emergency repairs. Child has not been a progressive auditive learner	Namibia was at the time of diagnosis uninformed about the technological possibilities and when we gained information about the implants, we had very limited critical time to get the bilateral implants done in SA

28	Costs of having the CI done and maintenance costs	When it's faulty she cannot go to school as she cannot hear, and I have to also stay with her at home until a solution comes
29	Trying to explain to her what is happening. Trying to discipline her	When her friends are speaking to her and trying to explain what game they're going to play
30	Worry that she would not be able to integrate into society. Fear that the operation would go badly. After first op, one side of her face had no sensation. Had to wait 6 weeks to see if facial muscle function would return. Tremendous stress on marriage, resulting in divorce. Long wait to see if implant would be successful	Her desire to hear without implants
31	That the processors work 100%	Doing sport (swimming)
32	Emotional factor of the child	Not being able to hear all sounds
33	The communication between the parent and the child	To fit in as normal as possible
34	Should she lose her device(s). I have no insurance on them and they're insanely expensive - R1500 per device	At this stage she's very comfortable and understands why she was born deaf and how she isn't able to hear without the devices, BUT she still doesn't always hear what is being said when there is too much of noise
35	Financial implications of the CI	Restricted to not playing contact sport
36	Being fully committed to the regular speech therapy at the beginning and working on that at home. Also, the care for and maintenance	Lack of spontaneity - she can't just jump or be pushed into a pool or river. And having to answer the same questions from new people/children about what is that on her head
37	Managing the technology	Not sure if she's experienced any challenges, maybe the operation itself
38	Stress about her getting into the right school that can cater for her needs and whether she'll be able to function on her own when she's older	Speech is a challenge and motor skills
39	The financial implications for the maintenance of the CI. Finding the right school that caters for her needs - private schools are very expensive. Having to deal with the child's anxieties and also the pressure from teachers	She hates when the coil does not sit properly on her head and moves or falls whilst she is doing sports at school. She would also like to swim with her hearing aid, but we can't afford that model at the moment
40	The non-stop therapy which is worse because of the hemiplegia	Challenges at school: she needs to keep up with normal kids despite her disabilities. Acceptance by other kids in the school is a challenge and also her being able to understand the reason for her deafness
41	Dealing with the grief of the disability. Challenge of not feeling sorry for your child	Because she is my second hearing impaired child, the journey has been much easier with almost no challenges
42	Time involved in the process. Restriction to where the family can live and restrictions to where and when the parents can work. Also, financial challenges: You need to earn more money but your job opportunities get limited. The other children can also feel a bit neglected	Learning; fitting into and functioning in society
43	Financial strain; intensive attention and assistance towards school work/social skills/emotional well-being etc. Not always knowing how to cope with the child's emotions/behaviour (lack of parent guidance or support). Emotional exhaustion: due to worries, developmental obstacles etc.	Catching up on language delay, school work, developmental issues (everything he missed out on before receiving CIs). Social interaction with his peers and finding acceptance as he is
44	You don't always know what the outcomes will be; and the device is very expensive to maintain	Keeping the implant on as it comes off. Not being mobile (mobility impaired) has been a great challenge also as the implant keeps coming off and he isn't able to wear his implant on his ear
45	If the CI gets misplaced it's very expensive to replace	When it irritates him, he doesn't wear it
46	Finances	Not being able to participate in all sports e.g. Rugby

47	Learning to let go of her - she is turning 10 now and doing so well	Water activities remain a challenge - the aqua processor is amazing, but there is always the fear of the processor going missing
48	Communicating with him	Communicating with others and delayed language development
49	Everyone assumes that she is now hearing. My greatest challenge as a parent of a deaf child is accessing sustainable equal education, which for my children means full access (visual support for an enriched curriculum). Eventually we had to start our own school and home-school my daughters. Schooling options were dismal, the previous school offered no support. Money is not a problem only because we'd give up anything and everything for the kids to get what they need. We'd waiter, work extra hours etc.	People now assume that she is now hearing. An advantage is that she is bilingual so when batteries go flat unexpectedly, or the processor is in for repairs, having a second language that isn't dependent on sound access is a life saver. It in no way competes for our enjoyment of the spoken language when we do have access
