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Barriers to Early Pediatric Cochlear Implantation in Kenya

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Abstract

Background: Cochlear implantation is the best management option for children with profound hearing loss and has received no benefit from hearing aids. Early implantation for these children is associated with good speech and language outcomes. **Objectives:** To determine the barriers to early pediatric cochlear implantation. **Methodology:** A qualitative cross-sectional study was conducted at Hearing Implants Centre in Nairobi Kenya from August 2022 to February 2023. The target population was 40 children who had undergone cochlear implantation under the auspices of Cochlear Implant Group of Kenya but data was only collected from 30 of them. The remaining were ruled out because 3 were unreachable over the phone, 5 refused to participate and 2 did not meet the inclusion criteria. **Results:** Patient file reviews and parental telephone interviews were conducted to collect information and analyzed using Microsoft excel and presented using graphs, tables and pie charts. The analysis of the gender showed 46.67% were male and 53.33% were female. Analysis on newborn screening showed that none had it done. The mode age of hearing loss suspicion was between the ages of 2 - 3 years. The hearing loss suspicion done was done by the mothers at 20 children the reminder being 3 by the father, 1 by a family friend, 4 by the school-teacher and 2 by the child's grandmother. A total of 17 participants noted a delayed in speech and language, 9 noted that the child did not respond to loud sounds, 4 noted that the children did not turn when called. Once hearing loss was identified, 73% saw the ENT, 17% saw a pediatrician, 7% went to see an Audiologist, and 3% saw a speech therapist. The mode age at diagnosis was 1.5 years. The mode age at implantation was 5 years. The mode time from diagnosis was 2 years. **Conclusions:** This study sought to investigate the barriers to pediatric cochlear implantation in Kenya. From the results it was determined that factors such as lack of newborn screening, high cost of cochlear implantation, lack of awareness have led to late cochlear implantation.

Keywords

Cochlear Implants, Pediatric, Barriers, Newborn Hearing Screening, Early Implantation

1. Introduction

According to the World Health Organization (2023), more than 1.5 billion people make almost 20% of the population be living with hearing loss. They estimated that in the next 27 years there will be 700 million people with disabling hearing loss. This means that 1 in every 10 people will have a disabling hearing loss.

The impact of the hearing loss if unaddressed can affect aspects of life such as communication and speech, cognition, education and employment, a lot of children in the developing countries do not often get schooling, social isolation, stigma, hearing loss impacts the society and economy.

Early identification is important as hearing loss often remains undetected which in cases of infants and adults can have a negative consequence on rehabilitation outcomes and cognition.

The universal screening program for newborns has shown great benefits in terms of early age of diagnosis, development of receptive and expressive language, while screening is an important part, it must be accompanied by a follow up and rehabilitation program.

WHO estimated only 3% of the hearing aid need is met. The impacts of hearing loss can be met by having early intervention and early detection. Interventions include hearing aids, cochlear implants, specialized education programs and sign language being taught to children and their families. There is a lot of benefit that can be gotten from speech therapy and aural rehabilitation [1].

According to Owino (2020), the prevalence of disability was of 0.9 million people, being more women than men. As seen in **Figure 1**, the highest rate was recorded in Western, Central and Eastern parts of Kenya. The lowest disability prevalence rates are found in the north eastern part of Kenya and Nairobi, Wajir being the lowest [2].

Represented in **Figure 2**, the prevalence rates of people with hearing difficulties range from 0.9% to 0.1% and communication difficulties from 0.5% to 0.1%.

A cochlear implant is an electronic device that improves hearing by bypassing the damaged portion of the inner ear to deliver sound signals to the auditory nerve. The signals created by the implant move through the auditory nerve to the brain. The brain interprets those signals as sounds. CI is an option for people who have severe to profound hearing loss from inner ear damage, who are able to get little to no benefit from hearing aids. Cochlear implants consist of various parts: the outer part called speech processor that fits behind the ear which has a microphone that picks up sound from the environment. The CI has a transmitter

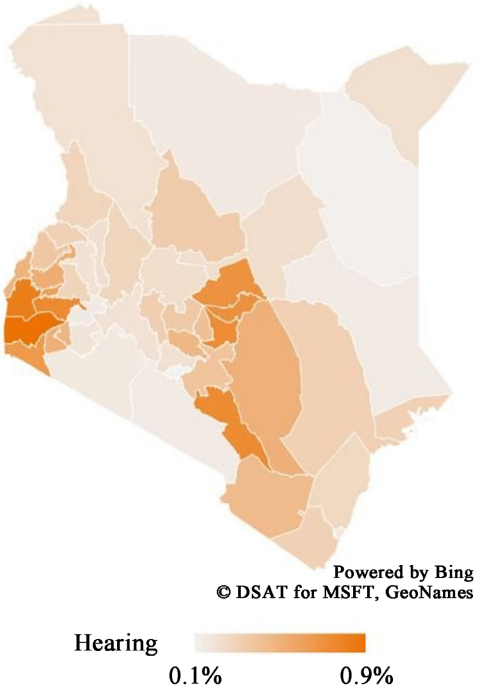

Figure 1. Distribution of people with disability by domain and residence: Hearing Difficulties. Owino, E. (2020). Status of disability in Kenya. Statistics from the 2019 census. Devinit. https://www.devinit.org/documents/727/Status-of-disability-in-Kenya__IF.pdf

