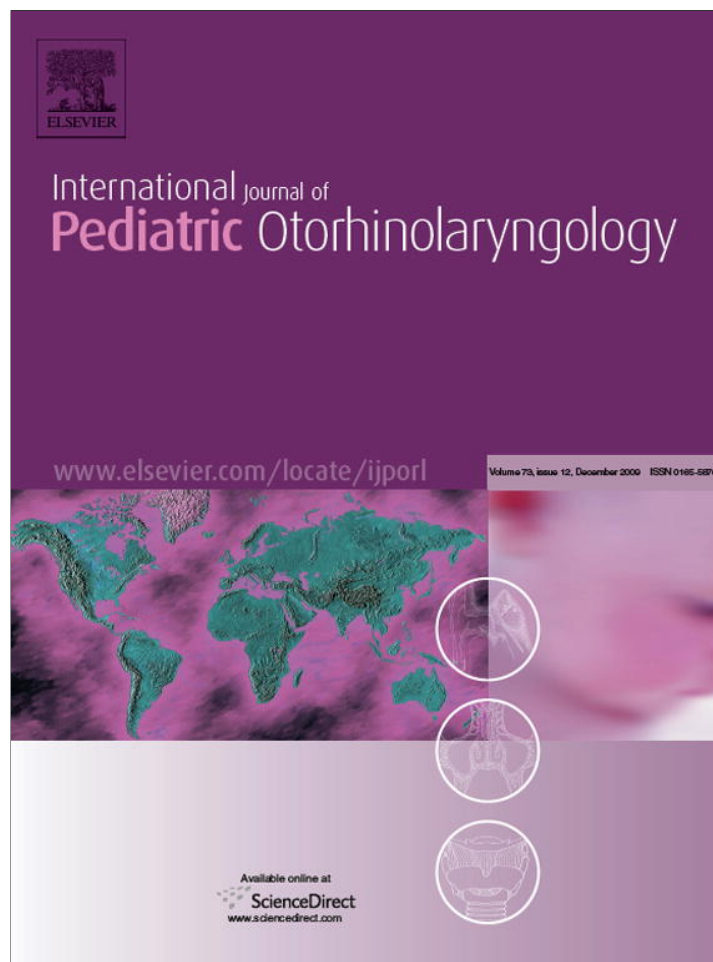


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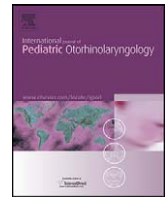
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Parents' views on the quality of life of their children 2–3 years after cochlear implantation

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ABSTRACT

Objective: Cochlear implants for children are known to have impact on the lives of recipients and their families in a variety of ways. To obtain a clearer picture of these benefits, we explored the quality of life of 36 Finnish children and their families 2–3 years after unilateral cochlear implantation.

Methods: The studied children were, on average 5 years old, and had received their implant at the median age of 2 years:5 months (range 1:6 to 12:3). Most (67%) of the children used speech, eight (22%) used speech and signs, and four (11%) used sign language as their main communication mode. A third of the children had concomitant problems in addition to their profound hearing impairment. A validated closed-set questionnaire “Children with cochlear implants: parental perspectives” (available, e.g., at <http://www.earfoundation.org.uk/research/questionnaires.html>) was used to find out parents' views and experiences on implantation and explore life after it.

Results: Parents were most satisfied with improved/expanded social relations, improved communication (the development of spoken language), general functioning with the help of hearing and improved self-reliance of the child. Benefit of cochlear implantation was also detected with the Categories of Auditory Performance (CAP), which was concordant with views of the parents on the progress of their child in the areas of communication and education. When deciding on implantation, the parents particularly expected auditory information to enhance their child's safety in traffic, joining socially the hearing world, and better employment prospects as adults. Concerning the process of implantation, parents especially valued the know-how and fluent services of the implant centre, positive attitude within the family and information received from other families during the time they were considering the implant decision. Parents also found it important that they have the possibility to influence the communication mode that is used in their child's educational setting.

Conclusions: Parents report that cochlear implants affect their children in a wide variety of ways that cannot be summarized by a single scale. A broader descriptive framework is required to capture their experiences adequately.

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1. Introduction

Cochlear implantation has already an established role as a treatment for profound hearing impairments in both adults and children. The effectiveness of this intervention depends, however, on many factors. Factors related to the children include, for example,

duration of sensory deprivation, the child's general developmental potential, possible concomitant problems, age at implantation, and anatomy and physiology of the inner ear and auditory pathways. Issues related to the family are parental expectations and resources to support the child in acquiring auditory experiences and spoken language, as well as dynamics of social relations within the family and with the relatives. Technological and surgical factors linked with the treatment itself also have important effects on the outcome together with the amount and quality of habilitation, education and assistance provided.

In health care, more attention is often paid to laboratory, imaging and structured behavioural measures of outcome than to

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collection of information at the everyday functional level from the patient and/or significant others. However, in paediatric cochlear implantation, factors affecting the outcomes are so numerous that only part of them can be tapped with tests and other clinical instruments. Measuring of outcomes even supplemented by quality of life instruments does not suffice. Zaidman-Zait and Most [1] emphasize that goals and wishes of parents have already to be taken seriously during planning of implantation and habilitation and in setting joint goals of intervention. Cheng and Niparko [2] also judged parental views on language and communication to be precursors to long-term outcomes, such as the psychosocial adjustment, school achievement and employment options of the child. Therefore, parents need to be recognised as important evaluators of services and a source of valuable information on quality of life that serves to guide the allocation of (re)habilitation procedures.

Physical state and mental and social functioning are all essential dimensions of quality of life. As communication and social life often change after cochlear implantation, effectiveness of implantation must be assessed not only through speech recognition or economic evaluation but also with instruments that measure ease of everyday communication, social relations, well-being, and other constituents of quality of life. Multidimensional generic instruments of health-related quality of life have been used widely with different adult populations, but they are not necessarily very sensitive in measuring audiological (re)habilitation outcomes, at least not in detecting clinically meaningful improvements [3,4]. Especially, psychosocial benefits potentially achieved with cochlear implants may not be tapped with generic wellbeing and functional health status measures [5].

Interviews and open- or closed-format or semi-structured questionnaires specifically constructed for follow-up after intervention are often more informative than generic instruments. They provide information on real-life situations and help to draw a broad picture of a person's level of activities and ability to participate in different social environments. Indeed, interviews and parental questionnaires have been used in those still relatively few studies conducted to explore the *parental expectations* [6–12], *satisfaction with implant habilitation* [6,7,13–16], *parental stress* [11,17,18], and the *quality of life* of implanted children and their families [6,11,13,17–19]. Because of cultural variation and differences between health care systems, change in quality of life after implantation needs to be studied in countries representing different kinds of cultures and views on preferred communication modes. Furthermore, after testing the utility of the survey instruments in clinical populations, they can widely be used in quality control and assurance in the clinics.

