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## Opportunities within and after rehabilitation for patients with hearing loss

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Quality of Life of Children with Hearing Loss  
in Special and Mainstream Education:  
a Longitudinal Study

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## ABSTRACT

**Objectives:** To compare the quality of life (QoL) of children with hearing loss (HL) and children with normal hearing (NH) and to examine how the QoL of children with HL changes over time, considering language skills, type of hearing device, degree of HL, and type of education.

**Materials & Methods:** This longitudinal study included 62 children with HL and their parents. Developmental outcome data were collected at two time points, when the mean ages of the children were 4 and 11 years. The Pediatric Quality of Life (PedsQL™) questionnaire, which includes assessments of Physical, Emotional, Social, and School functioning, was completed by parents at both time points and by the children with HL at the second time point. Receptive and expressive language skills at 4 years were assessed by the Reynell Developmental Language Scale. Results were compared with a Dutch normative sample.

**Results:** The QoL of children with HL was similar to that of children with NH at both time points on two of the four QoL scales, Emotional and Physical functioning. On the other two scales, Social and School functioning, children with HL who attended special education and children who switched to mainstream education showed lower scores than children with HL who were consistently in mainstream education and lower scores than children with NH. The School QoL of children with HL decreased over time, as did the School QoL of children with NH. Social QoL of children with cochlear implants decreased over time, but this was not the case in children with hearing aids. Language skills and the degree of HL did not clinically improve the QoL over time of preschool children with HL.

**Conclusions:** The QoL of children with HL in mainstream education and the Physical and Emotional QoL of all children with HL were satisfactory. It is essential to develop specific guidance regarding school activities for children with HL in special education and for children with HL who switch to mainstream education in order to increase their social QoL.

## INTRODUCTION

Hearing loss (HL) greater than 25 dB HL is a serious condition that affects 1–1.7:1000 infants worldwide at birth and this number increases with age due to progressive or late onset hearing loss (Korver et al., 2010; Mehra et al., 2009; van der Ploeg et al., 2015). Children who have been identified with permanent childhood hearing impairment which require auditory amplification must cope with their HL in everyday situations. They experience language and communication problems that are consequences of their diminished auditory input (Moeller et al., 2007; Stevenson et al., 2015; Yoshinaga-Itano, 2003b). In noisy environments, such as classrooms or school playgrounds, they regularly misperceive crucial information (A. E. Geers et al., 2013; McCreery et al., 2015; Nitttrouer et al., 2013; Picard & Bradley, 2001). The misunderstanding and/or misinterpreting of social situations can lead to feelings of exclusion and eventually to social and emotional difficulties (Fellinger et al., 2012; Moeller et al., 2007; Netten et al., 2015; Stephanie C P M Theunissen et al., 2014). Meta-analyses show that HL is associated with a lower quality of life (QoL) for social interactions and school activities (Nordvik et al., 2018; Roland et al., 2016). Although factors such as hearing devices (Liu et al., 2016; Roland et al., 2016; Schorr et al., 2009) and better language skills (Clark et al., 2012; Kushalnagar et al., 2014; Netten et al., 2015) contribute positively to the development and QoL of children with HL, these studies are cross-sectional, which prevents us from drawing conclusions about the causality of these relationships. Therefore, the present longitudinal study investigated the extent to which QoL of children with HL changed over time and whether language ability, type of hearing device, degree of HL, and type of education were associated with changes in QoL of these children.

Health-related QoL, which we refer to as QoL, encompasses the physical and psychosocial aspects of an individual's perception of their position in life (Whoqol Group, 1994). QoL is an important outcome measure that is widely used for clinical and research purposes to assess the impact of acute and chronic diseases, to compare affected individuals with healthy individuals, and to measure progress after treatment. It is known that QoL of children with HL increases after receiving auditory rehabilitation alongside their hearing device such as a hearing aid (HA) or cochlear implant (CI) (Liu et al., 2016; Roland et al., 2016; Schorr et al., 2009). However, there appears to be a lack of consistency within the literature regarding the comparison of QoL of children with and without HL. Some studies reported no difference (Borton et al., 2010; M Wake et al., 2006) and a number of studies showed that children with HL had a lower QoL compared to the children without HL (Rachakonda et al., 2014; Schick et al., 2013; Melissa Wake et al., 2004). When considering the different

domains of QoL, the outcomes of a meta-analysis showed that children with HL had lower general QoL in terms of school and social domains than their peers with normal hearing (NH), although children with and without HL did not differ in physical and emotional domains (Roland et al., 2016). The lower QoL with regard to school and social domains is often assumed to be related to the diminished auditory input received by children with HL. However, various other risk and protective factors affecting the QoL of individuals with HL have been identified.