50	To always make sure/worry that the child doesn't misplace the device	Apparent discomfort - child looks sad when the CI is on
51	Giving siblings equal attention whilst having to go through so much of stress financially to fund the implants. Having to go for regular appointments for the speech processor mapping and then speech therapy whilst having other kids is challenging as well	Having to learn to hear and then speak and communicate
52	Communication	Communication
53	Financial aspects involved with maintaining the implants	My son is only upset when he has to remove his implants and he cannot hear. Aqua kit was purchased so that he can hear whilst swimming
54	To be sure that she can handle herself in certain situations	People are impatient when she does not hear or react immediately. Social interaction is a challenge
55	Just getting used to the routine of charging the batteries; when going away to make sure you have all the stuff: charger, dry box etc.	When she was younger, a challenge was the device falling off her head; now when she's older it's children staring and keep asking what is that
56	To ensure that my child can experience sound and language	Listening to the radio
57	I think that when you leave Carel Du Toit all of the support falls away. That's the greatest challenge	Being bullied for being different. Accepting that she's deaf and that it's not necessarily a bad thing
58	Stress about her future - studies	Coping in 'normal' situations; very minimal understanding from teachers
59	The stress of a young minor having the responsibility of dealing with an expensive device	Difficulty participating in sports that he's interested in

60	<p>The stress of losing the device - as a toddler, my daughter used to take it off and stick the magnet to anything she could find, such as a trampoline, jungle gym etc. It would fall off easily and irritate her, despite using the devices and gadgets given to us in the implant bag. When we moved to PE, they told us to use wig tape and this has been a tremendous help. Another challenge is the lack of knowledge from general medical staff. My daughter once fell at a playground and we took her to 2 emergency rooms at the 2 private hospitals in PE. The first didn't want to treat her and referred us to the second, where the surgeon that did the implants in PE worked. He was in surgery and the ER staff phoned my daughter's specialist in Pretoria for her to explain to them how to apply a pressure bandage. In the end they gave me the roll of bandage to do it myself. I didn't know how to do it and the instruction from the specialist was to get on an airplane and go to Pretoria where she worked. I have no relatives in PE and had to take my second child out of school for the week to travel to Pretoria, not knowing how long we would be there. My husband worked in Mozambique, so I felt all alone and very scared for my child who showed signs of internal bleeding (grape-like sensation around the CI). Looking after the parts of the device is also a challenge. I constantly jam the microphone when I need to replace them, which drives me to tears as I'm forever thinking I've broken the device. Luckily the audiologist at my daughter's school is wonderful and has always helped and supported us with this. I also struggled to buy wig tape in PE and we ended up spending R150.00 for a roll of tape at one stage when I know that it costs less than R80.00 in Cape Town. However, we struggle financially and don't have credit cards. When we phoned the office in CT that sells it, the answering machine was on - tried several times. I also sent a family member to the hospital in CT to buy from the lady, but the office was closed. Luckily Meghan (PE CIU), has now started selling it. Because of the above, we also struggle buying the drying bricks, which we are still struggling with. Finding suitable child-minding facilities have also been a struggle. My daughter also missed out on sleepovers and playdates as other parents find it daunting to look after the devices. We have also found it stressful when she DID get invited, as the devices require care and caution when children play. One such playdate ended up in the abovementioned hospital trip. On top of all of the above, we have the responsibility of making sure our daughter progresses at the best rate she can. She is now on top of her challenges and has learnt a second language - Afr. She is doing her best so far, and she is passing, but I do feel that it's unfair given her exceptional circumstances.</p>	<p>My daughter has had to learn from a young age to be responsible with her device and has become a little OCD when it comes to looking after it, which is not a bad thing, but it is as a result of the stresses our household experienced around her misplacing the device at a young age. Our daughter is very resilient, but has had to face some rejection from her peers due to wearing the devices - which we won't complain about as the devices have helped her so much and she has always been proud wearing them</p>
61	Giving them the best education so that they can be independent when they're adults	Making a success - life after leaving a special school
62	To ensure that my son has every opportunity to develop to his full potential. The financial implications on the family (additional costs relating to the long-term maintenance of 2 CIs)	Developmental screening suggests that my son (6 years old), currently finds himself at approx. 4-5 years old in terms of his hearing and verbal communication (He has been part of the hearing world for 2 years). In my opinion bridging the gap is the greatest challenge he currently faces