Accumulating information on parental views after implantation helps the professionals of health care and educational systems to gain insight on what is important to families, what kind of

variation exists in parental views and (possibly) why, and how the views may change over time both within and across families. With these issues in mind, the present study aimed to explore the quality of life of Finnish children and their families after paediatric cochlear implantation by using a validated questionnaire. The second aim was to find associations between the quality of life results and some background and outcome factors related to the child and some factors related to the child's family.

2. Methods

The study protocol was approved by the Ethical Board of the Northern Ostrobothnia Hospital District (Oulu, Finland), and necessary approvals for conducting the study were obtained from the four tertiary care implant centres where the data collection took place. Originally, the questionnaire was given to parents of 38 children who had been consecutively unilaterally implanted in four implant centres and had used their implant either 2 or 3 years. Parents of 36 implanted children volunteered their written informed consent to the study (response rate 95%). Parents filled out the questionnaire either at their visit to the implant centre or at home.

2.1. Children and their families

Background and outcome information on the children was derived from their patient files (Table 1). Of the children (totalling 17 males and 19 females), half (18/36) were first-born, 12 (33%) were born as the second, and six (17%) as the third child in their family. They had, on average, two siblings (range 1–6). Finnish was the native language of all the parents. Of the children, 29 (81%) lived in a nuclear family with their biological parents, whereas parent(s) of seven (19%) children had been divorced or widowed or for some other reason the child did not live with both of his/her biological parents.

During the data collection, 16 (44%) of the children had used their implant for 2, and 20 (56%) for 3 years. The children were, on average, 5 years old. Inheritance was the most prevalent reason for the children's profound hearing impairment, as 14 (39%) children were found to have a hearing impairment of genetic origin. Hearing impairment was considered to have a hereditary origin only if there was evidence of a pedigree of transmission across three generations (autosomal dominant) or hearing impaired individuals within one sibship were affected (i.e., brothers or sisters also affected, autosomal recessive) (see Ref. [20]). Three children had an inner ear malformation (e.g., common cavity) and three had had meningitis. Despite careful aetiological examination, aetiology of hearing impairment in 16 (44%) children remained unknown. In this sample, 13/36 (36%) children had additional (concomitant) problems detected at a behavioural level, generally visual

Table 1
Demographic information of the children with cochlear implants (N=36).

	N	Mean	SD	Min	Max
Preoperative duration of profound HI	35	2 years 6 months	12 months	7 months	5 years 8 months
Age at activation of CI	36	3 years 5 months	2 years 3 months	1 year 6 months	12 years 3 months
Chronological age at the time of study (years)	36	5	2	3	15
Preoperative PTA _{0.5–4 kHz} with HA (dB)	24	88	23	53	130 ^a
PTA _{0.5–4 kHz} with CI (dB)	36	30	5	20	38
Speech recognition score with CI (%)	25	76	16	27	97
CAP score ^b	36	6	1	4	7
Intelligibility of the speech of the child (%)	10	56	34	7	99

PTA_{0.5–4 kHz} = pure-tone average over the frequencies of 0.5–4 kHz, HI = hearing impairment, HA = hearing aid, CI = cochlear implant.

^a No measurable hearing at the measured frequency area = 130 dB HL [23].

^b In the CAP (Categories of Auditory Performance) scores (the scale ranges from 0 to 7), 4 = discriminates at least two speech sounds (Ling's test sounds) without speechreading, 5 = understands common phrases without speechreading, 6 = understands conversation without speechreading with a familiar talker, 7 = can use the telephone with a familiar talker.

impairment, specific language impairment or problems with fine and/or gross motor development. Because of these problems, some of these children received, for example, occupational therapy and/or were in special education. There was only a marginally significant difference in the existence of additional needs of the children when comparing 2 years vs. 3 years of implant use ($\chi^2 = 3.763$, $p = 0.052$).

Median age at activation of implants was 2 years:5 months. Altogether, 86% of the children had a bilateral prelingual profound hearing impairment, and bilateral hearing impairment of five children had progressed to profound over 1–11 years. Profound hearing impairment was defined as better ear hearing threshold level (averaged over the frequencies 0.5–4 kHz) equal to or greater than 95 dB [20]. Of the children, 28 had been provided with a Nucleus CI24M or CI24R CS device with either a SPrint (26 children) or an ESprit 3G (two children) processor, and eight used a MED-EL C40+ device (five with a CIS PRO+ and three with a Tempo+ speech processor). This is in line with the general situation in Finland, where some 30% of the implanted children are currently provided with a MED-EL implant. Finnish children have received almost exclusively only one implant. Coding strategies in use were ACE (28), N of M (1), CIS (4), and CIS+ (3). All children used their implant regularly, defined as a minimum of 6 h a day at least on 6 days a week.

Main communication mode of the child was determined on the basis of general knowledge of a speech therapist (who took part in the data collection in each of the four implant centres) on each child and his/her family (Table 2). At the hearing age of 2 years, the children had the mean Categories of Auditory Performance (CAP) score [21,22] of 5.5 (range 4–7 on a scale of 0–7), and at the hearing age of 3 years, 6.3 (range 4–7). The CAP score is an index describing the highest typical level of functional hearing in everyday life. The CAP was assessed by the same speech therapists collecting the data who judged the main communication mode of each child. When all 36 children are viewed as a group, 2 (6%) children discriminated at least two of the so called Ling's test sounds without speechreading, 13 (36%) of the children understood common phrases without speechreading, 6 (17%) understood conversation with a familiar talker, and 15 (42%) were able use the telephone with a familiar talker. Speech recognition score had reliably been examined in only 5 of the 16 children (31%) with 2 years of implant use but in all 20 children with 3 years of implant use. According to their medical records, many of the children were able to fluently recognise words and/or sentences 2 years after implantation, but insufficient co-operation because of young age or some other reason hindered carrying out formal speech audiometry reliably. The mean speech recognition score of the children was 79% at the hearing age of 2 years (SD 8, range 70–90), and 75% (SD 17, range 27–97) at the hearing age of 3 years.

In one implant centre, information on intelligibility of speech produced by the implanted children was available in a sub-sample of 10 children. Speech intelligibility of these children was explored at the time they had used their implant for 3 years. In a naming task, children produced single words, and audio-recordings of these productions were played back to panels of five listeners not familiar with speech of persons with an impaired hearing. The listeners' task was to write down the words children had produced

and speech intelligibility of each child was determined by calculating the mean of correct identifications by five listeners. Speech intelligibility was expressed as a percent correct score (see [24] for details).

