

COCHLEAR IMPLANTATION IN AN EARLY INTERVENTION PROGRAMME IN SOUTH AFRICA

Störbeck, C. & Moodley, S.

HI HOPES Early Intervention Programme, University of the Witwatersrand

Johannesburg, South Africa

Summary

Since structured information on age of implantation and language development of children with cochlear implants is not available in South Africa, the aim of this research was to begin data collection and analysis of implanted children enrolled in an early intervention programme. 15 children that have been implanted were analysed with regards to implantation age, language modality choice and development, laterality of implantation and schooling. Results indicated that parents are more likely to choose a communication modality that allows for optimal communication development on the path to developing oral language. Large scale studies and research into scholastic achievement of implanted children is needed. Development of clear candidacy criteria and statutory requirements of adherence to criteria needs to be developed and implemented.

Introduction

South Africa has 16-17 babies born with a hearing loss per day (1). However, early detection of hearing loss (at 4 months of age according to HPCSA guidelines) (2) is a rarity with the average age of identification anywhere between 18 months and 3 years (3-5). Since newborn screening is not mandated and due to a lack of resources for screening in the public sector (which services 84% of the South African population) (3), these children are usually identified beyond the age for optimal outcomes. Additionally, many families battle to access early intervention services.

Early intervention for children with hearing loss in South Africa has traditionally consisted of provision of amplification and, when possible, centre-based therapy services. The multicultural and linguistic nature of the South African population and the cultural differences between therapist and child has made provision of therapy in the home language of the child, as well as understanding of and respect for cultural beliefs of the family, difficult. This cultural and linguistic diversity has meant that, to a large extent, early intervention services have been inaccessible to a large portion of the South African population in terms of finances, geography or cultural competence.

The need for accessible early intervention services regardless of financial status, culture and access to health care led to the development of the HI HOPES (**H**ome **I**ntervention **H**earing and language **O**pportunities **P**arent **E**ducation **S**ervices) early intervention programme. This program provides home-based support for families of deaf and hard of hearing infants (ages 0-3yrs with hearing losses ranging from mild to profound, unilateral and bilateral) and is available to all families (both within public and private healthcare sectors) at no cost. The programme provides information, skills and empowerment to the family (in the home

language thus ensuring maximum understanding), in order to equip them to make informed choices and advocate for their child when necessary (5-7)

The impact of hearing loss on the child and the family is significant, making the journey the family needs to travel a complex and challenging one on various levels. Foremost in this journey are the debates surrounding amplification, communication, language choices and schooling options available. This is often magnified by further advancements and choices as we learn and develop greater expertise in the field, and then compounded by the fact that most expertise is focussed and highly specialised with very little interdisciplinary teamwork. Parents acknowledge that this is one of the hardest parts of their journey with a child with hearing loss (8).

In order to ensure that parents participate fully in the holistic intervention of their child (developmentally, linguistically, socially and educationally) HI HOPES aims to consolidate and provide information to parents in an impartial manner, so they can understand all aspects of deafness and raising a child with a hearing loss (6). A central aim is the establishment of interdisciplinary collaboration, allowing parents to make an informed choice regarding their child and the spectrum of choices they are to make over their lifetime.

South Africa is a third world country with access to first world technology due to a good infrastructure, a developing economy and well developed medical and allied professional training. South Africa is one of only two countries on the African continent providing audiology as a university course (9). Thus, the reality is that there is a shortage of skilled audiologists and a reliance on the public health system to provide services to 84% of the population (3). While South Africa has guidelines for early hearing detection and intervention (2), to date there is no policy to ensure these guidelines are being followed or that there is any consistency in the field. Hearing screening pilot programmes implemented in both the public and private sectors (10, 11) indicated a poor return-for-follow-up rate, implying a lack of understanding of the importance of early diagnosis and intervention for children with hearing loss. Despite lack of newborn hearing screening policies and these limitations in audiology service provision (and reflecting the aim to provide quality services with minimum disparity between the public and private healthcare sector), there are 4 private and 3 state-funded cochlear implant programmes in South Africa. The HI HOPES programme, which has been running in 3 provinces in South Africa since 2007 has supported families that have accessed both the private and state-funded cochlear implants.

