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Treating options for deaf children

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Dedicated to the 6-month old angel that changed my life forever (PVV).

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ABSTRACT

Background/Aim: Although already established for metabolic diseases, universal screening programs for hearing have not been widely applied, despite the high incidence of profound congenital hearing loss. The present paper aims to review the current knowledge on the available treatment options for deaf infants.
Data synthesis: The acquisition of spoken language is a time-dependent process. For a child to become linguistically competent, some form of linguistic input should be present as early as possible in his/her life. Although objective audiological methods have certain weaknesses, their combination can give an accurate diagnosis in most of the cases. Later on, behavioural audiometry should confirm the diagnosis. Additional disabilities also need to be considered, although such assessments may be difficult in very young children. Congenital deafness should be managed by a multidisciplinary team (MDT). Affected infants should be bilaterally fitted with hearing aids, no later than three months after birth. They should be monitored and if they are not progressing linguistically, cochlear implantation (CI) should be considered after thorough preoperative assessment. Following CI, the vast majority of congenitally deaf children develop significant speech perception and production abilities over time. Age-at-intervention and oral communication, are the most important determinants of outcomes. Realistic parental expectations are also essential. The continuous support of a dedicated pediatric CI program, in collaboration with local professionals, and community members, are also necessary to achieve a successful outcome.
Conclusion: Congenitally deaf children should be detected early, and referred timely for the process of auditory rehabilitation to be initiated. Strong support by community members, and professional bodies, can maximize the future earnings of pediatric auditory rehabilitation with hearing aids and cochlear implants.

1. Introduction

The development of spoken language is one of the most spectacular accomplishments of a child and one of the main characteristics of human beings. Language is central to most aspects of the child's life, and plays an important role in the acquisition of a sense of self, and the achievement of social identity. In addition, the ability to share information regarding intentions, ideas and feelings plays a vital role in human interaction, and finally results in social integration [1].

It is widely accepted that if listening is not developed during the critical language learning years, the acquisition of spoken language is severely compromised [1]. Profound congenital sensorineural hearing loss (SNHL) is not so infrequent, as it is estimated to affect 1 to 2 of every 1000 newborns in western countries. Despite the relatively high incidence, universal hearing screening programs have not been widely applied, and most countries have only established screening programs for high-risk infants. By contrast, metabolic diseases such as phenylketonuria, with an incidence of approximately 1 in 15,000 births, are routinely included in newborn screening programs.

Early identification, referral, and diagnosis of children with hearing loss are necessary to initiate the process of auditory rehabilitation, which can help the hearing-impaired child to receive the maximum possible amount of auditory information during the critical periods for spoken language development, thus reducing the effects of auditory deprivation.

The aim of the present paper is to review the current knowledge on the available treatment options for auditory rehabilitation of profoundly deaf infants. The etiology of congenital SNHL, and its impact on all aspects of a child's development, both individually, and as a member of a family, will also be explored.

2. General considerations

2.1. The etiology of congenital SNHL

More than 50% of cases of congenital SNHL are thought to be of genetic origin. Up to 80% of cases are inherited in a recessive manner,

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and up to 70% are non-syndromic. The end of 20th century has brought to light a very important medical discovery; a mutation in the gap junction beta-2 (GJB2) gene, which controls protein connexin 26, an important regulator of potassium flow in the inner ear, and is responsible for 30–50% of congenital non-syndromic SNHL. In addition, around 300 known syndromes demonstrate HL (most commonly SNHL) as one of their clinical characteristics (Table 1).

Non-genetic congenital SNHL can be the result of intra-uterine infections, most commonly from CMV, herpes simple, rubella, syphilis, or toxoplasma. In addition, meningitis in prelingual children, though not congenital, can lead to profound hearing loss (and central processing disorders), and should be addressed in the same manner, as the aforementioned infections, or even quicker, due to the ensuing obliteration in the cochlea that may limit treating options, as cochlear implantation may become very difficult.

Non-infectious causes of congenital SNHL include hyperbilirubinemia, administration of ototoxic agents, and auditory neuropathy. The latter condition (also termed auditory dyssynchrony) is again a remarkable finding of the end of the 20th century and does not probably represent a single disease, but rather a spectrum of pathologies that affect the auditory pathways. The prevailing pathophysiologic mechanism, the dyssynchrony of neural discharges, seems to cause severe impairment in the patients' hearing abilities, without affecting the main amplification function of the inner ear.

