Opportunities within and after rehabilitation for patients with hearing loss

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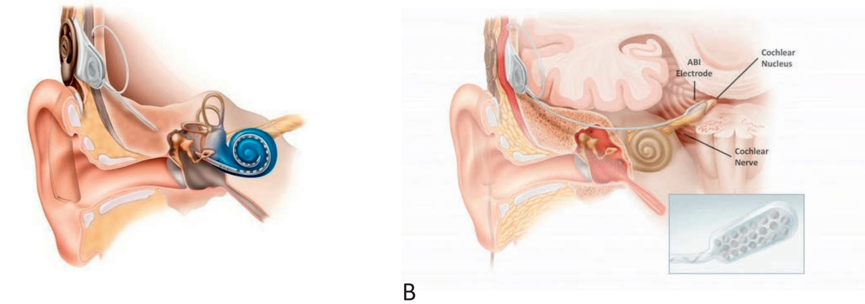
Introduction

Cochlear implantation procedures first started in the Netherlands in 1985, under scientific restrictions which led to the reimbursement and implementation of cochlear implants (CI) as a standard of care for the severely hearing-impaired in 2000. Until now, more than 7.500 individuals have received CI in the Netherlands and almost 600 implantations are performed every year (CI-ON, 2019). More recently, auditory brainstem implantation (ABI) became available for children with non-functional cochlea's or cochlear nerves (Figure 1). Over the past couple of years, 12 deaf children have undergone this new procedure at the Leiden University Medical Center (The Netherlands). These implantations and other developments in rehabilitation have significantly changed the lives and future prospects of hearing-impaired individuals. Yet, the actual impact of these recent implementations and expansions in rehabilitation remains unclear. What are current patients' expectations when it comes to rehabilitation? May an individual with hearing loss (HL) expect to fully participate in a world driven by sound and verbal communication after rehabilitation, or should he or she accept the consequences of a chronic handicap?



A B

FIGURE 1. The electrode array of the cochlear implant **(A)** is inserted circa 1.5 turns in the scala tympani of the cochlea and lays alongside nerve endings of the cochlear nerve. The array of an auditory brainstem implant **(B)** is inserted alongside the cochlear nucleus of the brainstem in the lateral recess of the fourth ventricle.

Developments in rehabilitation, a short history

In the early days of rehabilitation, individuals with HL were allocated to deaf communities until CI became mainstream in 2000 (Tijsseling, 2014). This new technique achieved several improvements in pediatric and adult rehabilitation, starting with auditory input and speech understanding. Initially, only profoundly deaf individuals were eligible for implantation (Frijns et al., 2002), but criteria gradually expanded to include severely hard of hearing individuals who could understand 30-40% of monosyllabic words. Nowadays, selection criteria have been expanded even further. At the Leiden University Medical Center, CI is already an option for individuals with residual hearing, who can still understand more than 60% of words but have severe problems in complex listening environments with background noise (CI-ON, 2013; Snel-Bongers et al., 2018).

Another important milestone in the development of rehabilitation for patients with HL, is the implementation of early identification of congenital HL. Initially, children were diagnosed with HL and rehabilitated with hearing aids (HAs) at around 2 years of age (Yoshinaga-Itano, 2004) and received their CI at 3 to 4 years of age (Lammers et al., 2015). However, the plasticity of the brain decreases with age, making the brain less susceptible to auditory and language input as children grow older (Niparko, 2010). Between 2003 and 2005, newborn hearing screening was implemented in the Netherlands, changing the lives of children with congenital HL (Korver et al., 2013). Today, early identification of HL in the first days after birth results in early intervention and is CI implantation possible at 6 months to 1 year of age (CI-ON, 2013). For these children, early implantation enables early auditory input during the linguistic development phase of the brain and significantly improves language skills (Boons et al., 2013; Niparko, 2010; Yoshinaga-Itano, 2003a).

Improved spoken language skills offer major benefits for children's development in many areas, as it enhances their possibility to participate in a world driven by verbal communication (Boons et al., 2013; Korver et al., 2010; Niparko, 2010; Pimperton & Kennedy, 2012; Yoshinaga-Itano, 2003a). Nowadays, a large proportion of children with CI are able to attend mainstream instead of special schools.