Materials and Methods

In the first four years of implementation the HI HOPES programme supported over 397 infants and families, of which 17 had cochlear implants. This paper presents longitudinal data of 15¹ of the HI HOPES children with cochlear implants. Data were collected via multiple methods including comprehensive registration documents and information gathered by early interventionists recorded on lesson plans over the extended period of intervention. In addition quarterly assessments of individual language development were conducted using the criterion referenced Language Development Scale. In the next section we will report on these statistics, demographic data, age at implantation, and communication modality chosen by the family.

¹ 2 of the 17 children were implanted after graduating out of the programme and thus longitudinal data on language development is not available. 15 children are therefore reported on.

Results

For the 15 implanted children the demographic data reflects the general demographics of the population of South Africa (see Table 1), with the

<u>Race</u>	
Black	43%
White	36%
Coloured	0%
Indian	21%

Table 1

gender split of 50%. As stated above, 84% of South Africans access public health with only 16 % accessing private health. HI HOPES statistics of the 397 families supported have the same split of 84% accessing public health and 16% using private health services. In our cochlear implant sample the ratio is almost the exact opposite with 71% of implantees in the private health sector. This appears to indicate that, in our sample, cochlear implantation is more accessible to the private health sector .

The HI HOPES programme statistics over the three years reveal that the average age of identification of hearing loss is 18 months and referral to early intervention occurs at 33 months. This indicates that South Africa is not meeting HPCSA guidelines of identification by 4 months and referral to early intervention by 8 months (2). The implanted children show slightly better statistics with an average age of identification of 13 months and referral to early intervention at 21.5 months (see Table 2). The average age of implantation of 24.1 months is at the internationally accepted age of implantation of 2 years (12) to ensure maximum benefit and optimal speech development.

The lack of a significant correlation between healthcare and age of diagnosis ($r=0.49$; $p=0.066$), as well as healthcare and age of implantation ($r= 0.55$; $p= 0.053$) indicates that both the public and private healthcare sector in South Africa are not identifying children with hearing loss early enough to ensure optimal development (12, 13). This implies that it is not only the lack of resources in the public sector that is responsible for late identification, but rather a general lack of hearing screening and lack of awareness across all health platforms.

80% of the children were referred to early intervention services prior to being implanted. This indicates the key role that early intervention services play in providing parents with unbiased information on all options available for the child with hearing loss, and guiding them and supporting them in making an informed choice based on the child and family's unique needs.

Parent Choices

As noted above and recognised internationally, the choices parents make are the largest cause of parental stress in the family journey with a child with a hearing loss (14). The choices and changes of language modality indicates that parents are using any communication modality accessible to ensure effective communication. There was no significant correlation between age of implantation and initial communication modality chosen ($r= 0.30$, $p=0.325$) or the second communication modality ($r= 0.43$, $p=0.143$). This shows that once parents are provided with information on communication modalities in an unbiased manner, they are able to choose what they believe to be of benefit to their child's communication and bonding within the family and ultimately their language development.

	Diagnosis (months)	Referral to Early Intervention (months)	Age of Implant (months)	Age of 2 nd Implant (months)	Health-care
Child 1	8	8	15		Private
Child 2	27	29 (2 month gap)	37		Private
Child 3	21	26 (5 month gap)	33		Public
Child 4	6	8 (2 month gap)	21		Private
Child 5	14	16 (2 month gap)	20	22	Private
Child 6	12	33(21 month gap)	35		Private
Child 7	1	2 (1 month gap)	9	18	Private
Child 8	6	21(15 month gap)	22		Private
Child 9	9	39 (30 month gap)	31 (implant prior to intervention)	49	Private
Child 10	6	26 (20 month gap)	26		Public
Child 11	18	19 (1 month gap)	22	36	Private
Child 12	9	20 (11 month gap)	40		Private
Child 13	8	16 (8 month gap)	38		Public
Child 14	25	35 (10 month gap)	42		Public
Child 15	12	29 (17 month gap)	13 (implant prior to intervention)		Private
MEAN	12.1	21.8 (9.7 month gap)	26.1		
STD DEV	±7.5	±10.6	±10.6		