Many studies emphasize the importance of language for the development of children with HL (Clark et al., 2012; Kushalnagar et al., 2014; Netten et al., 2015). Language delays are relatively common in children with HL and affect their communication, academic outcomes, and social-emotional functioning since they face more difficulties in expressing themselves and understanding others (Clark et al., 2012; Fellingner et al., 2012; Moeller et al., 2007; Stevenson et al., 2015; S.C.P.M. Theunissen, Rieffe, Kouwenberg, et al., 2014; Yoshinaga-Itano, 2003a). In addition, the type of educational setting is reported to be related to the QoL of children with HL. Children in special education report a lower QoL than children with and without HL in mainstream settings. This is associated with IQ level, additional disabilities, degree of HL, and communication abilities (Hintermair, 2011; Keilmann et al., 2007; Schick et al., 2013). Inclusive educational settings have made it possible to include children with HL without additional severe disabilities and who have adequate speech and language skills into mainstream schools with or without extra support (Chorozoglou et al., 2018; Marlatt, 2014; Raeve, de, 2010; Sontag, 2006; Xie et al., 2014). No studies to date have examined whether switching from special to mainstream education has an impact on the QoL of children with HL in comparison to children with HL who remain in special or mainstream education.

To the best of our knowledge, this nationwide study is the first to examine longitudinal changes of QoL outcomes of children with HL. Longitudinal studies can identify causal relationships and define developmental trends between groups. Data of this study were collected at two time points, when the mean ages of the children with HL were 4 and 11 years. These time points captured the beginning and end of their primary school years, allowing us to obtain an impression of the development of QoL of school-aged children with HL.

First, we compared the QoL of children with HL with the QoL of a normative group of Dutch children with NH (Roland et al., 2016). Second, we examined changes in the QoL of children with HL over time. Given the lack of research in children with HL, we based our expectations on research in children with NH and expected a decrease of QoL over time as life becomes more challenging with age (Bisegger et al., 2005; Meade & Dowswell, 2016). Third, we aimed to identify the risk and protective factors associated with changes in the QoL over time of children with HL. Based on existing literature, we expected that higher language skills and attending mainstream education would have a positive effect on the QoL (Hintermair, 2011; Keilmann et al., 2007; Moeller et al., 2007; Netten et al., 2015; Schick et al., 2013; Yoshinaga-Itano, 2003b). This study also considered the QoL of a novel group of children with HL, namely those who switched from special to mainstream education and compared them with those who remained in their educational setting between the ages of 4 and 11 years. Given the inconclusive results in terms of the level of QoL of children with either HAs or CIs (Anmyr et al., 2011; Looi et al., 2016) and the degree of HL (Patrick et al., 2011; Smith-Olinde et al., 2008), no specific expectations could be formulated in this respect.

## **METHODS & MATERIALS**

### **Procedure**

This longitudinal study is part of the DECIBEL study (Developmental Evaluation of Children: Impact and Benefits of Early hearing screening strategies Leiden). In this nationwide study, the parents of 204 children with HL aged 2 to 6 years agreed to participate in the first measurement, which took place from 2008 to 2010 (Time 1). After providing informed consent, the parents completed a QoL questionnaire (at this time children were too young to complete a self-report) and a general background questionnaire (characteristics of children e.g., mode of communication). With the parents' permission, the children's audiological and medical records were reviewed to collect background information and information on language skills. These outcomes were published previously (Korver et al., 2010; Netten et al., 2015; Netten, Rieffe, et al., 2017).

All 204 children who participated in the first study were invited to participate in a follow-up study 7 years later, just before they went to secondary school (Time 2). At this time point, 62 children with HL and their parents provided informed consent (a response rate of 30.4%). The main reasons for not participating at Time 2 were; additional non-auditory disabilities ( $n=6$ ), already participating in other research or medical/audiological assessments ( $n=2$ ), and the burden of the study along with exams during the last year of primary school together with switching to secondary school ( $n=2$ ). The remaining 132 children did not provide a reason for non-participation. Children were visited at home between 2015 and 2016 when they were 10 to 13 years old. At this age, they reported their QoL via a self-report questionnaire and completed a language task. The parents also completed questionnaires about their child's QoL and provided additional background information (e.g., preferred communication mode). Audiological and medical records were reviewed again. Ethical approval for this study was obtained from the Medical Ethics Committee of Leiden University Medical Center (LUMC, ref. P14.270 20-01-2015).

