Psychopathology in hearing-impaired children

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CHAPTER 1

General introduction and outline of this thesis

INTRODUCTION

Pediatric hearing impairment is a chronic handicap that has detrimental consequences for the development of speech and language [1,2]. The subsequent delay in communication skills can lead to limited access to the sound-dominated social world [3]. As a result, this vulnerable group of children is more likely to exhibit difficulties in their social and emotional functioning [3-11]. For example, hearing-impaired (HI) children have been found to experience lower Quality of Life and are more prone to developing mental health problems than their normally hearing (NH) counterparts [3-7,9-13].

Although the general concepts Quality of Life and mental health give a good first impression of the functioning of the HI population, they provide no knowledge regarding specific forms of psychopathology (such as depression, anxiety, or aggression). In fact, literature regarding specific forms is scarce and inconsistent [14]. Some researchers stated that HI children display similar levels of psychopathological symptoms as NH children [15,16], while others demonstrated that the prevalence is considerably higher [5-7,9,10,17,18]. Furthermore, it is a matter of debate which individual factors are most important for the development of psychopathology. Researchers stress the fact that the factors that increase risks for, or conversely, prevent from developing psychopathology must be inventorized [3,6,11]. Therefore, the aim of this thesis is three-fold:

1. To examine the levels of various forms of psychopathology in HI children, as compared to NH controls;
2. To investigate the influence of having cochlear implants or conventional hearing aids on the level of psychopathology;
3. To identify which individual factors, specific for the HI population, are associated positively or negatively with psychopathology.

This introductive chapter starts with background information on psychopathology and pediatric bilateral hearing loss. Subsequently, the consequences of speech and language delays on psychopathology are explained. Next, a short overview of the methodological issues often encountered in studies with HI individuals is given. Furthermore, the methodology of this research project is provided (i.e., study sample, procedure, and materials) and the last part of this Introduction gives the outline of this thesis.

PSYCHOPATHOLOGY

Good social and emotional development is, among others, characterized by the absence of psychopathology. Psychopathology refers to mental disorders. In the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), a mental disorder is conceptualized as a “clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e., impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be merely an expectable and culturally sanctioned response to a particular event, for example, the death of a loved one. Whatever its original cause, it must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual. Neither deviant behavior (e.g., political, religious, or sexual) nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the individual, as described above" [19]. However, the manual of DSM-IV states that "no definition adequately specifies precise boundaries for the concept of mental disorder", showing that a continuum between mental health and mental disorders exists, which complicates diagnosis. In pediatric psychology and psychiatry, psychopathology can be categorized into internalizing and externalizing symptoms. Internalizing symptoms involve depressive and anxious feelings, whereas externalizing symptoms refer to hyperactive, aggressive, and antisocial behavior [19]. These symptoms are disabling, have negative effects on academic and psychosocial functioning later in life, and are risk factors for substance abuse [19-25]. Moreover, comorbidities include obsessive-compulsive disorder, posttraumatic stress disorder, cognitive or learning disorders, eating disorders, and personality disorders [26,27]. More in-depth information on internalizing and externalizing symptoms as well as a literature overview of these symptoms in HI children, including the findings of the papers which are part of this thesis are given in chapter 7.

BILATERAL HEARING LOSS IN INFANCY

Permanent bilateral hearing impairment can be defined as hearing losses of at least 40 decibels (dB) in the best ear, due to sensorineural or structural conductive hearing impairment. Conventionally, in the Netherlands the severity is classified as moderate (40 - 60 dB), severe (61 - 90 dB), or profound (> 90 dB) losses. Speech in conversations varies around 50 to 70 dB, so children with severe to profound losses cannot understand speech without additional devices, although some are very well trained in lip-reading. HI children can be helped with conventional hearing aids, but for profoundly HI and deaf individuals who do not benefit from these hearing aids, a Cochlear Implant (CI) is a solution. This hearing device is a surgically implanted device that bypasses the damaged part of the ear and directly stimulates the auditory nerve in the cochlea using electrical pulses, which are perceived as sound in the brain. By restoring hearing, CI results in improved speech and language development, which can be age-appropriate [28-31].

Hearing loss in infancy affects approximately 1 to 1.3 out of every 1000 live births, and prevalence increases with age [32-34]. This increase can be explained by the fact that hearing loss can be detected or acquired later in life, has a delayed-onset, or a progressive course, meaning that the hearing loss becomes worse over time [33]. For children aged 9 years prevalence rises to at least 1.65 (and may be as high as 2.05) out of every 1000 births [33]. It can be caused by various environmental and genetic factors, although we have to bear in mind that in many cases no cause can be identified or diagnosed [35].

