

**CLIENTS OF THE PRETORIA COCHLEAR
IMPLANT PROGRAMME:
CHARACTERISTICS AND PERCEIVED
OUTCOMES OF CHILDREN AND THEIR
FAMILIES.**

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Dedication

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LIST OF ABBREVIATIONS

ACE	Advanced Combination Encoders
ADD/ADHD	Attention Deficit Disorder/Attention Deficit and Hyperactivity Disorder
BPCIP	Birmingham Paediatric Cochlear Implant Programme
CHRIB	Clinic for High Risk Babies
CI	Cochlear Implant
CMV	Cytomegalovirus
ECI	Early Communication Intervention
ECMO	Extracorporeal Membrane Oxygenation
FDA	American Food and Drug Administration
HL	Hearing Loss
IE	Inclusive Education
JCIH	Joint Committee on Infant Hearing
NICU	Neonatal Intensive Care Unit
NPCIP	Nottingham Paediatric Cochlear Implant Programme
PET	Positron-Emission Tomography
SE	Specialised Education
SIR	Speech Intelligibility Rating Scale
PCIP	Pretoria Cochlear Implant Programme
WS	Waardenburg Syndrome

ABSTRACT

TITLE: CLIENTS OF THE PRETORIA COCHLEAR
IMPLANT PROGRAMME: CHARACTERISTICS AND
PERCEIVED OUTCOMES OF CHILDREN AND
THEIR FAMILIES

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In order to provide evidence demonstrating the efficacy of cochlear implantation in the children enrolled in the Pretoria Cochlear Implant Programme (PCIP), an in-depth analysis of the numerous variables involved in determining each individual child's success with his/her cochlear implant needs to be undertaken. As the PCIP has been operating for over a decade, a standardised database that includes the variables identified by similar cochlear implant programmes world-wide as being related to outcomes of children with cochlear implants and their families, has to be assembled. As the PCIP functions partly as a paediatric cochlear implant programme, an Early Communication Intervention (ECI) approach with the emphasis on the family unit is of critical importance.

To address this need, a comprehensive questionnaire was used in a cross sectional study combining qualitative, and predominantly quantitative methods. The aim was to determine the perceptions of parents/caregivers of children with cochlear implants in the PCIP of the children's outcomes. The questionnaire was

further used to gather relevant data pertaining to children and their families' biographical, medical, environmental, audiological, linguistic and educational histories and current functioning. A total of 45 participants, all mothers of children with cochlear implants, returned questionnaires.

Results indicated that several key factors played a role in determining a positive outcome in the children's audiological, linguistic, social and educational functioning leading to placement in an inclusive educational setting. These included an early age at diagnosis and prompt fitting of hearing aids and subsequent cochlear implantation, the absence of prenatal and perinatal complications including feeding difficulties, a higher level of maternal education, achievement of developmental milestones within normal age norms, the use of an FM system in the primary school phase, access to ECI, the presence of an older sibling to act as a language model, the absence of birth trauma and congenital rubella syndrome as cause of hearing loss, and later (acquired) onset of hearing loss. Children whose cause of hearing loss was non-syndromic and hereditary or unknown, were more likely to have positive outcomes.

The clinical implications for the PCIP were synthesised and presented as a developmental systems model, providing guidelines for the entire process from referral to the cochlear implant programme to exiting of the system. The urgency of the need for a universal newborn or infant hearing screening programme as well as reliable systems of early referral to cochlear implant programmes, emerged strongly in the recommendations of the study.

Keywords: Pretoria Cochlear Implant Programme, outcomes, inclusive educational setting, paediatric cochlear implant programmes, early implantation, mode of communication, developmental systems model, variables affecting success, child with a cochlear implant, families.

