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Delayed Cochlear Implantation in Children: A Parental Survey

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Received: 22 / 02 / 2022; Accepted: 18 / 04 / 2022

الملخص:

المقدمة: فقدان السمع غير المعالج عند الأطفال يمكن أن يؤثر سلبًا على تطور الكلام واللغة بالإضافة إلى التطور الأكاديمي والاجتماعي والعاطفي والسلوكي. وجد أن زراعة القوقعة الإلكترونية في وقت مبكر قبل عمر 4 سنوات، خلال الفترة الحرجة لنمو السمع المركزي أمر بالغ الأهمية للحد من التأثير السلبي للحرمان السمعي على اكتساب المهارات السمعية والقدرة على التواصل، وتعطي نتائج أفضل من إجرائها في عمر متأخر.

الهدف: تحديد الأسباب والعوامل المرتبطة بتأخير زراعة القوقعة لدى الأطفال المصابين بفقدان السمع الخلقي.

منهجية البحث: أجريت الدراسة بأثر رجعي واستهدفت جميع الحالات التي أجريت لها عملية زراعة قوقعة إلكترونية في مركز الجراحات التخصصية؛ في مدينة بنغازي خلال الفترة بين أكتوبر 2017 ويونيو 2021. ورُوحِعَت السجلات الطبية وجمع البيانات الديموغر افية والحيوية. استُبْعِدَ الأطفال الذين يعانون من إعاقات أخرى والذين فقدوا قدرتهم السمعية بعد اكتسابهم اللغة وما بعد التهاب السحايا. وكذلك استُطْلِع رأي أولياء الأمور الذين خضع أطفالهم لعملية زراعة القوقعة بعد سن 4 سنوات عن طريق الهاتف حول أسباب التأخير في زراعة القوقعة الإلكترونية.

النتائج: شملت العينة 74طفلًا، نسبة الذكور (%51) والإناث (%49) كانت تقريبًا متساوية. وكان متوسط العمر عند الزراعة 47 شـهراً (تراوح من 21 شـهرًا إلى 99 شهرًا). اثنان وأربعون في المائة (%42) من الأطفال تلقوا القوقعة الإلكترونية بعد عمر الأربع سنوات، ثلثًا هؤلاء الأطفال يعيشون خارج بنغازي. وكان لدى معظم الأطفال على الأقل عامل خطر واحد مسبب لضعف السمع. وغالبية أولياء الأمور أشاروا إلى أكثر من عامل كان سبباً في تأخر التدخل المبكر.

الاستنتاج: تبين أن اتخاذ الوالدين القرار بشأن زراعة القوقعة أمر معقد ويتأثر بعدة عوامل، منها معتقداتهم وآراؤ هم الشخصية (مثل الإنكار والوصمة الاجتماعية والخوف من الجراحة) ونقص الوعي حول وجود تقنية القوقعة الإلكترونية والتكاليف المالية. يوصى بإنشاء وتنفيذ برنامج وطني لمسح سمع حديثي الولادة لغرض الكشف المبكر للتغلب على الكثير من الإعاقات السمعية وتقليل مضاعفاتها مما يوفر على الدولة تكاليف باهظة.

الكلمات المفتاحية: زراعة القوقعة، أطفال، ضعف سمع، تدخل مبكر، مرحلة حرجة، مطاوعة الدماغ.

Abstract

Background: Untreated childhood hearing loss can adversely affect speech and language development as well as academic, social, emotional, and behavioral development. Early cochlear implantation before the age of 4 years, within the critical period for central auditory development, was found to be crucial in reducing the negative impact of auditory deprivation and appears to provide better outcomes than late implantation.

aim: The aim of this study was to determine the reasons behind late cochlear implantation in children with congenital severe to profound sensorineural hearing loss.

Methods: A retrospective study was conducted on all cases who received cochlear implants at Specialty Surgical Center, Benghazi, Libya between October 2017 and June 2021. Patients' medical records were reviewed and demographic and clinical data were collected. Children with other disabilities, and post-lingual and post-meningitis implantees were excluded from the study. Information about the reasons for the delay in receiving cochlear implants was obtained over the phone from parents whose children underwent cochlear implant surgery beyond the age of 4 years.

Results: A total of 74 children were included, 38 boys and 36 girls. The mean age at implantation was 47 months. Forty-one percent (41%) of children were implanted after 4 years of age. Two-thirds of these children live outside Benghazi. Most of the children had at least one risk factor for hearing loss. The majority of parents reported more than one reason for the delayed implantation.