SPEECH AND LANGUAGE DIFFICULTIES

Hearing impairment can lead to delays in speech and language development, especially if the onset of hearing loss was already in childhood [1,2]. In the first phase of a child's life, being exposed to speech and language is essential for language acquisition [36]. Even though infants do not utter meaningful words, they exhibit a capacity to learn [36]. Reduced auditory input will lead to a marked delay in maturation of the structures in the auditory cortex [37]. This leads to the notion that the developing brain is particularly sensitive to auditory deprivation, while a decrease in auditory input results in a changed neural plasticity in the brain [37,38]. Therefore, a normal acoustic environment during these sensitive periods in early childhood is very important to guarantee normal speech and language development [39-41]. This is the main reason why the Neonatal Hearing Screening (NHS) has been introduced. NHS takes place at the age of approximately 2 weeks, making early detection of hearing loss in children possible. This early detection and subsequent intervention has been associated with better developmental outcomes, because the period of deprivation has been shortened considerably [42-44].

More issues arise when discussing speech and language development in light of pediatric hearing loss. That is, HI children cannot learn through 'incidental learning'; they fail to become indirectly aware of conversations between hearing family members or friends [45]. Moreover, the overwhelming majority of HI children (approximately 92 to 96%) are born to NH parents [46]. NH parents have usually had no experience with hearing loss before, and have to adjust to a new situation which necessitates the investment of time, effort, and resources [47-49]. Use of speech instead of sign language is more common than it is among families with parents who are HI as well. Hence, HI children, particularly the ones with severe to profound losses, have to rely on visual cues and visual orientation in the first months of life, and in the absence of normal speech, the child's ability to communicate is restricted [50].

Additionally, many acoustic environments are difficult to handle for most HI children. Large classrooms, crowded places on streets, or families with many siblings are situations where speech-in-noise occurs. This is complex for HI individuals, because they have difficulties focusing on the one sound they want to understand, and simultaneously filter all of the other sounds from the environment. Reverberation, where sound echoes many times in a room, complicates the comprehensibility of speech as well. Next to these external concerns, HI individuals have limited perception of affective prosody, such as intonation, while expressing emotions and using social language tend to require these kinds of acoustic properties [51].

To conclude, HI children face multiple problems involving their communication. Therefore, impaired language and speech abilities regularly arise in HI children, and they may not achieve an understanding of the refinements of social language. This makes them more vulnerable to problems in the field of social and emotional development and psychopathology [3,44,52].

METHODOLOGICAL ISSUES

In the last few decades, research in the field of social and emotional development and psychopathology in HI children has emerged gradually. As promoted by the World Health Organization, many studies reported on broad and general concepts, such as Quality of Life (QoL) and mental health [3,53]. Fairly consistent outcomes were reported by researchers, showing lower QoL and more mental health problems in children with hearing losses than in NH children [1,4-6,12-14,54-59]. For example, HI children have more difficulties with making friends and are more socially isolated [60-62]. Looking beyond QoL and mental health, few studies on specific psychopathological forms in HI children are available [63]. In addition to the fact that the body of literature is considerably small, divergent and inconsistent findings have been reported. These contradictory findings mainly are the result of three concerns:

1. Different informants. Studies often use different informants, varying from child, parent(s), or teacher. Past research showed that, particularly for emotional or internalizing problems, parents and teachers frequently underreported the level of problems, while for some behavioral problems parents and teachers gave accurate levels. So, perceptions per informant can truly differ, potentially leading to an informant bias [64,65].
2. Different methods of measurement. Each study uses different methods of assessment. For example, some researchers interviewed their participants, others performed behavioral observations, and a large group of researchers made use of surveys or reports. Generally, each method results in different outcomes [12].
3. Different study samples. The large heterogeneity in the group with HI individuals often results in different samples. For example, some studies only reported on HI children in special schools for the deaf, while others only examined HI children with minimal hearing losses [4,66]. So, it is important to know which sample exactly has been investigated, because this affects the extent to which the findings can be generalized to the HI population.