OPSOMMING

TITEL:	KLIËNTE VAN DIE PRETORIA KOGLEËRE INPLANTINGSPROGRAM: KENMERKE EN WAARGENOME UITKOMSTE VAN KINDERS EN HULLE GESINNE.
NAAM:	MARGUERITE ANNE JESSOP
STUDIELEIER:	DR A KRITZINGER
MEDE-STUDIELEIER:	MEV P VENTER
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GRAAD:	M.KOMMUNIKASIEPATOLOGIE

Ten einde bewyse te lewer van die effektiwiteit van kogleëre inplantings in die kinders wat deel is van die Pretoria Kogleëre Inplantingsprogram (PKIP), asook om die verskeidenheid van uitkomste beter te verstaan, moet 'n in-diepte analise van elke individuele kind se sukses met sy/haar kogleëre inplanting uitgevoer word. Aangesien die PKIP vir meer as 'n dekade funksioneer, moet 'n gestandaardiseerde databasis, wat inligting aangaande veranderlikes deur soortgelyke kogleëre inplantingsprogramme wêreldwyd geïdentifiseer as verbandhoudend met uitkomste van kinders met kogleëre inplantings en hulle gesinne, saamgestel word. Aangesien die PKIP gedeeltelik as 'n pediatriese kogleëre inplantingsprogram funksioneer, moet 'n vroeë kommunikasie-intervensie (VKI) benadering gevolg word, waarin die klem op die gesinseenheid van kritiese belang is.

Om hierdie behoefte aan te spreek is 'n omvattende vraelys gebruik in 'n deursnit studie met 'n kombinasie van kwalitatiewe, en hoofsaaklik kwantitatiewe metodes. Die doel was om die persepsies van die ouers/sorggewers van hulle kinders met kogleëre inplantings in die PKIP se uitkomste vas te stel. Die vraelys is verder gebruik om relevante inligting te versamel oor kinders en hulle

gesinne se biografiese, mediese, omgewings-, oudiologiese, linguistiese en opvoedkundige geskiedenis en huidige funksionering. A totaal van 45 deelnemers, almal moeders met kinders met kogleêre inplantings, het vraelyste teruggestuur.

Resultate toon dat verskeie sleutelfaktore 'n rol gespeel het in die positiewe uitkomst van kinders se oudiologiese, linguistiese, sosiale en opvoedkundige funksionering wat gelei het tot plasing van sekere kinders in 'n insluitende opvoedkundige omgewing. Hierdie faktore sluit in 'n vroeë ouderdom van diagnose en spoedige passing met gehoorapparate gevolg deur kogleêre inplanting, die afwesigheid van prenatale en perinatale komplikasies insluitend voedingsprobleme, 'n hoër vlak van die moeders se opvoedkundige peil, die gebruik van 'n FM sisteem tydens die laerskool jare, toegang tot VKI, die teenwoordigheid van 'n ouer kind in die gesin om as taalmodel te dien, die afwesigheid van trauma gedurende geboorte en kongenitale rubella sindroom, en latere ontstaan van gehoorverlies (verworwe gehoorverlies). Kinders by wie die oorsaak van die gehoorverlies nie-sindromiese, oorerflike gehoorverlies of 'n onbekende oorsaak was, het in meer gevalle positiewe uitkomst getoon.

Die kliniese implikasies vir die PKIP is gesintetiseer en voorgestel as 'n ontwikkelings-sisteem model, wat riglyne bied vir die hele proses vanaf verwysing na die kogleêre inplantingsprogram, totdat die sisteem verlaat word. The dringendheid van die behoefte aan 'n universele neonatale/baba gehoorsiftingsprogram sowel as betroubare sisteme vir vroeë verwysings na kogleêre inplantingsprogramme het sterk in die studie se aanbevelings na vore gekom.

Sleutelwoorde: Pretoria Kogleêre Inplantingsprogram, uitkomst, insluitende opvoedkundige konteks, pediatriese kogleêre inplantingsprogramme, vroeë inplanting, kommunikasiewyse, ontwikkelings-sisteem model, veranderlikes wat sukses beïnvloed, kind met 'n kogleêre inplanting, gesinne.