2.2. The development of speech

One of the main characteristics of human superiority over the other species is the ability to increase knowledge through the use of language. Language, however, does not just happen in an instance, but is a time-dependent process.

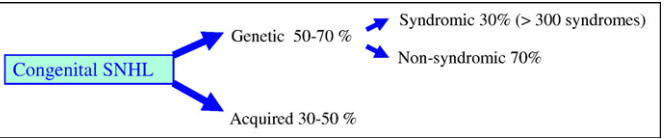
If children from birth and onwards are exposed adequately to spoken language and have efficient interactions with adults, which are almost always present in the early lives of normally developing infants in all cultures, receiving enough language input for successful language development is rarely a problem for them. Spoken language acquisition is a robust process for normally developing children, which fails only in cases of extreme deprivation. However, this is not the case for many profoundly deaf children who are not able to develop effective spoken language without amplification and rehabilitation.

The development of language appears to follow a hierarchical progression. It includes first the sound of words-phonology. It is then followed by the meaning of words-semantics, and finally by the rules of grammar–syntax. Semantics and syntax are, therefore, dependent on appropriate and timely phonological input. They can, however, develop further in the years to come. Both intrinsic (hearing, processing, neuroplasticity) and extrinsic mechanisms (linguistic input, social and cultural influences) affect the development of spoken language. Language acquisition seems, in fact, to be a product of both nature and nurture [1,2].

2.2.1. Animal studies

Animal development is hypothesized to be influenced by extrinsic and intrinsic processes. The former is imprinting, and results in the recognition of the natural genitor, by the newborn animal. The latter is the critical period; a time–period during which imprinting occurs, but beyond which imprinting cannot be efficiently reproduced.

Table 1
Etiology of congenital SNHL.



The consequences of inadequate auditory input on the vocal output of animals have been extensively studied. Deafness seems to be followed by deterioration in the segmental and supra-segmental properties of vocal output in many animal species.

Early deafness has a number of vocal output consequences that are not necessarily linguistically bound. Alterations in speech production may be expected in overall intensity levels, the range and mean fundamental frequency, the overall duration of segments, and the complexity of the syllabic-like structures. If auditory feedback is critical for developing or controlling these variables in species other than humans, one might also anticipate that similar parameters will be adversely affected in humans [3].

2.2.2. Human studies

Many studies have shown that hearing-impaired children use excessively high pitches and inappropriate variations in the fundamental frequency of their voice. Reduced sound repertoires, containing multiple errors, are also characteristic of profoundly hearing-impaired children. Substitutions of one sound for another, omissions, and distortions frequently occur. Hence, errors appear on both segmental and supra-segmental levels. Consonant and vowel productions also are replete with errors, and contribute to reductions in overall speech intelligibility [3]. Visible consonants produced in the front of the mouth are used more frequently, than less visible consonants produced in the back of the mouth. Front vowels appear to be produced with more errors than back vowels, thus suggesting that profoundly hearing-impaired children may have difficulty with the position of the tongue.

With regard to vocabulary growth, although there is not a universal agreement as to the extent of normal variation between hearing children, estimates range from 2000 to 10,000 words for a 5-year-old. Most children encounter new words by the tens of thousands per year, and learn thousands of them. For many children the speech of parents and peers may be the single most significant source of vocabulary growth. By comparing these numbers to those of a deaf child, some indication is given of the ensuing handicap as many profoundly deaf children have a very limited vocabulary without amplification and rehabilitation. In fact, in the absence of any rehabilitation, most congenitally deaf children will have little concept of the existence of spoken language, and effectively no experience of it, by the time they reach school age. By the time these children reach the end of their school career, and again in the absence of appropriate rehabilitation, their English vocabulary may not actually exceed that of a 6-year-old hearing child. Of course some of the related studies are relatively old and have certain weaknesses; for example they do not take into account sign language that many profoundly deaf children use.

2.2.3. Neuroplasticity

The presence of critical periods in animals and humans means in effect that there are time-periods when the central nervous system is more dependent, and also more susceptible ("plastic"), to environmental stimuli, in order to undergo function-specific changes.