Table 2

In terms of these choices that parents make, research indicates that communication modality choice is an evolving rather than a static choice, depending on the needs of the family and development of the child (15). Despite the specific preferences and biases from the different professionals involved in the various interventions, parents make decisions (declared on undeclared) based on the need and ability to cope at home with their child. This is evident in the HI HOPES data as well (table 3).

Of the 15 children receiving implants 60% transitioned into using oral language² by the time they graduated out of the programme. One child transitioned to Total Communication as she was a native signer that was implanted at 38 months, one child who has a deaf sibling has remained a Bilingual Bicultural communicator (meaning that the family use both oral and signing communication with him, but that the languages are usually kept separate and not mixed linguistically). One child started off oral, but due to the implant not being successful (as noted by post-implant response to sound) returned to using Sign Language as the primary mode of communication.

Language development scores indicate an initial average receptive language delay of 12 months for all 15 children. For the five children that were diagnosed earlier (11.5 months) and received a longer period of intervention, the initial average receptive language delay of 11 months was reduced to 2 months by the 4th language assessment. The average

	Modality 1	Modality 2	Receptive Language Delay	Expressive Language Delay	Schooling
Child 1	Bilingual Bicultural	Oral	3	3	Mainstream crèche
Child 2	Simultaneous Communication	Simultaneous Communication	17	20	Mainstream crèche
Child 3	Bilingual Bicultural	Oral	16	16	Mainstream crèche
Child 4	Bilingual Bicultural	Oral	1	9	Mainstream crèche
Child 5	Total Communication	Oral	-6	2	Mainstream crèche
Child 6	Total Communication	TC	7	14	Not at school
Child 7	Oral	Oral	5	7	Mainstream crèche
Child 8	Bilingual Bicultural	Oral	12	10	Mainstream crèche
Child 9	Oral	Oral	No data	No data	Mainstream crèche
Child 10	Bilingual Bicultural	Bilingual Bicultural	17	15	Mainstream crèche
Child 11	Oral	Oral	12	12	Mainstream crèche
Child 12	Total Communication	Total Communication	15	19	Mainstream crèche
Child 13	Sign Language	Total Communication	-9	-5	Not at school
Child 14	Oral	Sign Language	16	24	School for the deaf
Child 15	Oral	Oral	-5	12	Mainstream crèche
	MEAN		7.2 months	11.2 months	
	STD DEV		±9.2	±7.8	

Table 3

² The language breakdown of the families are as follows: 8 English, 2 Zulu, 3 Afrikaans, 1 Sepedi and 1 Setswana

expressive language delay was reduced from 14 months to 7 months. Two children achieved above typical receptive language development and one child achieved above typical receptive and expressive language development. Whether these language skills are maintained in language tasks in the academic environment will have to be determined through longitudinal tracking of these children across their schooling career.

The majority of the children (80%) are at mainstream crèches. International guidelines state that it is to be ensured that children with cochlear implants have access to a supportive school environment (16). However, the experience in South Africa has been that parents are expected to find a school that is willing to accept their child. This is coupled with a lack of training for teachers on how to facilitate communication development and provide support to children with cochlear implants. Two children are not attending school due to parents being told not to enrol them at a regular school for the Deaf (as Sign Language is the predominant mode of communication). However, not attending school should be a cause for concern due to concomitant cognitive and developmental delays. One implanted child attends a School for the Deaf due to the implant not being successful.