These three issues make it more complicated to compare and recapitulate research in this field. Again, the author would like to emphasize that in chapter 7, all relevant studies that have been performed on this topic, are summarized. At the start of this research project, an attempt was made to overcome the above-mentioned methodological issues by putting great effort in the preparation and execution of this research. First, per psychopathological symptom, care was taken to select the most accurate and appropriate informant. This entails that, generally, children were the informant when evaluating internalizing symptoms, and parents or caregivers were administered when assessing externalizing symptoms. Second, only questionnaires were used to measure psychopathology. Although the subjective component of gathering information by questionnaire can never be ruled out completely, we tried to minimize the differences in interpretation by adjusting the questionnaires to the HI population when necessary. This was carried out by formulating short items, in their preferred mode of communication to ensure children's understanding. HI children could choose between two versions: a written version or a version in which each item was presented in written text and sign language simultaneously. Third, to reach the complete spectrum of HI children and to reduce any possible selection bias, many different organizations and schools were approached. Participants were therefore recruited from Speech and Hearing centres, hospitals, primary and secondary schools (special schools for the deaf and mainstream schools), and via specific magazines and websites for HI people.

THE STUDY SAMPLE

The study sample consisted of HI and NH children and adolescents with ages ranging between 9 and 16 years old. We chose this specific age range because it is a transition phase marked by crucial emotional and behavioral changes which can pertain into adulthood. All HI participants had permanent hearing loss of at least 40 dB in the best ear, which were detected pre- (< 3 years) or perilingually (3 to 5 years). Thus, the hearing loss was not attributable to temporary losses, such as otitis. Participants who experienced additional disabilities, such as visual impairment, mental retardation, or Autism Spectrum Disorders, were excluded. Although in the general HI population approximately 30% of all children have additional problems [17,67,68], the synergistic effects of multiple disabilities are known to be extensive [67]. Cognitive development was assessed with IQ tests: only participants with a performal IQ of 80 or higher were included.

The HI sample was an adequate representation of the Dutch HI population at this age: approximately 50% attended regular schools and the other 50% attended special schools. The schools supported development of auditory and oral skills, with or without the use of signs. All participants were born before the introduction of the Newborn Hearing Screening Program, so many children were screened at a later moment than currently occurs. That is, circa 43% was screened and detected before the age of one year, 30% was screened before the age of two, and 27% was older than two years. For the CI recipients in particular, most children received their CIs at older age (mean age 3.8 years, range 0.9 – 10.8) while nowadays, the vast majority of children are implanted in their first or second year of life.

The majority of HI children received conventional hearing aids, while the more severely HI received CIs. With respect to the rehabilitation trajectories, a difference exists between these two groups. CI recipients receive more thorough counseling. After implantation, a rehabilitation program is organized, in which the child is trained and followed intensively. For example, in the Leiden pediatric CI program the child and its caregivers spend the mornings of six weeks in the first year in the center. Many different professionals (for example, doctors, audiologists, speech and language therapists, or psychologists) evaluate and counsel the child. After this, the CI child is followed the rest of his or her life (at a lower intensity). For children who received hearing aids, such intensive period is planned after receiving hearing aids. These children do have regular check-ups, especially at the audiologist to fit the hearing aid. Yet, when no (other) significant problems emerge, generally no further follow-up (at other professionals) is performed.

PROCEDURE

As mentioned above, after medical ethical approval, many different organizations and schools were approached to collect a representative study sample. In total 28 special schools (i.e., schools for deaf and HI children), 5 ambulatory care organizations (Speech and Hearing centers or residential schools), and 2 large university hospitals (LUMC and Radboud) were approached, of which 14 schools, all ambulatory organizations and the hospitals agreed to participate. The other schools refused for reasons related to, among others, time commitment or other research projects. In line with privacy policy, information packages and consent forms were sent to the parents or caregivers of the children via these schools, organizations, and hospitals. The NH controls were recruited at primary and secondary schools throughout the country, to reach a sample that was sociodemographically diverse.

All participants were individually tested at school or at home in two sessions to limit time per session, making it not too long for the children. Parents could fill in their questionnaires by paper or on internet (secured). Information of the children and parents were processed anonymously, but could be matched by using a unique code for each child.

MATERIALS

Eleven different questionnaires were used to measure social and emotional development. All questionnaires were validated and standardized for the NH population, except for the questionnaire measuring social anxiety. For social anxiety, a short index consisting of six items was developed especially for this study by a team of child psychologists, targeting the key aspects of social anxiety. For seven out of the eleven questionnaires (i.e., coping styles, mood states, child symptom inventories, aggression, psychopathy, self-esteem, somatization) the original items were used and for two other questionnaires (i.e., depression and general anxiety) the items had been adjusted to the HI children. That is, sentences were formulated short and simple, so HI children with language comprehension problems would be able to understand these items and respond to them coherently. The last questionnaire (on delinquency) was adapted from Baerveldt and colleagues [69]. The original version of this questionnaire consisted of 19 delinquent behaviors, but due to very low incidence of 9 items in a previous pilot study (with almost 600 NH participants) only the 10 most frequently reported items were selected.