With regard to phonology this may very well be between 6 months of fetal life through the 12 months of infancy [2]. Indeed, the 26 week old human fetus has been shown unequivocally to have the auditory capacity to detect sound, and auditory discriminative abilities have been demonstrated in normally hearing neonates, who have a preference for the voice they were mostly exposed to in utero. However, phonological specialization, as evidenced by the repertoire of phonemes which can be discriminated, is limited at the end of the first year of life. In addition, the speech perception capacities, which are exhibited by infants during the first six months of life, appear to be language-universal, rather than language-specific. Neurophysiological studies further suggest that the critical period for semantical organization may occur before the 4th year of life, whereas the development of syntax can extend up to the late teens [4].

The limits of linguistic neuroplasticity are outlined by case-series of children undergoing brain surgery, as well as examples from everyday life. Cases in which people reach puberty without having learned a language are rare. Examples include the wolf-children (who were found in the woods, brought up by animals), and some unfortunate children who have been subjected to extreme social and linguistic deprivation. Some of these children develop words or even immature sentences, but they are permanently incapable of mastering the full grammar of the language. Such cases contrast with children who are subjected to much shorter periods of deprivation. One such child, named Isabelle, was six and a half years old, when she escaped from the silent imprisonment of her grandfather's house. A year and a half later she had acquired 1500–2000 words, and produced complex grammar sentences. By contrast, the Aveyron child in southern France, a boy discovered in the woods at the age of 13, never developed speech, despite his normal hearing, and the intensive efforts of his teacher Jean-Marc Gaspard Itard. The remarkable difference between Isabelle and the Aveyron child may very well attributed to the younger age at which Isabelle started being exposed to spoken language, in comparison with the teenager. However, neuroplasticity, although decreases with age, never ends, and the situation is very complex, as numerous factors may also contribute to the final outcome.

2.2.4. Other aspects of deafness

As peers constitute a significant part in a child's life, there is a strong possibility that hearing-impaired children will begin to perceive themselves as 'different' from an early age, and run the risk of becoming stigmatized.

If the child's life is revolving around his/her disability, attempts to overcome it may continually reinforce the disability. In an environment that promotes the idea that a disability should be overcome, these children are always aware that they are outsiders. They are, however, not merely outsiders, but outsiders attempting to be on the inside [5]. In addition, any socially and psychologically undesirable behaviour that may be found in deaf children may very well be attributed to the social isolation, and the lack of adequate means of communication (sign language would be an effective alternative).

2.3. Diagnosis of profound congenital SNHL

Early referral, timely diagnosis and appropriate management of infants with profound SNHL are now considered of paramount importance in the developed world. It is, therefore, essential that the related methods accurately reflect the audiogram.

Even though clinical audiology has made a remarkable progress during the last decades, none of the three objective tests that may be applied efficiently in infants (otoacoustic emmissions — OAEs, auditory brainstem responses — ABRs and auditory steady state responses — ASSRs) are perfect. However, their combination provides in most cases a very reliable diagnosis that should be confirmed by behavioural audiometry later on.

In addition to auditory assessment, a reliable evaluation of the prelexical domains of infant development is very important [6]. The examination of complex prelinguistic vocalization types by measures of vocal development is necessary to document the progress of children who are expected to acquire speech at later-than-typical ages. However, the nature of prelinguistic vocalizations itself has long been a subject of speculation and model building, therefore, such assessments can only be considered as adjunctive to formal audiologic evaluation.

Additional disabilities (i.e. autism), which may not be able to be detected in infancy, also need to be taken into account before (and sometimes even after) establishing the diagnosis of profound SNHL. Diagnostic problems in this case are caused by the fact that a fundamental problem in cognition, language, or behaviour may have secondary effects on other areas, thus producing difficulties in separating cause from effect. Language and problem-solving milestones seem to provide the best insights into the infant's intellectual potential in doubtful situations [7].

2.4. Profound congenital SNHL and family

Apart from scientific dilemmas, reliable diagnosis and efficient rehabilitation are very important to parents and family as they may experience significant emotional stress during hearing assessment and rehabilitation.