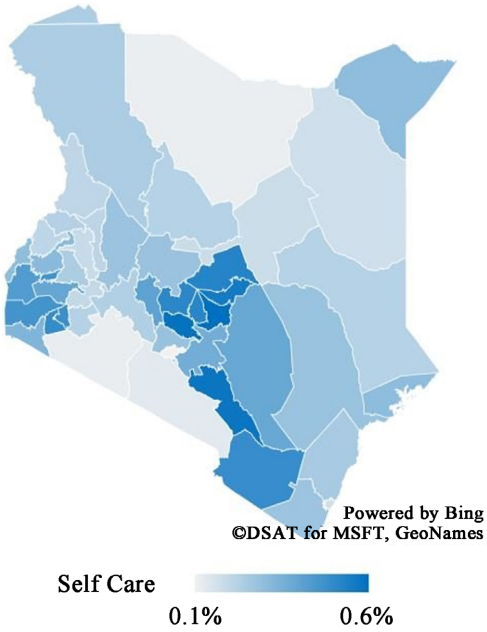

Figure 2. Distribution of people with disability by domain and residence: Communication difficulties. Owino, E. (2020). Status of disability in Kenya. Statistics from the 2019 census. Devinit.
https://www.devinit.org/documents/727/Status-of-disability-in-Kenya__IF.pdf

and receiver stimulator which receives signal from the speech processor and converts them into electric pulses. It also has an electrode array which is a

grouping of electrodes that collect impulses from the stimulator and send it to the auditory nerve.

1.1. Cochlear Implant Candidacy and Management in Kenya

Early implantation leads to better outcomes for children with bilateral severe to profound sensorineural hearing loss. The Cochlear Implant Program in Kenya is run by Cochlear Implant Group of Kenya (CIGOK).

The group consists of 3 ENT Surgeons, 2 Audiologists, 2 Speech and Language Therapist, 1 Neurologist and 1 Administrator.

1.1.1. Candidacy Criteria

The following candidacy criteria are what they use to determine if a patient is a candidate for cochlear implantation: profound sensorineural hearing loss in children. Age at implantation can be as young as one year. In Kenya, the youngest implanted child was at the age of 12 months and the oldest done pre lingual was done at 8 years old. They receive little or no benefit from hearing aids. The parents must have realistic expectations in terms of speech acquisition and are counselled on this. In Kenya, it is a requirement for the cochlear implanted children to have two sessions per week of speech therapy and the parents have to commit to attend these sessions. Parents also need to be ready to take the child to mainstream school.

1.1.2. Emergency Referral for Cochlear Implantation: Meningitis

When hearing loss is determined of bilateral severe to profound sensorineural hearing loss post meningitis as soon as the implantation is scheduled.

1.1.3. Diagnosis to Intervention Process in Kenya

In Kenya, in order for you to qualify for cochlear implantation you need to have followed the following procedure:

See the Audiologist to determine the severity of the hearing loss by doing the Brainstem evoked Response Audiometry (BERA), Pure Tone Audiometry including air and bone conducted thresholds, Otoacoustic Emission Test, test of speech perception including word and sentence recognition. Children who who score poorly in open-set word and sentence evaluation are good candidates for cochlear implantation. Confirm limited benefit from hearing aids. Recommend sequential vs. simultaneous implantation. Work with family to select the appropriate external processor. The purpose of the audiological evaluation is to look at a patient's pre-operative hearing, communicative status and use of prosthetic device. The results are then used to determine the expected outcome after cochlear implantation. After cochlear implantation, they assess internal device function, program processors, facilitate equipment maintenance. Usually setting up of the cochlear implant speech processor takes place approximately four weeks after implantation.

See the Otolaryngologist, who will review via MRI the temporal bones to confirm that the patient's anatomy can support implantation (rule out lesions such

as acoustic nerve lesions, significant cochlear malformation, etc.). Recommend additional evaluations due to bilateral sensorineural hearing loss (e.g., EKG, urinalysis, genetic and ophthalmologic consultations). Perform cochlear implantation procedure and provide post-operative monitoring as needed. High resolution imaging (CT and MRI) is used to estimate the patency of the cochlea and identify any variations in the anatomical variations that may affect the insertion of the electrode. Imaging may not always catch everything but based on the clinical history you can anticipate for example if a patient has a history of meningitis or otosclerosis this is commonly associated with cochlea ossification. The degree of the insertion may affect the implant performance and it also can increase facial nerve stimulation. Individuals with complete cochlear ossification who require a "drillout" of the bone to provide a space to lay the electrode do not achieve as high a level of auditory perception with their implant (Rauch *et al.*, 1997) [3].

See the Speech-Language Pathologist, who assesses prelinguistic communication-eye contact, eye gaze, gesture, pointing, vocalization, object & physical manipulation, turn taking, imitation, & willingness to maintain engagement. Pragmatic skills: communication for request, comment, gain attention or information, protest, choose & demonstrate social greetings. Coming up with a plan for rehabilitation of the child before implantation makes the intergration of the implant easier it also makes sure that the progress of the child is not hindered by lack of or very little follow ups.