These and newly implanted children will continue to be tracked longitudinally in order to gain a more in-depth understanding of the full, long term implications of early intervention and cochlear implantation in South Africa. Due to the unique linguistic and cultural diversity in South Africa, the criteria for implantation as well as decisions regarding language modality and education placement are topics that will need to be extensively studied. Preliminary data suggests that empowered parents are able to make decisions that are for the optimal development of the child. The effect of late identification and diagnosis as well as late referral to early intervention for implanted children in South Africa will have to be determined, along with ethical implications. This is the first of many longitudinal studies so that policy regarding best practice for cochlear implantation and post implantation intervention can be developed from actual outcomes data.

References

1. SWANEPOEL DW. In: Early intervention for hearing loss in SA: Cost benefits and current status. Ndiyeva audiology conference; 2008; Carel Du Toit Centre, Cape Town. ; 2008.
2. HEALTH PROFESSIONAL COUNCIL OF SOUTH AFRICA. Early hearing detection and intervention programmes in South Africa Position Statement. Pretoria, South Africa: Health Professions Council of South Africa; 2007.
3. THEUNISSEN M, SWANEPOEL DW. Early hearing detection and intervention services in the public health sector in South Africa. *Int J Audiol.* 2008;47(S1):S23-S29.
4. VAN DER SPUY T, POTTAS L. Infant hearing loss in south africa: Age of intervention and parental needs for support. *Int J Audiol.* 2008; 47:(S1): S30-35.
5. STÖRBECK C, PITTMAN P. Early intervention in south africa: Moving beyond hearing screening. *International Journal of Audiology.* 2008;47(S1):S36- 43.

6. STÖRBECK C, CALVERT-EVERS J. Towards integrated practices in early detection of and intervention for deaf and hard of hearing children. *Int Journal of Audiol.* 2008;153(3):314-321.
7. YOUNG A, CARR G, HUNT R, MCCRACKEN W, SKIPP A, TATTERSALL H. Informed choice and deaf children: Underpinning concepts and enduring challenges. *Journal of Deaf Studies and Deaf Education.* 2006;11(3):322-36.
8. HYDE M, POWER D. Informed parental consent for cochlea implantation of young deaf children: Social and other considerations in the use of the "bionic ear". *Australian Journal of Social Issues.* 2000;35(2):117,117-127.
9. SWANEPOEL DW, STÖRBECK C. EHDI Africa:Advocating for infants with hearing loss in Africa. *Int J Audiol.* 2008;47:S1-2.
10. SWANEPOEL DW, EBRAHIM S, JOSEPH A, FRIEDLAND P. Newborn hearing screening in a South African private health care hospital. *Journal of Pediatric Otorhinol.* 2007;71:881,882-887.
11. SWANEPOEL DW, HUGO R, LOUW B. Infant hearing screening at immunization clinics in south africa. *International Journal of Pediatric Otorhinolaryngology.* 2006;70(7):1241,1241-1249.
12. GRAY RF, JONES S, SHIPGOOD L, COURT I. Paediatric cochlear implantation - the balance between professional caution and urgency of treatment. *Cochl Implts Intl.* 2003;4(1):45-51.
13. YOSHINAGA-ITANO C, APUZZO ML. The development of deaf and hard of hearing children identified early through the high-risk registry. *American Annals of the Deaf.* 1998;143(5):416-424.
14. HYDE M, POWER D. Some ethical dimensions of cochlear implantation for deaf children and their families. *Journal of Deaf Studies and Deaf Education.* 2006;11(1):102-111.
15. WHEELER A, ARCHBOLD SM, HARDIE T, WATSON LM. Children with cochlear implants: The communication journey. *Cochl Implts Intl.* 2009;10(1):41,41-62.
16. http://www.childrenshearing.org/custom/implant_info.html Accessed on 20th June 2011