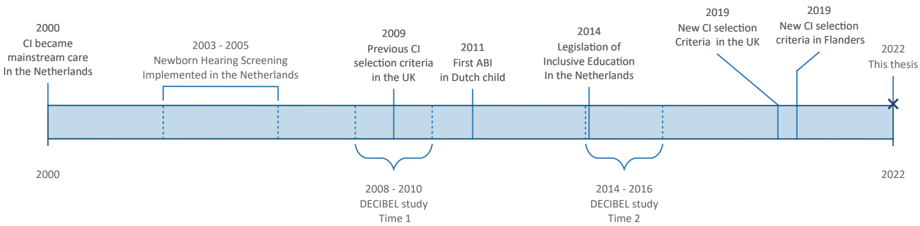


FIGURE 2. Timeline of important milestones in rehabilitation for patients with HL

In addition, new rehabilitation techniques have evolved, resulting in ABI implantation when CI is not suitable. Initially, only deaf adults with neurofibromatosis type 2 were candidates for this procedure (Schwartz et al., 2003). However, research by Sennaroglu et al. and Colletti et al. have shown that prelingually deaf children were also good candidates for this type of implant (Colletti et al., 2014; Sennaroglu et al., 2009). This led to the first pediatric auditory brainstem implantation in 2011 in the Netherlands. Indications for ABI implantations are congenital malformation of the cochlea or cochlear nerve (Figure 3) and ossification of the labyrinth after meningitis or after a base skull fracture (Sennaroğlu et al., 2016). Prelingually deaf children with ABI are now able to identify environmental and speech sounds and even develop intelligible speech within 5 years after implantation (Noij et al., 2015).

Impact of expanded rehabilitation for patients with HL

Rehabilitation for patients with HL has matured, with many improvements made over the past 20 years. However, the impact of these different developments in rehabilitation is still unclear. What would happen if we broadened the selection criteria for CI and ABI even further? Can one expect to fully participate in society after rehabilitation? To what extent can we assume changes in the social-emotional well-being and educational attainment of hearing-impaired individuals? In other words, what can we expect from rehabilitation nowadays? These are the questions patients and parents currently ask when faced with the choice between CI or ABI. In order to answer these questions, one needs to understand that the hearing-impaired population is very heterogenous. This requires examining different outcomes taking into account these individual differences within the population, in order to investigate the impact of rehabilitation. Therefore, this thesis aimed to investigate different aspects of outcomes of current rehabilitation for patients with HL. The next sections will further discuss current knowledge and missing links in rehabilitation. The sections are divided into speech perception after adult CI, language development after pediatric ABI, and developmental outcomes after pediatric rehabilitation, such as social-emotional functioning and level of education.

Current selection criteria for cochlear implantation

The main goal of CI is to enable individuals with HL to participate more easily in a aurally oriented society, and therefore to improve their speech understanding. This is difficult to measure in children because they are mostly implanted before speech understanding has developed, but it can easily be measured in post-lingually deafened adults. Moreover, CI should be provided to candidates who are likely to benefit from the implant, while avoiding unnecessary costs and medical interventions for patients for whom acoustic HAs are sufficient. Technical developments of the implant and changes in surgical techniques have allowed postoperative speech perception outcomes to improve and for residual hearing

> In the Netherlands, selection criteria for pediatric CI are based on the degree of HL (>70-80 dB) and the auditory response with HAs. Prerequisites for adults are primarily based on speech understanding (<60% word score or difficulty with listening in noise).

to be preserved (Blamey et al., 2013; Snel-Bongers et al., 2018). However, candidates with residual hearing exhibit relatively high preoperative speech scores which limit a 'remarkable' improvement of speech understanding postoperatively. Defining selection criteria therefore remains difficult, requiring further investigation.

Selection criteria are mainly based on preoperative audibility. Yet there is no golden standard worldwide and pre-implant prerequisites vary widely. Some countries only use the degree of HL as measured by pure-tone audiometry, since this test is easily available. Others use the level of preoperative speech understanding with or without taking into account the degree of HL. There are also different speech perception tests available and pure tone audiometry can be measured in various ways. Furthermore, the cut-off values of selection criteria vary from relatively strict in England and Flanders (Table 1) to lenient in the Netherlands (e.g., 80% of speech understanding), Germany, and Australia (Deborah Vickers et al., 2016a). These diverse type of measurements and selection criteria are remarkable as all countries pursue the same goal: rehabilitation for individuals with severe hearing problems, resulting in their increased participation and the improvement of their quality of life in a cost-effective way.

Therefore, we were interested in which preoperative measure would be most effective in indicating which post-lingually deafened candidate would improve after CI implantation. Previous research has found that the preoperative speech perception score is a valuable indicator for postimplant performance through prediction models (Cullen et al., 2004; Gomaa et al., 2003; Kraaijenga et al., 2016). However, the diagnostic value of different preoperative tests (the various speech understanding tests and pure tone audiometry) has not yet been analyzed. This was therefore our research aim in **Chapter 2**.