A neurologist review, whereby the neurologist reports on birth and neonatal history, immunization status, developmental milestones, genetic study, screening for anomalies involving sensory and motor system outside those routinely associated with communication deficits, this report is important, as it enables the audiologist to manage the expectations of the patients in terms of developing speech. According to a study done by Cejas (2015) they looked at the benefits of cochlear implantation for children with autism spectrum disorder, developmental delay, CHARGE syndrome, cerebral palsy, learning disorders, Usher syndrome, Waardenburg syndrome, and attention deficit/hyperactivity disorder. They determined that children with little to no cognitive impairment (e.g., Waardenburg syndrome, attention deficit hyperactivity disorder) have better outcomes than those with greater deficits in intellectual functioning (e.g., autism, CHARGE syndrome). Given these results, it is critical to evaluate these children's developmental milestones to provide early implantation and intervention, appropriately counsel families regarding realistic expectations for the implant, and facilitate family adaptation. [4]

2. Literature Review

Yoshinaga *et al.* (2018) research demonstrated that it was critical that identification of hearing loss and early intervention must occur within the first six months of life in order for the majority of children with congenital hearing loss to main-

tain language development commensurate with their normal hearing peers, indicating that there is a sensitive period of communication development that requires access to language development early in life [5].

According to John Hopkins Medicine (n.d.) hearing loss in children can be present at birth (congenital) or develop later in childhood (acquired). Congenital hearing loss can be hereditary (genetic) or caused by infections during pregnancy, including infection with cytomegalovirus or rubella. Hearing loss is more common in babies who are in the neonatal intensive care unit (NICU). Hearing loss can be an isolated condition or a feature of a syndrome that causes additional symptoms. Genetic testing can help determine the cause of hearing loss in some cases. Acquired hearing loss can be caused by infectious diseases, such as meningitis or recurrent ear infections, as well as trauma and certain medications [6].

Lester *et al*. (2011) took a group of 59 congenitally deaf children coming from a University medical center hospital in a state with mandatory newborn hearing screening (NBHS). Their main outcome measurements were based on the age at implantation. The results showed that thirty-four patients received implants at or before the age of 2 years with the average being 14 months and twenty-five patients received implants after the age of 2 years. They determined that the factors that significantly determined the age at implantation type of health insurance and the presence of NHBS other factors such as slow referrals for care and parental delays also played a huge role in the odds of receiving the implant before age 2. They concluded that increase in awareness on parents and primary care providers ensuring emphasis on the importance of early intervention and referral to an implant center would lead to reduced delays in children receiving CIs. They also concluded that more focus should be placed on children with associated risk factors such as premature births, etc. [7].

Armstrong *et al*. (2013) took a sample size of fifty-seven CI recipients of which 42 were patients with pre-lingual SNHL. SNHL criteria included: 18% cochlear dysplasia. 17% GJB2/GJB6, 10% acquired, 9% extreme prematurity and 46% idiopathic. The average age of implantation was 15 months. They concluded that the patients who had public insurance received diagnosis later than those with private insurance. Cochlear implant team members identified that delays in approval by the insurance and medical comorbidities as reasons for delayed implantation. The study determined that the most significant factor for late implantation of above 2 years is caused by parental delays in terms of delayed/ missed appointments or reluctance for evaluations for surgery. They concluded that it is important to educate families [8].

Dettman *et al*. (2016) looked at variables associated with pediatric access to cochlear implants. A sample size of 802 was selected of which 417 children were implanted under 3 years of age. They determined that the age at CI surgery reduced was linked to the implantation of NBHS. For those children implanted under 3 years, early CI was linked to higher family socio-economic status. Later CIs was associated with progressive hearing loss. Children with a Connexin 26

diagnosis received CIs earlier than children with premature and low birth weight history. They also determined the steps for pre-CI used affects the delay for surgery. The steps are as follows: 1) birth to diagnosis/Identification of hearing loss, 2) MRI scans to implant surgery. They concluded that implementation of NBHS is instrumental to early cochlear implantation [9].

In a study done by Gordon *et al.* (2022) on delayed cochlear implantation in congenitally deaf children, their selection criteria included children implanted at 3 and above and excluded those with a prior unilateral cochlear implant and those with sudden or progressive hearing loss. Variables included newborn hearing screen results, age at diagnosis, age at implantation and post op evaluation results. From those 31 children, the average age of implantation was 6.2 years and they were able to identify some reasons for the late implantation which was patients did not undergo NBHS, amplification with hearing aids given though the severity of the hearing loss and the speech assessment indicate that cochlear implants are more appropriate, delay from primary care doctors to refer patient for CI surgery, late diagnosis [10].