### **Participants of this study compared to the non-responders at Time 2**

The final study group consisted of 62 children with bilateral HL (Table 1). The 62 children with HL who participated at Time 2 and the 142 children who did not participate at Time 2 were not significantly different in terms of sex, degree of HL, or type of hearing device. The level of education of the mother, the Total QoL, and the Physical QoL of the child at Time 1 was higher in the follow-up group than in the group that participated only at Time 1 (for further information please see the supplementary table).

**TABLE 1.** Demographic characteristics of the children with hearing loss in this study (n=62).

	Time 1	Time 2
Age at time of assessment		
Mean, years;months (SD)	4;5 (0;9)	11;10 (0;10)
Range, years;months	2;6-6;0	10;5-13;6
Sex, n (%)		
Male	40 (64.5)	
Hearing amplification type, n (%)*		
Hearing aid	50 (80.6)	46 (74.2)
Cochlear implant	11 (17.7)	16 (25.8)
Bone-anchored hearing aid	1 (1.6)	0
Degree of hearing loss, n (%)**		
<40 dB (mild)	7 (11.3)	10 (16.1)
41-60 dB (moderate)	28 (45.2)	19 (30.6)
61-80 dB (severe)	14 (22.6)	14 (22.6)
>80 dB (profound)	13 (21.0)	19 (30.6)
Mean age at detection, months (SD)	13.40 (16.2)	
Age range at detection, months	0-50	
Mean age at amplification, months (SD)	21.44 (15.0)	
Age range at amplification, months	2-55	
Education, n (%)***		
Mainstream	20 (32.3)	47 (75.8)
Special	42 (67.7)	15 (24.2)
Preferred mode of communication, n (%)		
Oral language only	32 (51.5)	55 (88.7)
Spoken and sign-supported	18 (29)	7 (11.3)
Spoken, sign, and sign-supported	3 (4.8)	
Sign language only	2 (3.2)	
Sign-supported	2 (3.2)	
Sign and sign-supported	1 (1.6)	
Missing	4 (6.5)	
Receptive Language Skills, n (%)		
One standard deviation below average < 85	28 (52.8)	22 (35.5)
Average 85-100	14 (26.4)	18 (29.0)
Average >100	11 (20.8)	22 (35.5)



TABLE 1. Continued

	Time 1	Time 2
Expressive Language Skills, <i>n</i> (%)		
One standard deviation below average < 85	23 (37.1)	16 (25.8)
Average 85-100	14 (22.6)	23 (37.1)
Average >100	11 (17.7)	23 (37.1)
Maternal education, <i>n</i> (%)		
Primary/lower general secondary education	4 (6.4)	
Secondary vocational education	20 (32.3)	
Higher general secondary education	6 (9.7)	
College/university	32 (51.6)	

Time 1: 2008 to 2010; Time 2: 2015 to 2016. One child had a diagnosis of autism spectrum disorder, and another had a developmental delay with severe physical impairment. \*After Time 1, five children received cochlear implants, and one child used a hearing aid instead of a bone-anchored hearing aid. \*\*The degree of hearing loss was calculated by averaging unaided hearing thresholds at 500, 1000, 2000, and 4000 Hz. Between Time 1 and 2, three children changed from having moderate to having mild hearing loss because their middle ear problems resolved spontaneously or after surgery. Six children deteriorated from having moderate to having profound hearing loss from Time 1 to Time 2 due to progressive hearing loss. \*\*\*29% of the children with HL attended mainstream education at both time points, and 24.2% attended special education at both time points. Between 4 and 11 years of age, 47.8% of the children switched from special to mainstream education due to adequate speech and language skills. Of all the children in mainstream education, 44.7% received remedial teaching during school hours and 12.7% still used speech therapy at time 2.