Selecting candidates for CI also involves the evaluation of patient-related characteristics. For example, the time at which HL is acquired: at birth, in early childhood (pre-lingual) or at an older age (post-lingual). In a post-lingually deafened adult, the level of speech understanding facilitates prediction of the possible postoperative benefit with CI (Cullen et al., 2004; Gomaa et al., 2003; Kraaijenga et al., 2016). This is different in pre-lingually deafened adults where the intelligibility of their speech production relates to the acquired auditory speech input and the potential postoperative outcome (van Dijkhuizen et al., 2016). Which patient-related factors are used varies widely and each country evaluates different factors such as the duration of deafness, age at implantation, and etiology of HL (Gomaa et al., 2003; Kraaijenga et al., 2016; Zhao et al., 2020). The socio-economic status of a candidate is also important in some countries where implants are only available through self-funding (Deborah Vickers et al., 2016a).

The United Kingdom and Flanders (Dutch-speaking part of Belgium) have recently broadened their selection criteria for CI in post-lingually deafened adults (Table 1)(National Institute for Health and Clinical Excellence, 2009, 2019; Raeve, de & Wouters, 2013). This enabled us to examine the possible increase in candidates who are able to improve their speech perception postoperatively. This is investigated in **Chapter 3,** alongside the sensitivity and specificity rate of the new selection criteria in both countries.

TABLE 1. Selection Criteria for Cochlear Implant Candidacy in the United Kingdom and Flanders

	United Kingdom	Flanders
Old criteria	>90 dB at 2 and 4 kHz and <50% sentence score (2009)	Average of >85 dB at 0.5, 1, and 2 kHz and <30% phoneme score (2013)
New criteria	≥80 dB at ≥2 frequencies (0.5, 1, 2, 3, and 4 kHz) and <50% phoneme score (2019)	Average of >70 dB at 0.5, 1, 2, and 4 kHz and <50% phoneme score (2019)

Language development after auditory brainstem implantation in congenital HL

ABI is a new and complex procedure that continues to develop. Implantations in young children with ABI are particularly challenging as they have never heard sounds before. They will experience the variety of frequencies and patterns of sounds after stimulation of the electrode array on the auditory brainstem. Additionally, the tonotopy of the auditory brainstem in the pediatric population remains nearly unknown and is difficult to mimic (Long et al., 2005). Nevertheless, the plasticity of the pediatric brain is assumed to adjust the auditory pathway according to the stimuli received from the ABI. The first results indicated that children with ABI can develop speech perception and speech intelligibility (Noij et al., 2015). Their auditory skills develop relatively slowly and reach lower levels compared with children with CI (Colletti et al., 2014; Sennaroglu et al., 2009). However, a direct comparison between pediatric CI and ABI users has not been made. When doing so, one should consider the differences between children who are eligible for CI or ABI. The presence of congenital cochlear malformations and cochlear nerve deficiencies (Figure 3) may also imply an impaired auditory pathway in the brainstem and further on in the brain (Sennaroğlu et al., 2016) and are most often present in the context of complex syndromes and/or additional comorbidities.

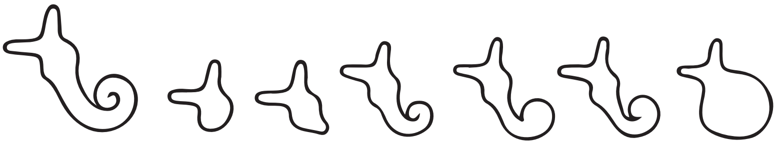


FIGURE 3. A normal cochlear anatomy and several congenital malformations of the cochlea (Jackler et al., 1987). CI is first attempted in some cases with mild cochlear hypoplasia. The other cases are not eligible for CI, but possible candidates for ABI.

Therefore, the prevalence of additional disabilities is expected to be higher in these children compared with children who receive CI (Sennaroğlu et al., 2016). Severe additional disabilities are related to lower levels and a broader variety of expected developmental outcomes in children with CI (Eze et al., 2013). Yet, the relation between additional disabilities and developmental outcomes in children with ABI has not yet been investigated. We will, therefore, examine the long-term auditory development of children with ABI and compare this with the auditory development of pediatric CI users in **Chapter 4**, taking additional disabilities into account.

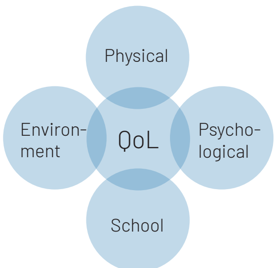
Developmental outcomes after pediatric rehabilitation

The direct benefit of rehabilitation in children with a HA or CI is difficult to capture. Children eligible for CI are unable to understand speech preoperatively which prevents us from examining direct benefits to speech understanding after implantation. Instead, the development of speech understanding and expressive language are closely monitored. Language development is therefore the first step in examining the impact of pediatric rehabilitation and has been studied extensively (Moeller et al., 2007; J. Bruce Tomblin & Moeller, 2015; van Schoonhoven et al., 2013). Nowadays, most children with CI or HA are expected to eventually acquire language skills comparable to normal hearing children (J. Bruce Tomblin et al., 2018). The age at intervention (implantation or amplification with HA) is one of the most important factors contributing to optimal and early language development in children with HL (Yoshinaga-Itano, 2004). It is clear that a child with HL can participate in a world driven by verbal communication, however, it is unclear to what extent. Research that examines the impact of HL on other areas of a child's development is relatively new and remains scarce. Two important pointers for examining the impact of rehabilitation are wellbeing and educational attainment of children with HL.