2.2. Procedure

A validated closed-set questionnaire "Children with cochlear implants: parental perspectives" was used in data collection. The development of this clinical and research tool has been described earlier in several reports [13,25,26]. It is available in printed form in some recent articles [26–28], and it is also loadable for storing and analysis of the results and sharing anonymous data at <http://www.earfoundation.org.uk/research/questionnaires.html>. This questionnaire surveying phenomena of multi-faceted nature has been found to be valid and satisfactorily reliable in exploring parental experiences and views on the quality of life of the child and his/her family following cochlear implantation [26,27,29]. It is currently used by numerous implant centres worldwide. Different shortened versions of the questionnaire have subsequently been used by, for example, Incesulu et al. [30], and used and studied by Damen et al. [28].

The questionnaire comprises 74 statements provided with multiple choices on a five-point Likert scale: strongly agree (coded as 5), agree (=4), neither agree nor disagree (=3), disagree (=2), and strongly disagree (=1). Of the statements in this questionnaire, 46 are phrased in a positive and 28 in a negative form. In the present study, scoring of negative statements was reversed to be comparable with the scoring of positive statements to achieve meaningful statistical representation. The higher the score, the more positive were the parental views. Altogether 40 questions of the questionnaire can be analysed quantitatively in subscales ("general issues"), 3–6 items forming each subscale. These subscale themes illustrating the situation of a child are *communication, general functioning, self-reliance, wellbeing and happiness, social relationships and education*, and themes related to the family are *effects of implantation and supporting the child*. Additionally, data covered by 34 questions can be analysed qualitatively. These statements are most often related to *decision process of implantation and actual process of implantation*. In the questionnaire, the order of statements was deliberately non-systematic; statements belonging to each larger subscale theme did not follow each other. The 74 statements were followed by an open question where parents were given space to make comments about issues not covered in the questionnaire.

The original questionnaire was translated into Finnish. Some additional information related to the Finnish health care and educational system was also collected. For example, some questions on day-care and educational setting were followed by supplementary questions like whether the child was attending day-care outside his/her home or going to pre-school or school. In Finland, voluntary pre-school building up a child's readiness for school is provided for all children at the age of 6 years, and children begin school at the age of 7. As an exception, some children are identified by public health service personnel and school authorities to need lengthened compulsory education (part or full time special education). In this case, like with many children with a severe and most children with a profound hearing impairment, the child begins school at the age of 6 years. Two-thirds of the children belonging to the present data were younger than 6 years of age, five were 6-year-olds (i.e., in pre-school or school) and seven were of school age.

The results were scored on a scale of 1–5 by item and computed to form general issue subscales. Higher scores indicate more positive views of the parents. Mainly non-parametric

Table 2

Main communication mode of the children studied either at 2 or 3 years after activation of the implant.

	2 years (N=16)	3 years (N=20)	All (N=36)
Speech	9	15	24
Speech and signs	6	2	8
Finnish Sign Language	1	3	4

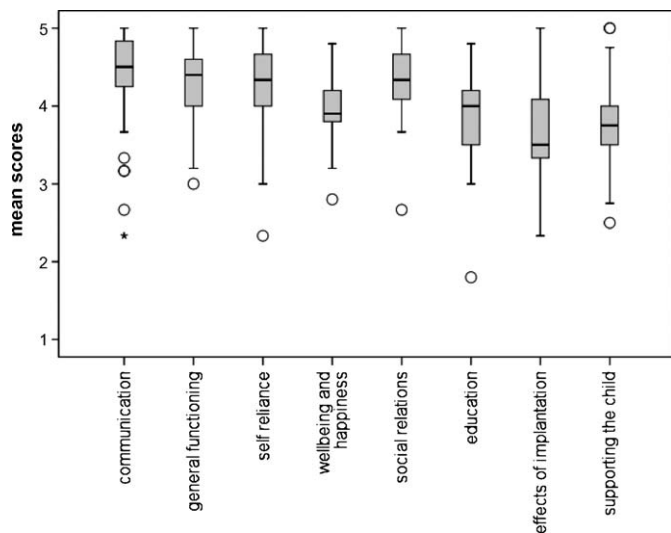


Fig. 1. Means of the parents' views on subscales related to children (from communication to education) and family (effects of implantation and need to support the child) presented as box plots. In the scoring (see Y-axis), 5 = strongly agree, and 1 = strongly disagree. The higher the score, the more positive were parents' views. Symbols represent outliers and extreme values.

statistical procedures were used in the analyses performed with the SPSS 16.0 software. Statistical significance was accepted at the $p < 0.05$ level.

3. Results

3.1. Quality of life of the children and their families

In the data, item non-responses were classified as missing values. Only 15 missing values (0.6% of the total of 2664 items [36 × 74 questions]) in altogether 13 statements were found in the returned questionnaires. Two ($N = 16$) or 3 years ($N = 20$) after implantation the parents expressed themselves to be satisfied (Fig. 1) especially with social relations (mean 4.3, with 95% confidence intervals of the mean [95% CI] 4.2–4.5, SD 0.49, range 2.7–5.0), communication (i.e., spoken language development (mean 4.3, 95% CI 4.0–4.6, SD 0.77, range 2.3–5.0), general functioning (mean 4.3, 95% CI 4.1–4.4, SD 0.46, range 3.0–5.0) and self-reliance (mean 4.3, 95% CI 4.0–4.5, SD 0.63, range 2.3–5.0)). Wellbeing and happiness, education, need to support the child and the effects of implantation on the family were rated somewhat lower (means 3.9, 3.8, 3.8 and 3.7, respectively).

Table 3

Associations (two-tailed Spearman's rho, p -values in parenthesis) between different quality of life subscales.

	Child						Family	
	Communication	General functioning	Self-reliance	Wellbeing and happiness	Social relations	Education	Effects of implantation	Supporting the child
Child								
Communication		0.165 (0.342)	0.412* (0.016)	0.066 (0.709)	0.617** (0.000)	0.723** (0.000)	0.417** (0.009)	0.089 (0.611)
General functioning			0.211 (0.225)	0.031 (0.863)	0.172 (0.355)	0.236 (0.173)	0.284 (0.122)	0.290 (0.087)
Self-reliance				0.264 (0.132)	0.460** (0.009)	0.279 (0.110)	0.216 (0.244)	0.278 (0.105)
Wellbeing and happiness					−0.160 (0.934)	0.037 (0.837)	0.081 (0.671)	0.371* (0.031)
Social relations						0.494** (0.006)	0.386* (0.035)	0.339 (0.062)
Education							0.231 (0.218)	0.172 (0.322)
Family								
Effects of implantation								0.091 (0.627)
Supporting the child								

* $p < 0.05$.