Conclusion: It is found that parent decision-making for cochlear implantation is difficult and affected by many factors, including their personal beliefs (denial, social stigma and fear of surgery), lack of awareness about the existence of cochlear implant technology, and financial constraints. It is recommended that a national newborn hearing screening program is established for early detection and intervention and cost-effectiveness.

Keywords: age, children, cochlear implant, early intervention, hearing loss, neuroplasticity.

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1. INTRODUCTION

Over the past three decades, cochlear implantation (CI) has become widely accepted throughout the world as an effective auditory rehabilitation technology for individuals with severe to profound hearing loss across the age span. According to the National Institutes on Deafness and Other Communication Disorders (NIDCD), more than 736,900 people have received cochlear implants worldwide.^[1]

Hearing loss is rising, as per World Health Organization (WHO). About 466 million people worldwide have disabling hearing loss, and 34 million of these are children. The number of people who need hearing rehabilitation over the next thirty years is expected to increase to 700 million.^[2] Globally, the prevalence of congenital hearing loss varies from 0.3 to 15 per 1000 live births.^[3] In developing countries that lack newborn hearing screening coverage, the incidence of early onset hearing loss is higher than in developed countries.^[4] The incidence of sensorineural hearing loss is 10 times higher in high-risk infants than full-term healthy neonates.^[5]

Since the establishment of newborn hearing screening programs in many developed countries, more and more infants born with hearing loss are identified each year.^[6] As a consequence, age at implantation is decreasing over recent years and evidence supporting earlier pediatric cochlear implantation is growing.

Many recent studies have highlighted the advantages of early cochlear implantation on speech and language development in children with profound hearing loss. Children implanted under 2 years of age developed receptive and expressive language skills comparable to their normal hearing peers and showed better auditory outcomes than children implanted at a later age.^[7] Moreover, cochlear implantation during infancy (prior to 12 months of age) provides the ability to enhance the development of the auditory cortex and to achieve normal speech and language milestones.^[8,9] Due to the importance of early intervention for children diagnosed with bilateral severe to profound sensorineural hearing loss, this study aimed to identify factors contributing to delayed pediatric cochlear implantation in Libya.

2. MATERIAL AND METHODS

A retrospective study was conducted on all patients who received cochlear implants at the Specialty Surgical Center in Benghazi, Libya between October 2017 and June 2021. Patients' medical records were reviewed and demographic and clinical data were collected, including address, parental educational level, cause of hearing loss, and age at cochlear implantation. Children with other disabilities, as well as post-lingual and post-meningitis implantees, were excluded from the analysis. Children who didn't undergo cochlear implant surgery until after the age of 4 years were targeted in this study. Information about the reasons for the delay in receiving cochlear implants was obtained from parents of the target population by asking an open-ended question over the phone after giving verbal consent. The survey responses were analysed by "Google forms" and interpreted. Descriptive statistics including frequencies and percentages were computed for the research variables.

3. **RESULTS**

A total of 74 unilaterally implanted children were included, 38 boys and 36 girls. Only 6 children (8%) were non-Libyans. Nearly half (47%) of the children live outside Benghazi. The mean age at implantation was 47 months (ranging from 21 months to 8 years). Forty-one percent (41%) of children were implanted after 4 years of age. Table 1 summarizes the subjects' demographic characteristics. Further analysis of the distribution of the geographic location of children who received cochlear implants after the age of 4 years, as observed in Figure 1, revealed that the majority (about two-thirds) reside outside Benghazi. According to the 2015 Libyan Bureau of Statistics and Census Annual Bulletin, (p.25)^[10], about 47% of our study target population had no access to a specialty center in their region (See Appendix).

Table 1: Demographic characteristics of study subjects

	Frequency Percentag				
Gender					
Male	36	49%			
Female	38	51%			
City	City				
Benghazi	39	53%			
Outside Benghazi	35	47%			
Nationality					
Libyan	68	92%			
Non-Libyan	6	8%			
Age at implantation)n				
Mean	Mean 4 years				
Range	21 months to 8 years				
Before 2 years	4	5%			
2 - 4 years	40	54%			
>4 - 6 years	20	27%			
After 6 years	10	14%			

Note. N = 74

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Figure 1: Geographic location of study subjects based on the age at implantation



Figure 2: Identified risk factors for congenital hearing los

A total of 30 parents of children who received their cochlear implants late were surveyed over the phone. About two-thirds (67%) of the parents have bachelor's degrees or vocational training. Table 2 presents the parents' educational levels. The majority (83%) of parents reported more than one reason for the delayed implantation. As much as 63% of parents attributed parental delays and/or healthcare system delays as barriers to early cochlear implantation. Less than half (47%) of parents mentioned financial constraints as a cause for delayed cochlear implant surgery. Half (50%) of parents reported other reasons like traveling abroad seeking treatment for their children, recent conflict and political instability, living far from specialty hospitals, and the presence of other medical conditions. Table 3 lists the causes of delayed intervention in children with congenital profound hearing loss as stated by their parents.