3. Management of profound congenital SNHL

3.1. Multidisciplinary approach

The multidisciplinary team (MDT) for the management of congenital (or early acquired) SNHL includes the Paediatrician, the ENT Surgeon, the Genetic Scientist, the Clinical Audiologist, the Speech and Language Therapist, the Psychologist, the Teacher for the Deaf, and the Social Worker.

The role of the Paediatrician is central, because he/she is the first Specialist, who will come across the child and family. The Paediatrician frequently needs to take the parents through the related examinations, and co-ordinate the management of potentially co-existing illnesses.

The Specialist ENT Surgeon is responsible for the accurate and reliable diagnosis of deafness. He/she should be in a position to intervene surgically, or to decide a more conservative approach. The ENT Surgeon is responsible for the audiologic follow up of the child, and the related rehabilitation.

The Clinical Audiologist is responsible for the audiometric testing, and the re-tuning of hearing aids or cochlear implants, during the child's regular follow ups.

The Genetic Scientist can provide information to the Team, about the potential genetic basis of the child's deafness, as well as expected additional disabilities. He/she should also provide genetic counseling to the family, especially in view of future pregnancies.

The Speech and Language Therapist will assess the Team's intervention on speech development and language learning.

The Teacher for the Deaf has to design an educational program, according to the child's needs and potentials, taking the views of the family, and the limitations of the educational system into account.

The Psychologist will deal with the child's personal problems, and address the child's emotional problems, social relationships, and integration.

Finally, the Social Worker can assist in social and financial considerations for the child and family.

3.2. Hearing aids

Profound hearing loss, by definition, ranges from a hearing threshold of 90 dB to the region of 120 dB. People with 120 dB hearing loss are probably totally deaf, and respond to sound only through the sense of touch.

Hearing aid amplification should be attempted to all profoundly deaf infants and if not effective, cochlear implantation should be considered. Ideally, infants with profound congenital SNHL should be bilaterally fitted with hearing aids, no later than three months after birth. The child's progress should be monitored by the members of the MDT with regard to two different, but highly related domains, which emerge in infancy; the auditory skills and the prelinguistic vocalizations. Undoubtedly, the related outcome measures are in their vast majority subjective, and indirect, and are quite frequently based on parental views. Such tools include the categories of auditory performance (CAP), a global measure of auditory receptive abilities,

the listening profile (LiP), a summary of listening skills development that covers a wide range of auditory abilities, and the infant-toddler meaningful auditory integration scale (IT-MAIS), a criterion-based measure for parental assessment of the child's auditory responses.

The evaluation of preverbal skills is also of critical importance to document the link between the auditory and prelinguistic domains of infant development, as they are considered natural precursors of language development. Preverbal skills include appropriate eye contact, conversational-style turn-taking, autonomy and auditory awareness of the sound of speech. Finally, the onset of babbling and babbling spurt, may serve as critical time points in prelinguistic development.

The emerging need of early outcome measures has led the Nottingham team to propose the Nottingham early assessment package (NEAP), which combines a number of assessment scales and tests which can be applicable in very young children [8].

The aforementioned tools should be used to monitor the child's progress, with regard to spoken language acquisition, the months following hearing aid fitting. Hence, any additional disabilities (i.e. autism) can also be assessed, although sometimes this is very difficult in very young children. Having other disabilities would not usually preclude further auditory rehabilitation of the child, but would certainly alter the level of parental expectations. If the child is profoundly deaf, and is not progressing linguistically, despite the consistent use of bilateral hearing aids, and the intensive rehabilitation, the MDT may consider cochlear implantation.

3.3. Cochlear implants

Cochlear implants represent one of the most important achievements of modern medicine, as for the first time in history an electronic device is able to restore, at least to a significant extent, a lost sense — hearing.

A cochlear implant system comprises of the following components (Figs. 1–3):

1) a multi-channel receiver – stimulator, which has several electrodes, and is placed under the skin and the periosteum behind the ear at the time of surgery (cortical mastoidectomy and posterior tympanotomy). The other end of the receiver (the electrodes) is delicately placed in the scala tympani of the cochlea.