** $p < 0.01$.

3.2. Associations between different subscales related to quality of life

Spearman's correlation coefficient was used to detect possible associations between different subscales related to quality of life. Some statistically significant associations between various subscales were found (Table 3). For example, the better the child's spoken language communication, the more independent was the child (i.e., had better self-reliance) and/or the better was his/her self-esteem (subscale social relations). Better spoken language development was also associated with more fluent interaction with friends, family members and relatives, with better level of functioning at day-care or school (in mainstream setting) and more positive views of the parents on the effects of implantation. Child's increased wellbeing and happiness at the level of his/her overt behaviour was associated with the reduced need of the parents to assist the child in everyday life of the family (subscale supporting the child). As assessed by the parents, better quality of the child's social relations was statistically significantly associated not only with good spoken language development but also with more positive effects of implantation, the child's better self-reliance and level of functioning in day-care or school. Nonetheless, only eight of a possible 28 correlations are significant, showing that the subscale scores represent somewhat different dimensions of variation; they do not all simply reflect a single scale of performance with the cochlear implant. This finding is in accordance with the construction of the subscales, which were based on a factor analysis that attempted to make the scales orthogonal.

3.3. Associations between background factors, some outcome factors, and different subscales related to quality of life

In our second research question we wanted to explore if some of the children's background and outcome factors and factors related to the child's family could shed light on the parental views on quality of life issues.

The parents' views on the child's communication ability were significantly associated with the CAP score (Table 4 and Fig. 2). This implies that better hearing ability promotes spoken language development. In the parental questionnaire, improved general functioning illustrates child's increased reliance on auditory information and functional hearing in his/her everyday environment. However, in this sample of children, general functioning was not associated with speech recognition score measured in the clinic or with the CAP score. Instead, better CAP score (speech recognition ability in everyday life) was associated with higher scores assigned by parents concerning progress at pre-school/school; that is, better scores in the subscale education. Speech

Table 4
Associations (p-values in parenthesis) between certain background and outcome factors of the children and quality of life subscales related to the child and his/her family.

	Child						Family	
	Communication	General functioning	Self-reliance	Wellbeing and happiness	Social relations	Education	Effects of implantation	Supporting the child
Number of additional needs (range 0–3) ^a	-0.323 (0.058)	-0.216 (0.205)	-0.092 (0.598)	-0.014 (0.559)	0.031 (0.868)	-0.350 [*] (0.039)	0.017 (0.930)	-0.205 (0.230)
CAP (on a scale of 0–7) ^a	0.498 ^{**} (0.002)	0.184 (0.284)	0.233 (0.178)	-0.300 (0.085)	0.348 (0.055)	0.437 ^{**} (0.009)	0.264 (0.151)	-0.124 (0.473)
Speech recognition score ^b	0.149 (0.477)	0.268 (0.195)	0.204 (0.327)	0.089 (0.673)	0.449 [*] (0.036)	0.457 [*] (0.022)	-0.173 (0.440)	0.066 (0.754)
Speech intelligibility of the child (N = 10) ^a	0.710 [*] (0.022)	0.399 (0.253)	0.329 (0.353)	-0.295 (0.408)	0.085 (0.827)	0.778 ^{**} (0.008)	-0.105 (0.774)	0.025 (0.945)

^a Two-tailed Spearman's rho.
^b Pearson's correlation coefficient.
^{*} p < 0.05.
^{**} p < 0.01.

recognition score, obtained from 25 children, was rather well in line with CAP as it was also statistically significantly associated with *education* and, additionally, with *social relations* (Table 4).

It was of particular interest to investigate if the situation of the 13 children (36% of all the children studied) with additional needs (concomitant problems) and their families differed from those children with no known additional needs. Children with one or more additional needs had lower mean scores (on average, 0.31 lower) in all quality of life subscales except *effects of implantation*. It is understandable that parents of children with additional needs may sometimes perceive progress of their child as particularly positive, because their prior expectations have not been very high. However, number of additional needs (range 0–3 per child) correlated significantly (Spearman's correlation coefficient -0.350, p = 0.039) only with the subscale *education*; the more concomitant problems the child had, the more negative the parents rated their child's situation in education (Table 4). Additionally, children with additional needs did not differ from children without them in any of the quality of life subscales. This may be related to the finding that neither their age at activation, hearing thresholds with implant nor speech recognition scores differed statistically significantly from those of the children (N = 23) with no additional needs.

Main communication mode, as an easily detectable indicator of child's auditory development after implantation, is an important

issue to be looked at more closely. Statistically significant differences were found on how satisfied the parents were with *communication* (Kruskal–Wallis test, Z = 12.66, df = 2, p = 0.002) and *education* (Kruskal–Wallis test, Z = 9.09, df = 2, p = 0.011); parents were more content with these areas related to quality of life when their child used spoken language (Fig. 3). Parents had clearly sought spoken language development with the implant decision, as parents whose child used speech were more content with his/her *communication* than parents whose child used speech and signs (Mann–Whitney test, Z = -2.57, p = 0.010) or Finnish Sign Language (Mann–Whitney test, Z = -2.76, p = 0.006). Additionally, parents whose child used spoken language were more satisfied with the *educational* issues than those of children using Finnish Sign Language as their main communication mode (Mann–Whitney test, Z = -2.68, p = 0.007). Similar difference in the parental views on *effects of implantation* was also found between speaking children and children using Finnish Sign Language (Mann–Whitney test, Z = -2.16, p = 0.031).

Children using speech and signs (N = 8) seemed to differ from those using Finnish Sign Language (N = 4), as their CAP scores were statistically significantly higher (Mann–Whitney test, Z = -2.01, p = 0.044), number of additional needs lower, and all of their and their families' mean scores in quality of life subscales higher compared with the children using sign language. However, the only statistically significant difference in quality of life subscales

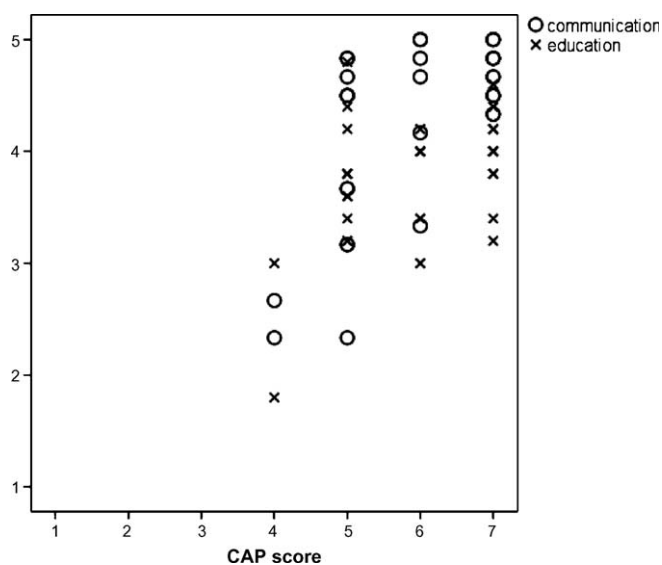


Fig. 2. Association of the child's level of functional hearing in everyday life (CAP score) with mean scores of parents' views on the child's *communication* (spoken language development, Spearman's rho = 0.498) and *education* (r = 0.437).