Education Level	Father	Mother	Percentag e
Primary school	1	-	1.67%
Middle school	6	3	15%
Secondary school	4	2	10%
College graduate	6	15	35%
Vocational training	10	9	32%
Uneducated	-	1	1.67%
Dead	3	-	5%

Table 3: Reasons	for delayed	intervention a	is reported by	parents
			1 .	1

Reason	
Parental causes/factors	19/30 (63%)
Lack of awareness Denial of hearing loss itself/Social stigma Social issues Fear of surgery Family indecision (reluctance) The child is too young, will talk later Lack of trust in local hearing health care providers Wait and see (hope with hearing aids)	10/30 5/30 3/30 2/30 4/30 1/30 1/30
Hearing healthcare system reasons	19/30 (63%)
Delayed diagnosis Lack of age-appropriate hearing test Different professional opinions/recommendations Surgical wait list	16/30 3/30 7/30 3/30

Financial restrictions	14/30 (47%)
For hearing aids/aural rehabilitation For cochlear implant	
Other reasons	15/30 (50%)
Geographic location Related to the civil conflict Travel abroad Medical conditions	2/30 8/30 10/30 3/30
Delay due to more than one reason	25/30 (83%)

4. **DISCUSSION**

Pediatric cochlear implant candidacy criteria have continuously changed since its FDA approval for children in 1990. Age at implantation was reduced to 18 months from \geq 24 months in 1998; then lowered to 12 months in 2000, and recently further reduced to 9 months in 2020. These continuous updates are driven by the positive impact of early cochlear implantation on the maturation of the auditory system and the development of speech perception.^[11-13]

Neuroplasticity - the ability of the brain to change and adapt to a new situation (either external or internal stimulus) like maturation, injury, or learning - occurs during a

restricted timeframe during development called the critical period. The critical period for the central auditory system is before 6-7 years of age with the first 4 years of life being the best age for children to receive cochlear implants as it is the period of greatest neural plasticity.^[7,11,14-16]

Furthermore, cochlear implantation in young infants is considered surgically safe with no serious anesthesia or postoperative complications reported.^[9,18] Karltorp and her colleagues in Sweden (2019)^[19] assessed the surgical safety of cochlear implantation in children younger than 12 months of age and concluded that there were no increased surgical risks and interestingly, it led to normal language development in children implanted before 9 months of age.

Early implantation improves auditory and communicative skills necessary for the development of receptive and expressive language skills. Early cochlear implantation has a positive impact on quality of life; it is associated with better employment opportunities and educational achievement. It also provides benefits to society by lowering the cost of care for congenitally profound hearing loss individuals.^[11,20] Age at implantation is considered the best predictive factor for speech intelligibility performance in prelingually hearing impaired children.^[16]

Over the last two decades, newborn hearing screening was implemented in many countries, with the goal of screening all infants before 1 month of age; confirming the diagnosis of hearing loss no later than 3 months of age; and ensuring initiation of essential intervention by 6 months of age.^[21] Neumann et al. $(2020)^{(3)}$ indicated that the average age of diagnosis of congenital hearing loss was reduced significantly to less than 5 months in screened children compared to 35 months in non-screened

children. As a result, children with hearing loss began to receive early intervention before 7 months of age, in contrast to at 35 months before the start of newborn hearing screening programs.

As seen in the results section, parental factors and healthcare system delays were the two most frequently reported reasons for delayed implantation. This is supported by numerous studies that evaluated factors that may delay the process of getting cochlear implants in children. Results of a Kothari et al (2015)^[22] study in Indore, India indicated that lack of information about the availability of cochlear implant technology and unawareness of the benefits of early intervention among parents were the most commonly identified causes for receiving implants late. In addition to Kothari et al's (2015) findings, Armstrong et al. $(2013)^{\left[23\right]}$ confirmed that parental-related delays like poor compliance with appointments/follow-up visits, reluctance toward evaluations, and fear of surgery were the most common causes associated with a delayed intervention. Other parental factors are found to be responsible for the delay in seeking medical help, like uneducated parents, and denial or nonacceptance of hearing loss.^[20,22,24,25] However, regarding illiteracy, our study did not show a significant effect of parents' education level on why our target group received cochlear implants after 4 years of age.