According to Chu *et al.* (2016), children who receive early intervention and cochlear implants at a young age often receive greater benefit in learning and understanding spoken language as the brain is provided with auditory stimulation during a critical learning period. This early advantage can lead to improved literacy and academic performance.The factors known to affect language outcomes in Pediatric Cochlear implant (CI) users are:

- Early Intervention: children who received EI with an aural/oral emphasis had significantly better receptive and expressive language outcomes compared to those who received EI with a sign emphasis.
- Age at implantation: children who were implanted earlier received less frequent and lower doses of EI services compared to those who were implanted later.
- Socio-economic advantage: children from families with relatively greater socio-economic advantage receive greater frequency and doses of EI.
- Maternal education and family involvement: higher levels of maternal and family involvement are notably related to better language outcomes and earlier intervention [11].

In a study done by Colletti *et al.* (2005) on cochlear implantation at under 12 months, they focused on 10 children who were implanted at less than 12 months old. The results were all the children had a CAP score of 3 within 6 months of cochlear implant activation, onset babbling had occurred within 1 month to 3 months of activation. They concluded that the earlier the activation of the cochlear implant the closer the results were to the outcomes of normally hearing children. Children acquire better audio-phonologic parameters, which enable them to be as similar as possible to their normal hearing peers [12].

3. Methodology

This was a qualitative cross-sectional study from August 2022 to February 2023.

The main objective was to identify what are the barriers facing Kenya to having early pediatric cochlear implantation in children with severe to profound hearing loss.

Given that it is critical that identification of hearing loss and early intervention must occur within the first six months of life in order for the majority of children with congenital hearing loss to maintain language development commensurate with their normal hearing peers, indicating that there is a sensitive period of communication development that requires access to language development early in life.

We therefore looked at the age of child at diagnosis, age of child at cochlear implantation, the duration of time between diagnosis and cochlear implantation intervention, if there was hearing intervention before cochlear implantation.

The study was conducted at Hearing Implants Centre in Nairobi, Kenya. The target population is congenitally deaf children who have undergone cochlear implantation under the Auspices of Cochlear Implant group of Kenya.

The inclusion criteria included all consenting congenitally deaf children who have had cochlear implantation under the Auspices of Cochlear Implant group of Kenya.

The exclusion criteria included any child with post lingual deafness and patients who do not consent.

The sample size was determined from Hearing Implants Centre database. Convenient sampling will be done by collecting data from the patient files identified from Hearing Implants Centre database that meet the inclusion criteria and by administering the questionnaire by calling their parents or caregivers.

The research team consists of the Principle investigator. Selection of participants will be generated by going through the patient files and identifying the children who meet the criteria of congenitally deaf children with severe to profound hearing loss. Consent will be obtained from each parent or caregiver. A brief history will be taken from the files and the questionnaire will be administered. The patients will be allocated numbers *i.e.* 001, 002, 003 and the results will be entered in the data collection sheet. The equipment used was a laptop and telephone. All the data collected will be coded and stored in a lockable cabinet with restricted access to maintain confidentiality. The data will be analyzed using Microsoft Excel and the data will be summarized using graphs and pie charts.

The participants will receive full disclosure of the nature of the study. No extra cost will be encountered by the patient. The cost for airtime will be incurred by the principle researcher. Confidentiality will be maintained by making their bio data anonymous with codes and questionnaires locked and secure. At the end of the study, the raw data will be coded and backed up for further study. The results will be published in scientific journals and presented in medical conferences, regular print and electronic media where necessary for the benefit of the lay public. There are no conflicts of interest or otherwise in this study by the principle investigator, supervisors and the hospital or with the original manu-

facturers of the implants. The patient will have the right to withdraw from the study without victimisation.

The study will be disseminated to the medical fraternity through publications made in at least one peer reviewed journal. The results will be presented in scientific meetings and recommendations sent to the national ear and hearing care committee (Table 1).

The study is set to be carried out within the following timeline:

4. Results

A total of 40 cases were identified from the Hearing Implants Centre database. Out of the 40 patients, only 30 were evaluated. The remaining were ruled out because 3 were unreachable over the phone, 5 disagreed to participate and 2 did not meet the inclusion criteria as the children were post-lingual. The parents of the implanted children were administered a questionnaire that captured information on socio demographic, newborn screening, age of hearing loss suspicion, who suspected the hearing loss, what problem was noted, first healthcare professional they visited, how long was the hearing aid usage, age at implantation.

4.1. Socio Demographic Characteristics

The children were split according to their gender. The results were that 46.67% were male and 53.33% were female.

4.2. Newborn Screening

Out of the 30 children none underwent newborn hearing screening assessment.

4.3. Age of Hearing Loss Suspicion

The parents were asked at what age did they suspect their child has a hearing loss and the results showed that suspicion in 26.67% of the target population was at <1 year, 10% of the target population was between the ages of 1 - 2 years, in 36.67 % of the target population was between the age of 2 - 3 years, and 13.33% of the target population was between 3 - 4 years and 13.33% of the population between 4 - 5 years. This shows that most hearing loss suspicion is done between the ages of 2 - 3 years (Figure 3).

Table 1. Timeline.