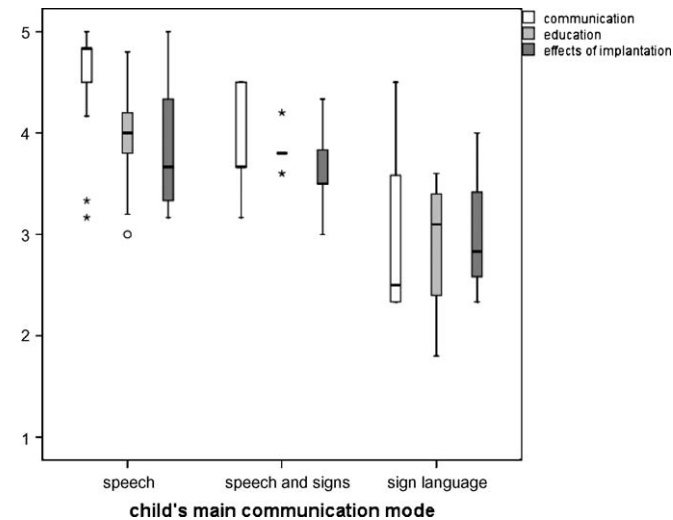


Fig. 3. Speech as a main communication mode of the child implied parents' more positive views on *communication*, *education* and *effects of implantation*. Two to three years after implantation, speech was used by 24, speech and signs by 8, and Finnish Sign Language by 4 children. All of the children using Finnish Sign Language had concomitant problems in addition to their hearing impairment.

between these two groups was related to *education*: children using speech and signs outperformed the children using Finnish Sign Language in their level of functioning in different educational environments (Mann–Whitney test, $Z = -2.39$, $p = 0.017$). It has to be noted, that all four children using Finnish Sign Language as their main communication mode had additional needs. Additionally, three of them had inner ear malformations or had had meningitis, and their speech recognition score was, on average, lower than that of children using speech or speech and signs. No change (i.e., continuing use of Finnish Sign Language) in the child's preoperative main communication mode can therefore be inferred to be a consequence from the child's health situation. In our data, none of the families shared the bilingual–bicultural approach in raising their child/children with a hearing impairment. Instead, use of sign language was related to, e.g., verbal dyspraxia or only modest development of auditory skills. Main communication mode can hence be considered as a true outcome measure in the present data.

Association between speech intelligibility and parental views was explored within a sub-sample of the present study. This was carried out by combining two sources of data related to 10 children in one implant centre. Speech intelligibility of these 10 children was explored at the time they had used their implant for 3 years. It was found that better speech intelligibility was rather strongly associated with more positive views of parents on their child's communication ($r = 0.710$) and education ($r = 0.778$). This implies that parental views on their child's spoken language development were realistic and corresponded with the actual identification of the children's productions by lay listeners.

Those families that had a first-born child with a profound hearing impairment reported on somewhat lower quality of life scores of their child compared with other families. In these families, scores of the subscale *wellbeing and happiness* were statistically significantly (mean score 3.76 vs. 4.13; Mann–Whitney test, $Z = -2.32$, $p = 0.022$) lower than of those implanted children, who had been born as the second child in their family. Hearing impairment ascertained in the first-born child may therefore be a bigger challenge for the families than hearing problems of the second child. These results may, however, be confounded by the fact that relatively more (44%) of the first-born children had at least one concomitant problem in addition to their hearing impairment, compared with the children born as the second child (25%) in their family. Furthermore, *effects of implantation* were seen to be somewhat more positive in children born as the second child compared with those born as the third child (mean score 3.79 vs. 3.22; Mann–Whitney test, $Z = -2.46$, $p = 0.013$). Of the children born as the second ($N = 12$) or third child ($N = 6$) in their family, 14 (78%) had a normally hearing older sibling(s), three had an older sibling with a hearing impairment, and one had both. Neither number of children in the family nor family type (both biological parents in the family or not) was associated with the subscale results.

3.4. Issues analysed qualitatively

As explained in Section 2, altogether 34 of the statements of the parents' questionnaire were meant to be analysed qualitatively. Of the statements belonging to the subscale *decision process of implantation* parents agreed most strongly with issues related to their child's safety, social relations and future employment prospects as adults (Fig. 4).

During the *process of implantation* parents especially valued the knowledge (know-how) and coherent services of the implant centre, positive attitude within the family and information from other families during the time they were thinking about the implant decision (Fig. 5).

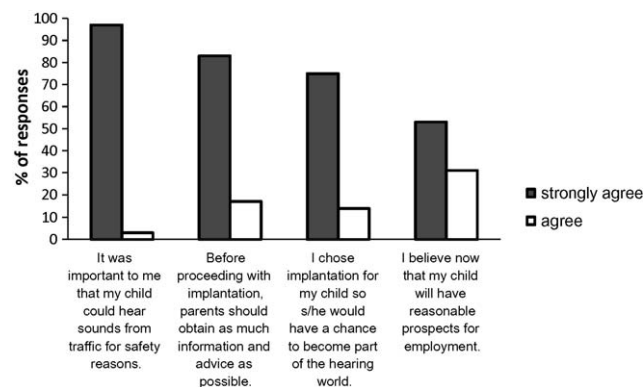


Fig. 4. Statements belonging to the subscale *decision process of implantation* the parents most strongly agreed with.

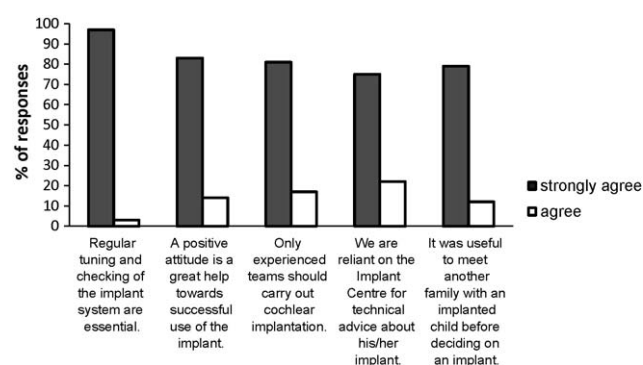


Fig. 5. Statements belonging to the subscale *process of implantation* the parents most strongly agreed with.