Along with parental delays, CI surgery timing may be influenced by healthcare system delays, which may lead to delayed confirmation of hearing loss. Slow referral to cochlear implant centers, long duration of preoperative evaluation, wait-time for sedated auditory brainstem response (ABR) testing appointments, and lack of age-appropriate audiometric testing were determined as barriers to early cochlear implantation.^[20,26-28]

Although cochlear implant surgery was funded by the government for all CI recipients in this study, a significant number of parents reported financial restrictions as a factor for the delay in getting cochlear implants. Further analysis revealed that the high cost of hearing aids, care and cost of cochlear implant external device parts and replacements, and post-implantation rehabilitation services were a burden for many families.^[29]

Coexistence of medical conditions for example middle ear disease or neurological/developmental problems noted to delay confirmation of hearing loss and therefore lead to late intervention even despite the successfulness of early detection of

prelingual hearing loss with the implementation of newborn hearing screening in Canada.^[27]

Less than a third (27%) of parents mentioned the recent conflict as a barrier to early cochlear implantation. Reviewing the Post Conflict Assessment of Hospitals report by El-Zanaty & associates $(2012)^{[30]}$ revealed that about 16% of hospitals in Libya were entirely damaged post-2011 conflict in terms of human resources, technical equipment, adequacy of the allocated budget, support from authorities, and drug supplies.

Our research pointed out several challenges for early cochlear implantation in our community, including:

• Lack of national newborn hearing screening

• Lack of awareness of hearing loss within the community

• Shortage of hearing healthcare professionals: experienced cochlear implant surgeons, pediatric audiologists, speech-language pathologists, trained hearing aid technicians

• Lack of interdisciplinary teams

No standard clinical audiological assessment protocols

- Unavailability of age-appropriate testing
- Cost of hearing aids

Additional factors have been identified in the literature that can delay the process of cochlear implantation such as no newborn hearing screening program, socioeconomic status, age of parents, number of children, experience with previous CI child, access to audiology center, transportation, hearing aid use, and duration of preoperative assessment.^[20,26,31-33] These factors were not thoroughly studied here, so future research is suggested to investigate their role in delaying cochlear implantation in Libya.

With the significant drop in the age of identification of hearing loss since the implementation of early hearing detection and intervention programs in some regions of the world, it is strongly recommended to establish a national newborn hearing screening program to early identify infants at risk for hearing loss who need further audiological testing and monitoring.

In general, the limitations of this study are attributed to its retrospective design, which may lead to recall bias as some of the information studied was recalled by parents. Also, the small sample size and limited data from one center may affect the ability to generalize the results. Additionally, the lack of previous studies on the same topic in our region could be considered a limitation. All of these limitations may make the results not representative and inconclusive.

5. CONCLUSION

The pediatric cochlear implant decision-making process is complex and influenced by several factors. In summary, placing special focus on children with associated risk factors, establishing newborn hearing screening, educating parents and primary care providers on the importance of early identification, and supporting families of children with hearing loss would likely limit delays in intervention and ensure access to rehabilitation services in a timely manner.

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Appendix

عد المستشفيات بليبيا حسب نوعها لسنة 2015 Number of Hospitals In Libya According to Type ,2015

Tobruk			Suburban	General	Central	Specialist	المنطقة
	540	3	2	1	0	0	طبرق
Dama	632	3	2	0	1	0	درنة
Al gebel Elakdar	752	4	2	0	1	1	الجبل الأخضر
Al marj	615	4	3	1	0	0	المرج
Benghazi	3645	15	2	0	3	10	بنغاز ی
Alwahat	60	1	0	1	0	0	الواحات
Ajdabia	342	3	1	0	1	0	اجدابيا
Alkufra	180	2	1	1	0	0	الكفرة
Sirt	283	2	1	0	1	0	سرت
Aljoufra	196	2	1	1	0	0	الجفرة
Misurata	1360	6	1	1	2	2	مصراته
Almrgb	864	6	3	2	1	0	المرقب
Tripoli	6497	15	0	1	4	10	طرابلس
Aljfara	402	2	0	0	0	2	الجفارة
Zawia	616	2	0	1	1	0	الزاوية
Zwora	843	4	0	3	1	1	زوارة
Algabla Algarbi	1110	9	6	2	1	0	الجبل الغربي
Nalut	552	5	3	2	0	0	نالوت
Sebha	540	2	1	0	1	0	سبها
WadialShati	240	3	2	1	0	0	وادي الشاطئ
Murzuk	180	2	1	1	0	0	مرزق
WadialHaya	120	1	0	1	0	0	وادي الحياة
Ghat	120	1	0	1	0	0	غات
Total	20689	97	32	21	18	26	المجموع