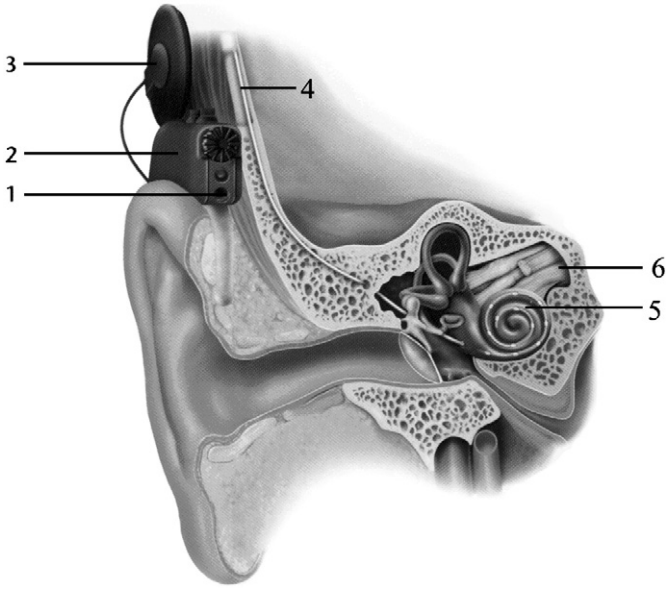


Fig. 1. Cochlear implant (schematic presentation). 1) Microphone 2) Speech processor 3) Receiver/Stimulator 4) Electrodes 5) Cochlea (electrodes inserted) 6) Cochlear nerve.

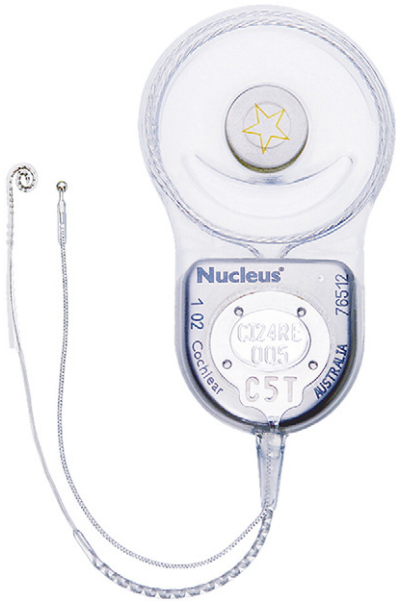


Fig. 2. Receiver–stimulator.

2) a transmitter coil — a small external device (usually about 30 mm in diameter), which is held securely in place over the internal receiver/stimulator by magnetic attraction.
3) a microphone which is fitted behind the ear.
4) a speech processor — a device that looks like a post-auricular hearing aid.

The microphone picks up sounds from the environment and sends them to the speech processor, through a thin cord that connects them. The speech processor converts the sounds into electronic signals, which are sent to the transmitter coil, through a cable. The transmitter sends these signals to the receiver across the intact skin, via an FM carrier wave. The signals are then converted back into electronic signals, and stimulate the implanted electrodes, and the cochlear nerve fibers. The nerve fibers send the signals to the brain, and a sensation of hearing is experienced. Hence, unlike a hearing aid, a cochlear implant can by-pass the damaged hair cells, and directly stimulate the auditory nerve fibers, in order to restore hearing. In other words hearing aids have a certain limitation — the number of alive hair cells that is usually very small in profound deafness. Cochlear implants do not have this limitation as they stimulate the

Fig. 3. Behind-the-ear speech processor.

ganglion cells which are usually intact, or at least to an adequate proportion, in profound deafness.

The preoperative assessment includes a detailed history, and thorough clinical examination, in order to clarify, if possible, the cause of the deafness and other co-existing syndromes or disorders. In addition, detailed radiological assessment with MRI and CT scan is essential to diagnose the presence of middle and inner ear malformations, cochlear obliteration, absent or abnormal cochlear nerves, and defects of the central auditory pathways [9]. Genetic assessment should also be performed.

It is also essential that parents have realistic expectations prior to embarking on cochlear implantation. In addition, parents and carers should be informed in detail about the need for long-term commitment to the child's rehabilitation. Moreover, the continuous support of a dedicated pediatric cochlear implant program, in close collaboration with local professionals (teachers and speech/language therapists), is desirable if a successful outcome is to be achieved. It is more than obvious that an environment that does not promote acoustic perception, and spoken language acquisition, can result in suboptimal related outcomes after cochlear implantation.