### Quality of life

The Pediatric Quality of Life Inventory (PedsQL™) (James W. Varni et al., 1999; James W. Varni & Limbers, 2009) incorporates four domains: Physical functioning (e.g. “I have problems with running”; 8 items), Emotional functioning (“I feel sad”), Social functioning (“Other children are teasing me”), and School functioning (“It is difficult to pay attention in class”)(the last 3 domains have 5 items each for a total of 15 items). Each of the 23 items are scored on a 5-point Likert scale: never, 0 points; almost never, 1 point; sometimes, 2 points; often, 3 points; almost always, 4 points. Each answer is reverse-scored and rescaled to a 0 to 100 scale, where higher scores indicate better QoL. The parent questionnaires are parallel versions of the children’s self-reported questionnaires, with differences in the use of age-appropriate language and first- or third-person tense. In this study, the questionnaire was completed by parents at both time points and by children with HL at the second time point. The mean QoL as reported by the parents at Time 1 and by the children with HL themselves at Time 2 were compared with the available QoL outcomes of Dutch children with NH within the same age range (mean differences presented in Table 2)(Engelen et al., 2009; Schepers et al., 2017). A clinically significant difference was considered when the reported QoL was exceeded by the absolute value of 4 (Roland et al.,

2016). Both the English and Dutch versions of the questionnaire have shown good reliability and validity (Engelen et al., 2009; Schepers et al., 2017; J W Varni et al., 2001).

### Language skills

Both receptive and expressive language skills were measured with age-appropriate tests. The Dutch version of the Reynell Developmental Language Scale was administered at Time 1 (appropriate for children aged 1;2-6;3 years and language levels of 55-145) (van Eldik, 1998) and the Clinical Evaluation of Language Fundamentals - Fourth Edition (CELF-4<sup>NL</sup>) at Time 2 (appropriate for children aged 5-15 years and language levels of 40-160) (Kort et al., 2008; Semel et al., 1987). Receptive language abilities were assessed with a verbal comprehension scale and expressive language abilities were assessed with word and sentence development scales. All language outcomes are standardized to norm scores according to age, using quotients in which the population mean for hearing children is 100 with a minimal clinically important difference of one standard deviation (SD) of 15 (e.g., 85 is below average and indicates language difficulties).

### Intelligence

At Time 1, the nonverbal intelligence quotient (IQ) was derived from the child's medical files (either the Snijders-Oomen nonverbal intelligence tests or the Bayley Scales of Infant and Toddler Development-III) (Tellegen & Laros, 1993). Nonverbal IQ at Time 2 was assessed at home using the block design and picture concepts components of the Wechsler Intelligence Scale for Children-Third Edition (WISC-III) (Kort, W., Schittekatte, M., Compaan, E.L., Bosmans, M., Bleichrodt, N., Vermeir, G., Resing, W.C.M., Verhaeghe, 2002; Wechsler, 1991).

### Statistical analysis

Statistical analysis was performed on the final study group consisting of 62 children with bilateral HL. To compare the QoL of children with HL with Dutch normative data, summary independent sample *t*-tests were performed for the Total QoL score and for each domain separately (Engelen et al., 2009; Schepers et al., 2017). To compare self-reported QoL with parent-reported QoL at Time 2, we used a dependent sample *t*-test. To evaluate whether QoL of children with HL had changed after 7 years, linear mixed models were used. Because we were interested in the development of QoL over time, parent-reported data of the final 62 children with HL were used as they reported the QoL of their children with HL at both time points. To control for confounders, sex and age at Time 1 were added as fixed effects in these linear mixed models (Bisegger et al., 2005). Next, we examined the

effects of the following factors on changes in the QoL over time: language skills at Time 1, type of hearing device, degree of HL, and educational settings (mainstream education, special education, or switched from special to mainstream education between the two time points). Accordingly, each variable was sequentially added (first main effect and second interaction effect with Time). In addition to sex and age at Time 1, level of IQ was added as a confounder to the model with educational settings. Due to the large number of missing IQ scores at Time 1, the IQ-score at Time 2 was used in the analyses (Pearson's correlation between IQ Time 1 and Time 2 = 0.385,  $p = 0.027$ ) (Neisser et al., 1996). All linear mixed models contained a single random effect for each subject and fixed effects for the independent variables. Statistical analyses were performed using the IBM SPSS Statistics 23.0 software package.