All questionnaires were examined for their internal consistency for both the HI and NH study sample. The internal consistencies of all questionnaires were sufficient (Cronbach's Alpha between 0.70 and 0.80) to excellent (Cronbach's Alpha > 0.90), except for the Conduct Disorder scale of the *Child Symptom Inventories* and the General Self-esteem scale of the *Children's Self-Confidence and Acceptance Scale*. Children were assured that their reactions would be processed anonymously and instructions were provided in the child's preferred mode of communication. The participant could choose between two versions of assessment: the first version comprised written items exclusively and in the second version each item was presented in written text and sign language simultaneously (by means of a video clip). Back translation of all signed items showed good convergence with the original items. Each questionnaire used in this research project is described in detail in the chapter involved and example items are given.

In addition, intelligence, language, and communication were assessed. This was performed by using the *Wechsler Intelligence Scale for Children (WISC) - Third Edition* [70,71], the *Clinical Evaluation of Language Fundamentals® - Fourth Edition (CELF®)* [72,73], and the *Children's Communication Checklist version - 2* (CCC-2) [74]. The influence of these skills on psychopathology was examined. The reason for using the CELF and CCC-2 tests was that they both are validated for children in this age range. Secondly, they do not only test language comprehension, but also assess social and pragmatic language, an important link to social and emotional development. Moreover, the reason for not choosing standard receptive and expressive language tests (for example, Reynell [75] or Schlichting [76]) was that they are not validated for children aged 9 and older, but only for younger children.

The three tests were administered by a linguist, a medical doctor, or a psychologist. For the HI participants who used sign or sign-supported language, it had to be confirmed that they had sufficient sign language skills to interpret all questionnaires correctly, their sign language skills were tested with the *Assessment Instrument for Sign Language* of the Netherlands (AISL) [77] by a sign language interpreter. Medical records as well as parental questionnaires provided information on individual characteristics and medical background.

OUTLINE OF THIS THESIS

This thesis concerns several different forms of psychopathology and the factors that contribute positively or negatively to the level of each psychopathological problem. By investigating a representative sample of the total HI population, conclusions and findings can be generalized more easily to the whole population, although we always must be aware of the heterogeneity. Hopefully, this knowledge will lead to more awareness for professionals working with this group of children, in order to help the HI child to reach his or her full potential.

Chapter 2 describes research involving the level of self-esteem, an important factor which can initiate psychopathology. Self-esteem is assessed in four relevant domains typical for this age range: parents, peers, physical, and global self-esteem. The influence of communication, education, environment, and audiological characteristics on levels of self-esteem was also examined.

In **Chapter 3** the level of depressive symptoms in children with hearing loss are compared to those of NH control children. The influence of type of school and preferred mode of communication (sign or spoken) are investigated. Furthermore, two aspects of emotional functioning, which are key factors in the development of depression in NH children, are examined in HI children to see whether the developmental pathway to depression differs from the pathway of NH children.

Chapter 4 concerns anxiety in HI children. The group with HI children is divided by their type of device (CIs or conventional hearing aids), because this factor appeared to be significantly related to anxiety. Moreover, the influence of other factors, such as age, gender, socioeconomic status, language skills, intelligence, and age at implantation on the levels of anxiety are scrutinized.

Chapter 5 reports on behavioral problems, including aggression, delinquency, symptoms of psychopathy, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, and Conduct Disorder. The purpose is to examine these problems in hearing-impaired children with hearing aids or cochlear implants, compared to normally hearing children. Additionally, sociodemographic, linguistic, and medical factors that contributed to the level of behavioral problems are studied.

In **Chapter 6** both psychopathological symptoms in HI children are investigated and the levels are compared to those of NH children. Furthermore, the influence of the type of hearing device on the level of problems is scrutinized.

Chapter 7 provides a systematic review of all literature on psychopathology in HI children and adolescents. The review reports on strengths and weaknesses of past research as well as the reasons for the similarities and differences in outcomes between the studies.

Chapter 8 discusses about the overall findings of this research project. Moreover, this chapter presents the clinical relevance and implications. Finally, future directions and concluding remarks are given.

Chapter 9 summarizes chapter 1 to 8 (in English and Dutch).

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