Concerning those qualitatively analysable statements not belonging to either of the thematic subscales *decision process of implantation* or *process of implantation*, the parents agreed most with the statements "A parent of a child with an implant needs to be patient as benefits may take time to show" (issue of *supporting the child*; 64% strongly agreed, and 31% agreed), "Parents should have a choice in the use of sign language at school" (*education*; 61% strongly agreed, and 28% agreed), "Before implantation s/he obtained no benefit at all from his/her hearing aids" (*general functioning*; 58% strongly agreed, and 19% agreed), and "S/he was very dependent on us before the implantation" (*supporting the child*; 42% strongly agreed, and 28% agreed).

Eight parents had given their free comments in a text box on the last page of the questionnaire. Four of these parents expressed their satisfaction with their child's development. One parent/family had commented the statement "I can now let him/her play outside as s/he is aware of the sound of traffic". This parent had noted that during the winter, winter clothes (winter cap and/or hood) sometimes made it difficult for a child to hear the sound of traffic. This parent also valued the use of signs when the speech processor was not in use. Another parent/family expressed a strong concern about their teenager and desired more support from the implant centre on issues related to social relations.

4. Discussion

In this sample of 3–15-year-old implanted children and their families, Finnish parents usually expressed great satisfaction with the quality of life of their child and the family 2–3 years after implantation. Parents' expectations were fulfilled best in improved/expanded *social relations*, improved *communication*

(the development of spoken language), *general functioning* with the help of hearing, and improved *self-reliance* of the child. Benefit of cochlear implantation was also shown by development of speech recognition ability, and functional hearing, as measured with the CAP score; the latter was also concordant with the personal views of the parents on child's progress in the areas of *communication* and *education*. However, when thinking about the *effects of implantation*, parents were rather worried about the possibility of device failure, and recognised the need to still *support their child*. In line with the present study, improved communication and self-confidence/self-reliance of a child, and better social relations within the family after cochlear implantation, have been reported earlier [7,8,13,19,31–35].

Correlation statistics generally showed relatively weak associations between the quality of life subscales and background factors, with statistically significant associations found between functional hearing (CAP score) and the subscales *communication* and *education*. Speech recognition score was associated with the subscales *social relations* and *education*. Additionally, those children having concomitant problems had lower scores in *education*, and the child's good speech intelligibility measured with listening tests was associated with better level of functioning in *communication* and *education*. Main communication mode and speech intelligibility was also indicative of parental views on *communication* and the child's level of functioning in *education*. As two-thirds of the children in the present data were not yet at school, but in the majority of cases in mainstream kindergarten provided with a personal aid, functional hearing may well illustrate child's ability to adapt him/herself to the company of hearing age mates in day-care. Distribution of different main communication modes across the children matches rather well information provided by the other sparse Finnish reports published [40–42].

In a 5-year follow-up study, Huttunen [24] reported on speech intelligibility and narrative abilities of 18 Finnish children who had used their implant for 3–5 years. Ten of these children were also included in the present data on parental views. Listening tests, in which lay listeners wrote down words the children had produced, revealed that 3 and 5 years after activation of the implant the 18 children had reached mean intelligibility scores of 53 and 81%, respectively. Intelligibility of children's speech was found to be associated with parental views on *communication* and *education*; that is, children speaking more clearly, as verified by listening tests, were perceived by their parents to have better level of spoken language and progress in education. Although large variation in speech and language acquisition of implanted children is a fact [18,33], and sometimes very high expectations of mothers with a child using a cochlear implant have been reported [36], the results of the present study confirm that parents' views and experiences on their child's communication abilities can be very realistic. Speech intelligibility has not only been found to be associated with parental satisfaction with implantation. It has also been detected to affect the child's social and emotional feelings in mainstreamed settings. Most [37] found that individually integrated teens who were rated by their peers as having better speech intelligibility, rated themselves as feeling less lonely and as having more coherence than those whose speech intelligibility was lower.

When studied in larger child groups than that of the present study, research may uncover more associations between background factors and quality of life subscales. This information is important for cochlear implant teams to be used in family counseling, in helping parents to set realistic expectations. Although reports have been rather consistent that parents' preoperative expectations have been realistic [7,11,16,33], parental expectations are known to change as a function of their child's progress [33,38,39]. Parents who perceive the implant as a

beneficial device will probably take more care of its maintenance and support its use better than parents that do not think so. Clinicians have therefore to be sensitive to parental views as the parents naturally are the closest and the best resource of support for the child, and parental involvement is an important predictor of a child's development [43].

When a child grows, s/he is expected develop in the area of communication and to be more confident and socially mature. In follow-up studies related to effectiveness of intervention, and especially in proxy measures like parental questionnaires, validity of an instrument may be threatened by maturation as an intervening factor. However, when giving their informed consent, the parents of the present study were explicitly told that the purpose was to examine the effects of cochlear implantation on the basis of parental views, expectations and experiences. Additionally, the introduction and instructions section and the statements of the questionnaire clearly inform the parents that their answers are expected to reflect the possible changes that cochlear implantation has brought to the life of their child and the family, compared to the situation before implantation, and to the expectations of the parents on how life would have turned out without implantation. Face validity of the questionnaire has a strong basis because the statements the questionnaire comprises are derived from interviews of implanted children's parents [13,25].

It was possible to directly compare the results of the present study with those of Damen et al. [28], to examine possible cultural differences in outcomes of implantation. Of the total of 40 quantitatively analysable statements, in 28 (70%) the situation of Finnish children ($N = 36$) and their families were rated as more positive compared with those of Dutch children ($N = 130$) and their families. Finnish parents viewed their child's situation to be better than Dutch parents, especially in the areas of self-reliance and social relations (differences between the two countries in these subscale means were 0.52 and 0.48, respectively). It is difficult to find reasons why this was the case, but at least the Dutch children (mean age 8 years) were, on average 3 years older than the Finnish children. They also had received their implant, on average, a year later than the Finnish children, and a third had meningitis as a cause of their profound hearing impairment compared with only three children (8%) in the present Finnish data. Greater age of the Dutch children with meningitis, having possibly caused also other problems than profound hearing impairment, may partly explain the difference between the Finnish and the Dutch children. Additionally, the Dutch sample consisted of children that had used their implant for 1 year at minimum, whereas the present data were derived from families where the child had received the implant 2 or 3 years before the questionnaire was filled out by the parents. More experience with the implant may possibly serve as a partial explanation for the somewhat more positive Finnish findings. It has to be noted, however, that our Finnish sample size was only less than one-third of the Dutch one, and individual variation may hence affect it much more. The response rate in Finland was 95% compared with 74% in the Netherlands, and both of the samples comprised consecutively implanted children, so they both are probably free from a major bias.