PERIOD	ACTIVITY
August 2022-November 2022	Proposal writing
December 2022	Proposal Presentation
January 2023	Ethics Approval
February 2023	Data Collection
February 2023	Data analysis
February 2023	Final presentation

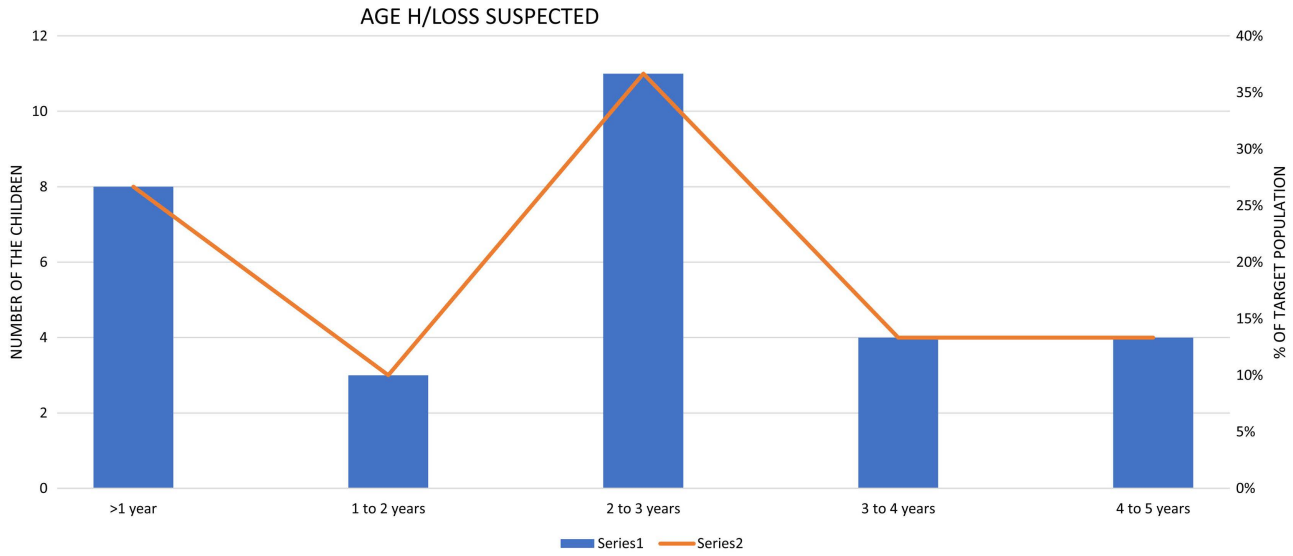

Figure 3. Age at which hearing loss was suspected.

4.4. Who Suspected the Hearing Loss

The parents were asked who detected the hearing loss first and the results analysis showed that out of the thirty participants, hearing loss was suspected in 1 case by a family friend, 20 by the child's mother, 3 by the child's father, 4 by the class teacher and 2 by the child's grandmother.

4.5. What Problem was Noted

The parents were asked what did they notice that made them think that maybe their child had a hearing problem. Results showed that 17 participants noted a delay in speech and language, 9 noted that the child did not respond to loud sound, and 4 noted that the children did not turn when called.

4.6. Who was the First Healthcare Professional Contact Person

The parents were asked once hearing loss was suspected which healthcare professional did they take their child to. The analyzed responses of the questionnaire showed 73% saw the ENT as the first contact person, 17% went to a Pediatrician first, 7% saw the Audiologist as the first contact person, 3% saw the speech therapist (**Figure 4**).

4.7. Age at Diagnosis

The parents were asked when their child was diagnosed with bilateral severe to profound sensorineural hearing loss. The analyzed responses showed that at 1 year only 1 child was diagnosed making it 3.33% of the target population, at 1.5 years 7 children were diagnosed making it 23.33%, at 2 years 5 children were diagnosed making it 16.67%, at 2.5 years 6 children were diagnosed making it 20%, at 3 years 5 children were diagnosed making it 16.67%, at 4 years 4 children were diagnosed making it 13.33%, at 4.5 years 1 child was diagnosed making it 3.33%,

at 6 years 1 child was diagnosed making it 3.33%. The mode age of diagnosis was 1.5 years of age (Figure 5).

4.8. Age at Implantation

The mode age of implantation is 5 years with 10 children. At 3 years of age, 9 children were implanted, at 4 years 7 children were implanted, at 6 years 1 child was implanted, at 7 years 1 child was implanted and at years 2 children were implanted. All these children were all bilateral severe to profound sensorineural with a delayed speech and language (Figure 6).

4.9. Time from Diagnosis to Cochlear Implantation Intervention

This was determined by taking into account two factors when the diagnosis was done and when cochlear implantation was done. The time in between was then calculated which produced the following results:

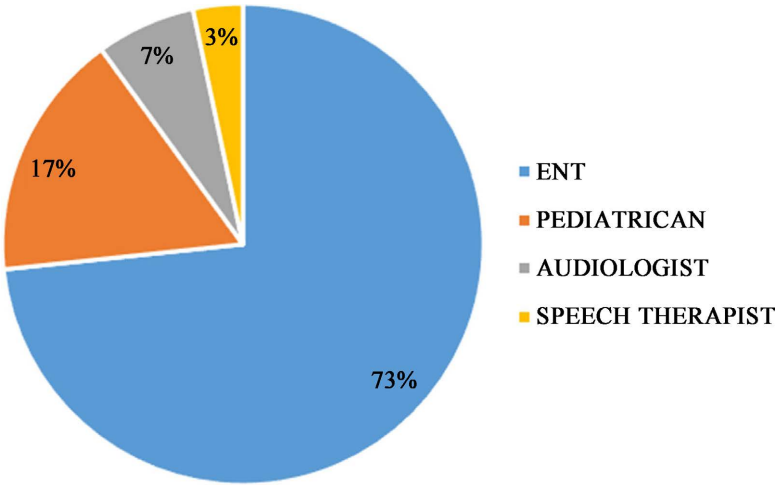

Figure 4. First contact healthcare professional.