3.4. Surgical, anesthetic, and other considerations in infants and toddlers

The steadily younger age of implanted children has raised concerns, with regard to a potentially increased anesthetic risk. However, young age alone is not the only determinant of pediatric anesthetic risk [10]. The procedure-associated anesthetic risk for cochlear implantation is not expected to be high, as the operation is typically performed on a scheduled basis. In addition, even prolonged surgery may not be independently considered as a risk factor for cochlear implantation, if good anesthetic practise by an experienced pediatric anesthetist has been ensured, and the blood loss remains minimal.

Small incision cochlear implant surgery seems ideal for infants and toddlers, as it may improve the aesthetic outcome and reduce the flap-related postoperative complications [11]. In addition, several other surgical parameters should be taken into account in very young children.

Vaccination against pneumonococcus, meningitidococcus, and H. influenzae is necessary before implantation, depending on the child's age. One of the reasons is that certain subpopulations of these children demonstrate inner ear anomalies, which may increase the risk of postoperative meningitis.

With regard to the additional challenges, device parameters, such as postoperative fitting, may be related with certain difficulties in infants and toddlers. Audiological experience and objective methods may overcome most of these problems.

3.5. Outcomes and predictors in pediatric cochlear implantation

Prelingually deaf children develop significant speech perception and production abilities over time. These achievements may appear limited in the first two years, but show significant improvement after the second year of implantation, and do not reach a plateau, even 5 years following implantation [12].

Prelingually deaf children also develop significant speech intelligibility, but a long period of cochlear implant use is needed prior to the emergence of intelligible speech [13].

The age at intervention, and the mode of communication are the most important determinants of outcomes following cochlear implantation in young prelingually deaf children [14]. Implanted children ought to be operated early in life, and placed in an environment that has a strong oral component, in order to maximize the respective outcomes. In addition, speech intelligibility in young prelingually deaf children 4 and 5 years following their implantation can be predicted by measures of earlier auditory receptive abilities. Children implanted prior to educational placement are significantly more likely to go to mainstream schools following implantation, than those implanted when they are already in school [15].

Finally, the existence of a dedicated cochlear implant MDT, with long-term commitment to the rehabilitation of the young patients, the adequacy of resources, and the strong support of the implant program by parents, community members, professional bodies, and political authorities, can also maximize the future earnings of pediatric cochlear implantation for human societies.

4. Conclusion

Despite the high incidence of profound congenital SNHL universal hearing screening programs have not been widely applied, and most countries have only established screening programs for high-risk infants. However, early identification, referral, and diagnosis of children with hearing loss are necessary, to initiate the process of auditory rehabilitation.

The acquisition of spoken language does not just happen in an instance, but is a time-dependent process. For a child to become linguistically competent, some form of linguistic input should be present as early as possible in his/her life.

The combination of the three objective tests (OAEs, ABRs, and ASSRs) with behavioural audiometry in experienced centers usually results in a very accurate diagnosis. Additional disabilities (i.e. autism), which may not be able to be detected early in life, also need to be taken into account.

Profound congenital SNHL is managed by an MDT, which includes the Paediatrician, the ENT Surgeon, the Genetic Scientist, the Clinical Audiologist, the Speech and Language Therapist, the Psychologist, the Teacher for the Deaf, and the Social Worker. Ideally, infants with profound congenital SNHL should be bilaterally fitted with hearing aids, no later than three months after birth. The child's progress in an intensive rehabilitation environment, with regard to spoken language acquisition, should be monitored and if it is not adequate, cochlear implantation should be considered after thorough preoperative assessment.

Unlike a hearing aid, a cochlear implant can by-pass the damaged hair cells, and directly stimulate the auditory nerve fibers, in order to restore hearing.

Congenitally deaf children develop significant speech perception and production abilities over time. Age at intervention and oral mode of communication are the most important determinants of outcomes. It is also essential that parents have realistic expectations, prior to embarking on cochlear implantation. The continuous support of a dedicated pediatric cochlear implant program, in close collaboration with local professionals, and community members, are also desirable, if a successful outcome is to be achieved.

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