It will be interesting to see if bilateral cochlear implantation will bring added value in the area of quality of life of children and their families. Scherf et al. [44] already reported such a finding on 35 Belgian children. In the future, it is also necessary to study more closely what are the effects of different parts of care and habilitation in paediatric cochlear implantation. Finding the optimal quantity and quality of habilitation each child needs helps cochlear implant centres and local rehabilitation personnel to plan their activities and reserve resources for services in the long run. For example, Zeng [45] has argued that part of the variation in

results after cochlear implantation may be explainable by the amount of rehabilitation services provided.

Thus far, research from different countries has shown that parents report quite similar benefits of their child's unilateral implantation. This is not to say that cultural variation would not exist in the parents' expectations and in the degree they are met, depending on the amount, nature and quality of services of each health care and educational system. For example, sometimes the main communication mode used in day-care of implanted children may also solely be sign language [46], or either bilingual or monolingual approaches may be used depending on the part of the country [47]. Therefore, information from many countries and cultures is needed to draw a detailed enough picture on the effects of implantation for tailoring service provision.

5. Conclusions

In the present study, cochlear implantation, habilitation and education provided after the surgery improved quality of life of both Finnish implanted children and their families. Access to auditory information helped the children to join the hearing world and to learn to speak. Parents perceived this to have positive effects on the self-reliance, communication, general functioning and social relations especially of their children.

In accordance with a large body of earlier research, it was found that implanted children, like children with hearing impairments overall, do not form a homogeneous group. We also noticed that parents' experiences on the effects of implantation were multifaceted in nature. There is therefore a need to use a qualitative instrument, like the one used in the present study, to explore the richness and variety of parental views: a single, one dimensional quantitative scale does not suffice.

Conflict of interest statement

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References

- [1] A. Zaidman-Zait, T. Most, Cochlear implants in children with hearing loss: maternal expectations and impact on the family, *Volta Rev.* 105 (2) (2005) 129–150.
- [2] A.K. Cheng, J.K. Niparko, Cost-effectiveness of the cochlear implant in children, in: *Cochlear Implantation: Cost Creating or Cost Saving?* Proceedings of Conference on Health Technology Assessment, Queen's Medical Centre, Nottingham, UK, 18 May 2001, Hughes Associates, Oxford, UK, 2001, pp. 111–119.
- [3] F. Bess, The role of generic health-related quality of life measures in establishing audiological rehabilitation outcomes, *Ear Hear.* 21 (4, Suppl.) (2000) 74S–79S.
- [4] P. Karinen, M. Sorri, T. Välimaa, K. Huttunen, H. Löppönen, Cochlear implant patients and quality of life, *Scand. Audiol.* 30 (Suppl. 52) (2001) 48–50.
- [5] T. Sach, Current knowledge and future directions: the economics of cochlear implantation, in: *Cochlear Implantation: Cost Creating or Cost Saving?* Proceedings of Conference on Health Technology Assessment, Queen's Medical Centre, Nottingham, UK, 18 May 2001, Hughes Associates, Oxford, UK, 2002, pp. 35–70.
- [6] T.P. Nikolopoulos, H. Lloyd, S.M. Archbold, G.M. O'Donoghue, Pediatric cochlear implantation: the parent's perspective, *Arch. Otolaryngol. Head Neck Surg.* 127 (4) (2001) 363–367.
- [7] D.M.R. Kelsay, R.S. Tyler, Advantages and disadvantages expected and realized by pediatric cochlear implant recipients as reported by parents, *Am. J. Otol.* 17 (6) (1996) 866–873.
- [8] T.N. Kluwin, D.A. Stewart, Cochlear implants for younger children: a preliminary description of the parental decision process and outcomes, *Am. Ann. Deaf* 145 (1) (2000) 26–32.
- [9] Y. Li, L. Bain, A.G. Steinberg, Parental decision-making in considering cochlear implant technology for a deaf child, *Int. J. Pediatr. Otorhinolaryngol.* 68 (8) (2004) 1027–1038.
- [10] S. Okubo, M. Takashi, I. Kai, How Japanese parents of deaf children arrive at decisions regarding pediatric cochlear implantation surgery: a qualitative study, *Soc. Sci. Med.* 66 (12) (2008) 2436–2447.
- [11] B. Richter, C. Spahn, I. Zschocke, M. Leucter, R. Laszig, E. Löhle, Psychische Belastung, Informiertheit und Behandlungswartung von Eltern mit einem Cochlear Implant versorgten Kind, *HNO* 48 (9) (2000) 675–683.
- [12] A. Steinberg, A. Brainsky, L. Bain, L. Montoya, M. Indenbaum, W. Potsic, Parental values in the decision about cochlear implantation, *Int. J. Pediatr. Otorhinolaryngol.* 55 (2) (2000) 99–107.
- [13] S. Archbold, M. Lutman, S. Gregory, C. O'Neill, T. Nikolopoulos, Parents and their deaf child: their perceptions three years after cochlear implantation, *Deaf Educ. Int.* 4 (1) (2002) 12–40.
- [14] S. Archbold, T. Sach, C. O'Neill, M. Lutman, S. Gregory, Outcomes from cochlear implantation for child and family: parental perspectives, *Deaf Educ. Int.* 10 (3) (2008) 120–142.
- [15] R. Chmiel, L. Sutton, H. Jenkins, Quality of life in children with cochlear implants, *Ann. Otol. Rhinol. Laryngol. (Suppl. 185)* (2000) 103–105.
- [16] J.K. Cunningham, Parent's evaluations of the effects of the 3M/House cochlear implant on children, *Ear Hear.* 11 (5) (1990) 375–381.
- [17] E. Beadle, A. Shores, E. Wood, Parental perceptions of the impact upon the family of cochlear implantation in children, *Ann. Otol. Rhinol. Laryngol. (Suppl. 185)* (2000) 111–114.
- [18] S.C. Purdy, L.L. Chard, C.A. Moran, S.-A. Hodgson, Outcomes of cochlear implants for New Zealand children and their families, *Ann. Otol. Rhinol. Laryngol. (Suppl. 166)* (1995) 102–105.
- [19] K. Huttunen, M. Sorri, T. Välimaa, Parents' views of their children's habilitation after cochlear implantation, in: *Measuring the Immeasurable? Proceedings of a Conference on Quality of Life in Deaf Children*, Nottingham, UK, 17 May 2002, Hughes Associates, Oxford, 2003, pp. 87–96.
- [20] EU Working Group on Genetics of Hearing Impairment, in: A. Martini (Ed.), *European Commission Directorate, Biomedical and Health Research Programme Hereditary Deafness, Epidemiology and Clinical Research (HEAR)*, Infoletter 2 (1996) 8–9. Available also online at <http://audiology.unife.it/www.gendef.org/index.html>.
- [21] S. Archbold, M. Lutman, D. Marshall, Categories of Auditory Performance, *Ann. Otol. Rhinol. Laryngol.* 104 (Suppl. 166) (1995) 312–314.
- [22] S. Archbold, M. Lutman, T. Nikolopoulos, Categories of auditory performance: inter-user reliability, *Br. J. Audiol.* 32 (1) (1998) 7–12.
- [23] British Society of Audiology recommendation, Descriptors for pure-tone audiograms, Technical Note, *Br. J. Audiol.* 22 (2) (1988) 123.
- [24] K. Huttunen, Development of speech intelligibility and narrative abilities and their interrelationship three and five years after paediatric cochlear implantation, *Int. J. Audiol.* 47 (Suppl. 2) (2008) S38–S46.
- [25] S. Archbold, T. Nunes, M. Lutman, U. Pretzlik, S. Gregory, Parental perspectives of children with cochlear implants: the validated questionnaire, in: *Measuring the Immeasurable? Proceedings of a Conference on Quality of Life in Deaf Children*, Nottingham, UK, 17 May 2002, Hughes Associates, Oxford, 2003, pp. 97–108.
- [26] C. O'Neill, M. Lutman, S. Archbold, S. Gregory, T. Nikolopoulos, Parents and their cochlear implanted child: questionnaire development to assess parental views and experiences, *Int. J. Pediatr. Otorhinolaryngol.* 68 (2) (2004) 149–160.
- [27] T. Nunes, U. Pretzlik, S. Ilicak, Validation of a parent outcome questionnaire from a pediatric cochlear implantation, *J. Deaf Stud. Deaf Educ.* 10 (4) (2005) 330–356.
- [28] G. Damen, P. Krabbe, S. Archbold, E. Mylanus, Evaluation of the Parental Perspective instrument for pediatric cochlear implantation to arrive at a short version, *Int. J. Pediatr. Otorhinolaryngol.* 71 (3) (2007) 425–433.
- [29] T. Nunes, U. Pretzlik, An independent Assessment and Evaluation of a Profile from Parents of Deaf Children with a Cochlear Implant, Oxford Brookes University, Oxford, 2003.
- [30] A. Incesulu, M. Vural, U. Erkam, Children with cochlear implants: parental perspective, *Otol. Neurotol.* 24 (4) (2003) 605–611.
- [31] Y. Bat-Chava, D. Martin, J. Kosciw, Longitudinal improvements in communication and socialization of deaf children with cochlear implants and hearing aids: evidence from parental reports, *J. Psychol. Psychiatr.* 46 (12) (2005) 1287–1296.
- [32] K. Huttunen, T. Välimaa, P. Karinen, M. Sorri, Vanhempien ja puheterapeuttien odotusten toteutuminen sisäkorvaistutetuntoutuksessa (Fulfillment of expectations of parents and speech therapists in cochlear implant rehabilitation), in: E. Lehto, M. Hasan, R. Parkas (Eds.), *Satakieliseminaari 2008, Satakieliohjelma*, Helsinki, 2008, pp. 90–99.
- [33] T.H. Sach, D.K. Whyne, Paediatric cochlear implantation: the views of parents, *Int. J. Audiol.* 44 (7) (2005) 400–407.
- [34] L.M. Watson, T. Hardie, S.M. Archbold, A. Wheeler, Parents' views on changing communication after cochlear implantation, *J. Deaf Stud. Deaf Educ.* 13 (1) (2008) 104–116.
- [35] S. Wiley, M. Jahnke, J. Meinzern-Derr, D. Choo, Perceived qualitative benefits of cochlear implants in children with multi-handicaps, *Int. J. Pediatr. Otorhinolaryngol.* 69 (6) (2005) 791–798.
- [36] A. Weisel, T. Most, R. Michael, Mother's stress and expectations as a function of time since child's cochlear implantation, *J. Deaf Stud. Deaf Educ.* 12 (1) (2006) 55–64.
- [37] T. Most, Speech intelligibility, loneliness, and sense of coherence among deaf and hard-of-hearing children in individual inclusion and group inclusion, *J. Deaf Stud. Deaf Educ.* 12 (4) (2007) 495–503.
- [38] J.L. Perold, An investigation into the expectations of mothers of children with cochlear implants, *Cochl. Impl. Int.* 2 (1) (2001) 39–58.
- [39] C. Spahn, B. Richter, T. Burger, E. Löhle, A comparison between parents of children with cochlear implants and parents of children with hearing aids regarding parental distress and treatment expectations, *Int. J. Pediatr. Otorhinolaryngol.* 67 (9) (2003) 947–955.
- [40] M. Hasan, E. Lonka, Sisäkorvaistutetta käyttävien lasten kommunikaatio-, koulu- ja päivähoitotilanne Suomessa (Communication, education and day-care of children using a cochlear implant in Finland), in: E. Lehto, M. Hasan, R. Parkas (Eds.),