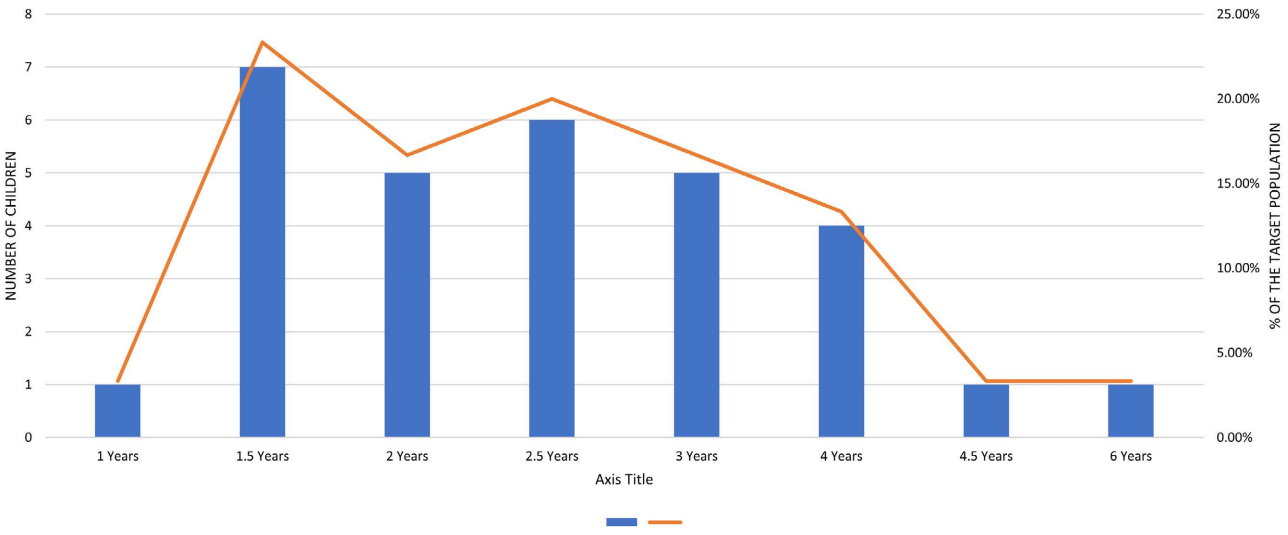

Figure 5. Age at diagnosis.

In <1 year 2 children were implanted, 1 year 8 children were implanted, 1.5 years after diagnosis 4 children were implanted, 2 years after diagnosis 9 children were implanted, 2.5 years after diagnosis 1 child, 3 years was 3 children, 4 years was 1 child, 4.5 years was 1 child and 5 years was 1 child (Figure 7).

5. Discussion and Recommendations

5.1. Discussion

In Figure 3 we look at the age at which hearing loss was suspected. We see that this is mostly between the ages of 2 to 3 years which is when children begin school. Suspicion was mostly by the parents and for some it was the teacher. Even with the children having delayed speech and language development, most of the parents believed that it was just a delay and speech will just develop. A lot