Wellbeing

Growing up in a world driven by sound and verbal communication can have a considerable impact on the development and identity of children with HL. Hearing impairment interferes with unplanned ('incidental') learning opportunities as not every conversation can be overheard and learned from (Luckner & Cooke, 2010), especially in social situations with a lot of background noise or voices coming from different directions, like at a playground or sport club. Studies have found that children with HL engage less in peer relationships and friendships than hearing children (Rieffe et al., 2018; Stevenson et al., 2015; S.C.P.M. Theunissen, Rieffe, Kouwenberg, et al., 2014). It might be due to the inability to keep up with their peers in conversations (Luckner & Cooke, 2010) or the incapacity of knowing how to socially communicate and interact (Netten et al., 2015; Rieffe et al., 2018; Anat Zaidman-Zait & Dotan, 2017). Misinterpretation of social situations can lead to feelings of exclusion, social isolation, and consequently, a lower quality of life (Contrera et al., 2017; Lin et al., 2013; Mathers et al., 2000). Elevated levels of psychopathologic symptoms (depression, anxiety, aggression, and behavioral problems) are found in children and adolescents with HL (S.C.P.M. Theunissen, Rieffe, Netten, et al., 2014). It is therefore unsurprising that children with HL appear to have a lower quality of life compared to their hearing peers (Roland et al., 2016). Within the quality of life domains, social interactions and school activities appear to be the principal problems these hearing-impaired children face.

Previous studies examining quality of life and its relation to HL related factors were performed in cross-sectional designs. These designs lack information relating to the effect of time and, consequently, the direction of causality. Therefore, we also need to study the development of children over time in order to identify causal factors. This research focus formed the basis for **Chapter 5,** where we examined the longitudinal development of quality of life in children with CI and HA. By studying the extent to which the quality of life of children with HL changes over time, the influence of language skills, type of hearing device, degree of HL, and type of education may be analyzed as possible risk or protective causal factors for a lower quality of life among hearing-impaired children.



The World Health Organization defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (1995). This illustrates the main value systems for developing children.

Education

Great enhancements for the development of children with HL were brought about by the various improvements in rehabilitation. Pre-school and extra guidance at school have also enormously contributed to their development (Marschark & Spencer, 2011; J. Bruce Tomblin & Moeller, 2015). Children with HL and their parents are nowadays able to choose between special education for the deaf or mainstream education. When a child is able to keep up with mainstream education, it does not directly imply that school is not challenging for children with HL. They often need extra assistance in class, and face the challenge of misunderstanding teachers due to background noise or the direction in which they speak (Curle et al., 2017; Anat Zaidman-Zait et al., 2019). Learning to read is one of the biggest challenges for many hearing-impaired children (A. E. Geers & Hayes, 2011; Trybus & Karchmer, 1977; Worsfold et al., 2010) and they appear to underachieve in mathematical subjects (Gottardis et al., 2011). Consequently, pupils with HL frequently fail to pass grades (Gilani et al., 2017). It is therefore expected that pupils with HL are at risk of lower educational attainment and unemployment later in life (Dammeyer & Marschark, 2016; Qi & Mitchell, 2012). There is a lack of knowledge regarding the educational level of adolescents with HL during secondary education and the longitudinal effect of the different types of primary education (special and mainstream). In **Chapter 6**, this issue is addressed.

Outline of this Thesis

The PhD-project described in this thesis has investigated the various potentials of current rehabilitation, including pre-lingual and post-lingual HL, a direct benefit of speech perception after implantation, and the long-term effect on child development. This was performed in both cross-sectional (**Chapter 4**) and longitudinal studies (**Chapter 2, 3, and 5**), including a nation-wide study that included all individuals with HL born between 1995 and 2013 in the Netherlands (**Chapter 6**). The main outcomes of the studies are discussed in **Chapter 7**. In this chapter, we reviewed what one can expect from rehabilitation for patients with HL nowadays. We discussed the questions raised by patients and parents when faced with rehabilitation and further elaborated on prospective studies in future perspectives. A Dutch summary of this thesis can be found in **Chapter 8**.

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