63	When they're playing with other kids and they play rough it is a stress. Sometimes I have to be next to her every time so that the CIs are not stolen	She is still young - only 4 years old. No apparent challenges
64	Didn't complete	Didn't complete
65	We cannot afford to pay for the CI maintenance	Learning to speak
66	Additional time you need to give to your child. Financially straining -costs of maintenance. Remembering to charge the device overnight. Having to learn all of the information about the CI and processor. Teaching other family members who come into contact with her about the CI. Coming to terms with the fact that my child can never have a 'normal' life like kids her age. The fear of her losing her processor	Stares when we are in public - some kids wanting to touch the device. Not being able to play freely - constantly check and worry about the CI/processor. Closing the learning gap and language gap. She is learning in English in School - it's difficult for her to understand or speak her home language

67	The stress of when she's playing and falls down and bumps her head on the side of the CI	Adapting to the CI
68	Didn't complete	Didn't complete
69	Looking after the CI every day and saving money so that there's money to buy things for the device that is needed e.g. Battery's cable. Disciplining a child with a CI	No challenges thus far
70	The child with a CI needs your full attention. The costs of the CI parts when they're damaged. You must check every day that the CI is working and that the batteries are full all of the time	Having to undergo and attend all of the numerous CI appointments
71	The financial implications of maintaining the devices as well as the fear of the stigma that my child would have to endure. Being different in a mainstream school setting where the devices are unfamiliar	In his younger years at a mainstream school, making friends was the hardest. Now as he gets older and is a teenager, when people look at him oddly because of his implants it is beginning to bother him more
72	Financial implications of replacing broken parts of the CI	Listening in a noisy environment
73	Maintenance of the device as cables, batteries etc. is needed at a certain time and the moment I'm unemployed	No challenges thus far - he adores his device
74	The greatest challenge was always having that thought if my child would speak and to be able to listen to all of the sounds. The other challenge is money and having money to maintain the implant	The greatest challenge was sickness at first - headaches, ear infections. But as time goes on this has changed and his health has improved
75	As with any disability, it is the loss of what than you thought life would be. It is very emotionally challenging on the parents as you feel unprepared and uncertain of what lies ahead. Financially it is very hard even after the implant, it is the maintenance costs and insurance etc. Having to take time off from work to attend sessions. Now needing to send him to a special school which also has more costs involved for fees and transport	Keeping the device on as he is a busy little boy and it then comes off. It's challenging for him to be himself and keep the device on
76	Teaching language, new words and new concepts; need a lot of learning aids to teach new concepts; financial requirements for servicing, new parts and mapping, especially in the initial years after implantation; lack of technical and speech-therapy support in Zimbabwe; getting the teachers to understand the need for extra explanation and repetition to hear, especially when teaching new concepts	Incidents of flat batteries exclude her from communication; sometimes teachers do not give her attention when she hasn't understood a concept
77	Breaking of certain parts or the loss thereof	When batteries go flat before the time during the day
78	Initially tiring to understand my child's needs and wants. I could not communicate with him fully. It was stressful for me as he is my second child and I could communicate with my older child and not fully with my younger	He cannot have fun with friends when in the pool, even though we have an aqua kit. The sound is too loud for him, certain rides restricts him due to the cochlear. But my child has coped very well overall and does not feel sorry for himself
79	Constant support, assistance, guidance with language. Also, what is being taught in school and lack of understanding from teachers and pupils	Functioning and coping in a mainstream school environment because the challenges are many and there isn't a suitable alternative
80	The greatest challenges - implant drawbacks - including breakdown and failures, maintenance of parts and troubleshooting faults. The costs associated with the CI device. Educating others - the need to explain my child's loss of hearing and communication to others	Communication with people who don't know about CIs is a challenge. The fact that people would like to touch the CI and he doesn't like it and withdraws from it.
81	The expenses involved especially as the child sometimes loses the cochlear processor and you have to buy a new one	Looking after the processor at school, especially during sporting activities and that's when the processor usually gets lost
82	Communication	Learning to hear and speak