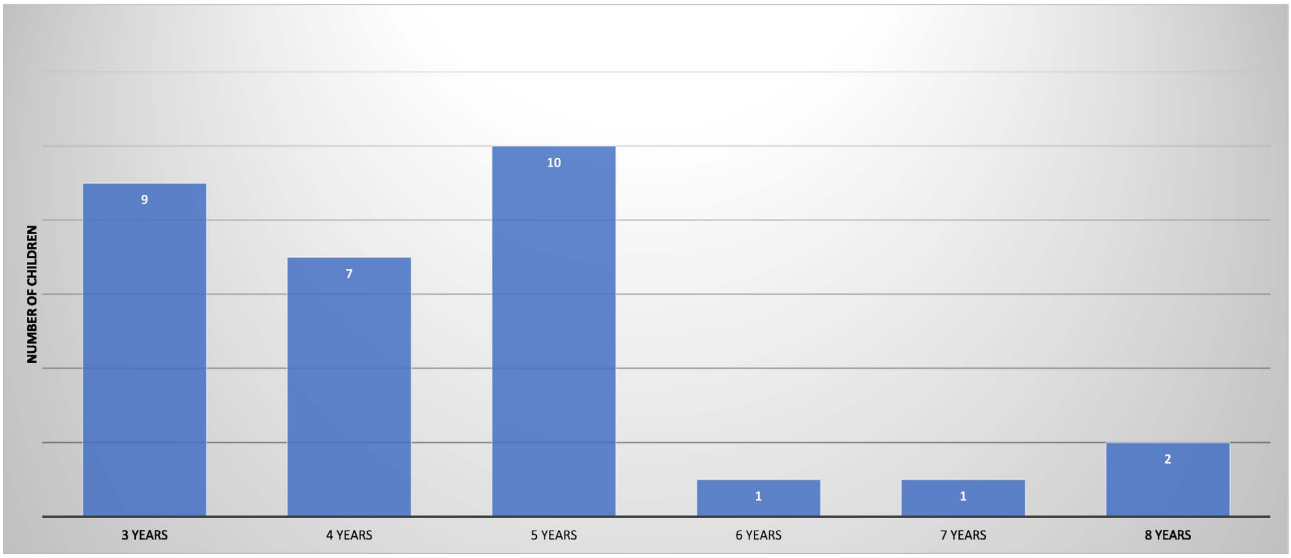

Figure 6. Age at implantation.

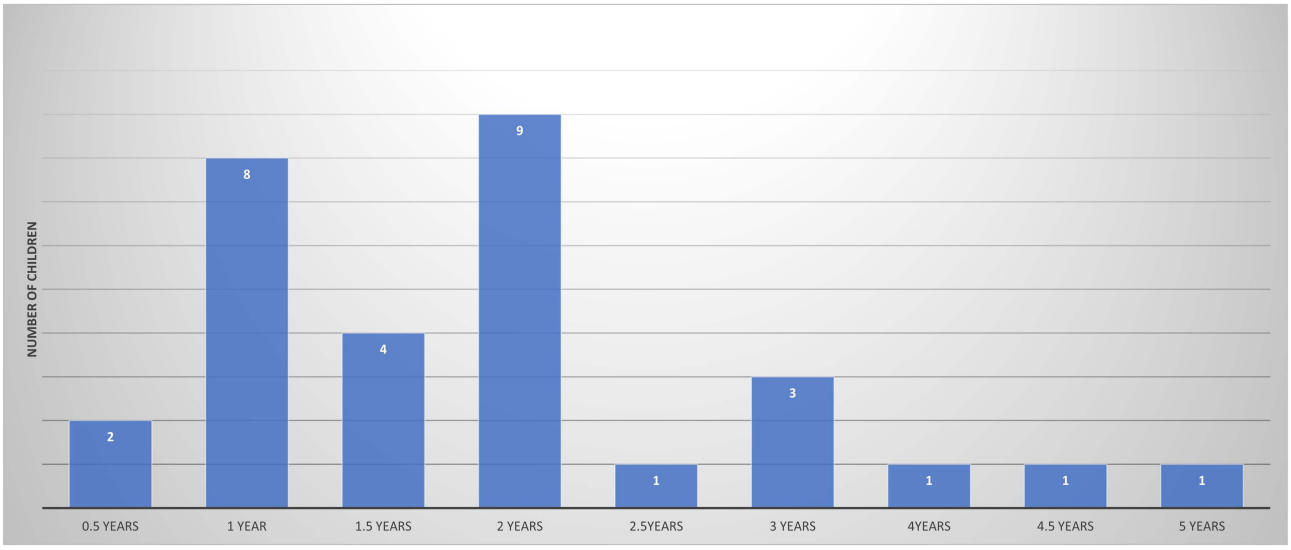

Figure 7. Time from diagnosis to cochlear implantation.

of the children had other developmental issues such as autism, others were born premature, others were in and out of hospital for ear infections, and other comorbidities. So most parents focused more on the other comorbidities and hearing loss remained undetected for longer.

In **Figure 4** we see that 73% of the parents first contact with a healthcare professional is with an ENT mostly for other illnesses. These parents also indicated that there is also lack of awareness in the healthcare community as 60% of them said when they told their concerns to their doctor's they were told to give it time the child will develop speech. This also then leads to late age of diagnosis as seen in **Figure 5**.

Niparko *et al.* (2010) determined that age at implantation is considered to be the biggest determinant of pediatric cochlear implantation outcomes. They determined when the children are implanted under the age of 2.5 years they had higher scores of vocabulary, expressive syntax and pragmatic judgements than children who are over 2.5 years [13].

As shown in **Figure 6**, the mode age of implantation was 5 years of age which was 33.33% of the participants. On discussing with the participants, 100% indicated that they lacked awareness about how to identify a hearing loss.

Our data confirmed the importance of newborn hearing screening. All the children in the study did not have newborn hearing screening done. Lester *et al.* (2011) determined that children who received newborn hearing test had a 68% reduction of receiving a CI after the age of 2 years than those children who did not receive it. Currently in Kenya newborn hearing screening is not a mandatory requirement in the hospitals. For pediatric hearing assessment is mostly done by a referral basis so if the primary care giver does not recommend this hearing loss may remain undetected for much longer.

According to **Figure 7** we see that the mode duration of time taken between diagnosis and when cochlear implantation was done was 2 years with 23.33% of the children having the hearing loss diagnosed at 1.5 years. Once diagnosis is identified and cochlear implantation is recommended they then have to begin the process for implantation, which includes MRI and CT scans, speech therapist assessment, some cases require neurological review, other instances counselling of the parents then surgery. Implementation of newborn hearing screening is vital to early cochlear implantation. For some parents the time taken between diagnosis and when cochlear implantation was done was increased by parental denial, some did not understand the urgency of implantation, for others it was too expensive and they could not come up with the money.