- Satakieliseminaari 2006, Satakieliohjelma, Helsinki, 2006, pp. 73–79 (summary is available also online at <http://www.satakieliohjelma.fi/kartoitus.htm>).
- [41] E. Lonka, Children with cochlear implants acquiring the Finnish language, in: A. Klippi, K. Launonen (Eds.), *Research in Logopedics. Speech and Language Therapy in Finland*, Multilingual Matters, Clevedon, 2008, pp. 206–220.
- [42] H. Sume, *Perheen pyörteinen arki. Sisäkorvaistutetta käyttävän lapsen matka kouluun (Turbulent life of the family, Way to school of a child with cochlear implant)*, Jyväskylä Studies in Education, Psychology and Social Research, 334, Dissertation, Jyväskylä: University of Jyväskylä, Finland, 2008.
- [43] R. Calderon, Parental involvement in deaf children's education programs as a predictor of child's language, early reading, and social-emotional development, *J. Deaf Stud. Deaf Educ.* 5 (2) (2000) 140–155.
- [44] F. Scherf, L. van Deun, A. van Wieringen, J. Wouters, C. Desloovere, I. Dhooge, et al., Functional outcome of sequential bilateral cochlear implantation in young children: 36 months postoperative results, *Int. J. Pediatr. Otorhinolaryngol.* 73 (5) (2009) 723–730.
- [45] F.-G. Zeng, Trends in cochlear implantation, *Trends Amplif.* 8 (1) (2004) 1–34.
- [46] O. Bo Wie, E.-S. Falkenberg, O. Tsvete, B. Tomblin, Children with a cochlear implant: characteristics and determinants of speech recognition, speech-recognition growth rate, and speech production, *Int. J. Audiol.* 46 (5) (2007) 232–243.
- [47] C.H. Wiefferink, G.W.G. Spaai, N. Uilenburg, B.M. Vermeij, L. De Raeve, Influence of linguistic environment on children's language development: Flemish versus Dutch children, *Deaf Educ. Int.* 10 (4) (2008) 226–243.