5.2. Recommendations

5.2.1. Newborn Hearing Screening

Yoshinaga *et al.* (2018) determined that there is a critical age of identification of hearing loss for the majority of children with a congenital hearing loss to develop speech, which is commensurate with their peers. Newborn hearing screening

is associated with early diagnosis and early intervention and it also decreases the time interval for cochlear implantation. Early intervention increases speech intelligibility and improved language outcomes. This then indicates that newborn hearing screening should be mandatory in Kenya. Normally after birth parents are given an immunization card, I would recommend that Pediatric screening and newborn screening be added onto this book [5].

5.2.2. Awareness Campaigns

Lester *et al.* (2011) determined that increase in awareness on parents and primary care providers ensuring we emphasise on the importance of early intervention and referral to an implant center would lead to reduced delays in children receiving CI's. Delays from primary care doctors to refer a patient for cochlear implant surgery can lead to late diagnosis which then leads to late intervention with a cochlear implant. In order to greatly reduce such outcomes, the first step is creating awareness in the health care professional by providing information during scientific seminars, having the criteria and what signs to look for be placed in the medical journals and newsletters. During the medical degree course work they can emphasise more on cochlear implantation and the criteria for implantation [7].

This then will translate to the parents to be made aware about hearing loss during the doctor visits and the regular checkups for their children.

For the parents who get the diagnosis at an early age but opt to do it later due to assumption that there is no age limit for cochlear implantation. It is important that the parents are counselled appropriately so they understand what the delay will cost the child in terms of developing speech.

There is not much local information on C.I for the general public. The Kenya cochlear implant team can create a website for people to access information about C.I and include testimonials from already implanted children. Also they can have more presence in the mainstream media by advocating more for early implantation through talk shows and hosting seminars for the medical personnel.

It is also important to come up with a way to reach also parents and guardians who are located in the rural areas. This can be done by reaching out to the local clinics and midwives in the rural towns.

It is also important to train teachers to be able to identify hearing impairment in children. The teachers are then able to recommend the children to go for a hearing test.

5.2.3. Lobbying Insurance Companies

The cost of cochlear implantation is high and a high number of insurances in the country do not cover. The National Health insurance fund caters fully for a selected group which includes civil servants. These are people who work for the government and the police and military forces. This is huge but not everyone belongs to this group. Lobbying will be important to request them a way to help the remainder.

6. Conclusion

This study sought to investigate the barriers to pediatric cochlear implantation in Kenya. From the results we were able to determine that factors like newborn screening, finances, and lack of awareness have led to late cochlear implantation. The data suggests that a special focus should be placed on the outcomes above and this will likely limit delays in children receiving CIs.

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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Abreviations

C.I: Cochlear Implant
NBHS: New-Born Hearing Screening
SNHL: Sensorineural Hearing Loss
CAP: Categories of Auditory Performance
HA: Hearing Aid
H/LOSS: Hearing Loss
MRI: Magnetic Resonance Imaging
CT: Computed Tomography
WHO: World Health Organization

Appendices

Appendix I: General Patient Information Form and Consent form

My name is Irene Wairimu Ndegwa. I am the principal researcher in this study. The study has been approved by the SAERA Ethics and Research Committee.

I am conducting a study on the BARRIERS TO EARLY PEDIATRIC COCHLEAR IMPLANTATION IN KENYA.

The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research:

1) Your decision to participate is entirely voluntary.

2) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal.

3) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities.

We will give you a copy of this form for your records.

May I continue? YES/NO

How will you participate?

a) I will ask you a series of questions from a questionnaire.

b) You will incur no extra financial costs and the confidentiality will be maintained at all times.

c) There will be no monetary benefits for participating in the study and it will be purely on a voluntary basis.

d) You will reserve the right to withdraw from the study at any time without discrimination.

In Case of any questions or inquiries, contact the following:

Principle investigator

Irene Wairimu Ndegwa

SAERA

P.O. Box 216-00202

Email: irynnimo@gmail.com

Mobile Phone: 0708289130

Consent Form

Patient study number: ……

Consent by patient:

I……. freely give consent to take part in the study conducted by Irene Wairimu Ndegwa, the nature of which has been explained to me by her. I have been informed and I have understood that my participation is entirely voluntary and I understand that I am free to withdraw my consent at any given time if I so wish and this will not in any way alter the care being given to me. The results of the study may directly be of benefit to me, my kin and other patients.

…….

Signature

Date…….

Appendix 2: Data Collection Tool

Code……..... Age (years) …….. Sex Male/Female Residence……

Occupation/s.....……

Other relevant history.....

1. Did your child ever get newborn or infant screening? If yes at what age?

2. At what age did you first suspect your child has a hearing loss?

3. Who suspected the hearing loss?

4. Once you suspected what action did you take?

5. Which healthcare professional was your first contact?

6. At what age was your child diagnosed with a hearing loss?

7. It appears you took a while from the time you suspected to when you got your child diagnosed why was this?