### Missing data

In our final study sample of 62 children, receptive language, expressive language, and IQ scores at Time 1 were missing for 9, 12, and 28 children with HL, respectively (Table 2). At Time 2, one child was unable to complete the QoL-questionnaire and IQ measure due to her additional non-auditory disability, one child lost her focus while completing the IQ measure at the end of the testing session, and six parent-reported QoL outcome questionnaires were incomplete. The pattern of missing data was examined using Little's MCAR test ( $\chi^2 = 483.47$ ,  $DF = 529$ ,  $p = 0.92$ ), which indicated that the data were missing at random. When conducting standard analyses, such as independent  $t$ -tests, incomplete cases will automatically be excluded (Netten, Dekker, et al., 2017). This can introduce bias and lower statistical power if these participants were excluded from the analyses. This type of missing data can be reconstructed using multiple imputations (Buuren, 2012; Netten, Dekker, et al., 2017; Sterne et al., 2009). We used 10 imputations to create good estimates of the missing data (Sterne et al., 2009). The imputations were based on the child's age at Time 1 and Time 2, language skills, IQ, sex, educational status of the parents, and QoL outcomes. Ten imputations were performed, and the pooled results are reported in Tables 3 and 4 (Sterne et al., 2009). There were no differences between outcomes with the original data and the imputed data.

## RESULTS

The outcomes are reported in order of the three aims of this study.

### Comparison of the QoL of children with HL versus normative QoL data from Dutch children with NH

The psychometric properties and mean QoL results of the final study sample of 62 children with HL are shown in Table 2. At Time 1, parents reported a clinically lower Total QoL for children with HL compared to the parent-reported normative data from Dutch children with NH. When considering the different subscales reported by parents, QoL scores among children with HL were clinically lower compared to children with NH in the Social and School domains at Time 1. At Time 2, the children with HL self-reported a clinically lower Total QoL compared to the self-reported normative data from Dutch children with NH. Concerning the subscales, the School QoL scores among children with HL were clinically lower compared to children with NH at Time 2. Parent-reported and self-reported QoL scores of children with HL were not significantly and clinically different at Time 2, except for the Physical QoL, which was reported more positively by the parents.

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### Changes in QoL over time and the relation with risk and protective factors

Changes in QoL over time were analyzed using the parent-reported data of 62 children with HL and a linear mixed model with Time as the time-dependent variable. A positive coefficient of time indicates an increase in QoL over time and a negative coefficient indicates a decrease in QoL over time (Table 3).

The parent-reported Total QoL of children with HL decreased significantly from Time 1 to Time 2, but this was not clinically different as the absolute value of 4 was not exceeded (Roland et al., 2016). When considering the different subscales, no clinical differences were observed in parent-reported Physical QoL and Emotional QoL between Time 1 and Time 2, but the scores on the School QoL and Social QoL subscales had significantly and clinically declined at Time 2. Notably, the decrease in parent-reported Social QoL was found only in children with CIs (Figure 1A and Table 4), while children with HAs had similar parent-reported Social QoL outcomes at both time points. Post-hoc analyses showed that 75% of children with CIs (12 of 16 children), but only 37% of children with HAs (17 of 46 children), had switched from special to mainstream education ( $p < 0.05$ ). Changes in parent-reported Total QoL, Physical QoL, Social QoL, and School QoL were not influenced by language or degree of HL. Only parent-reported Emotional QoL was influenced by receptive language (Figure 1B and Table 4). Children with HL with average receptive language skills (100) at Time 1 had significantly but not clinically higher Emotional QoL at Time 2 (Figure 1B).

**TABLE 2.** Psychometric properties and mean scores for quality of life, language skills, and intelligence quotient of the children with hearing loss in this study (n=62).

Time 1							Time 2		
Number of items	Answer range	Cronbach's alpha		Mean (SD)	Mean (SD)	Mean difference compared to norm (95% confidence interval)	Mean (SD) Child	Mean (SD) Parent†	
		Child	Parent	Parent	Parent				
				n=61		n=56			
Pediatric Quality of Life Inventory 4.0									
Total score	23	0-4	0.88	0.89	<b>84.43 (10.77)</b>	<b>-4.1 (-6.9;-1.3)</b>	<b>78.05 (13.67)</b>	80.61 (10.99)	
Physical	8	0-4	0.79	0.80	90.52 (12.86)	-1.3 (-4.5;1.9)	84.52 (14.34)*	91.05 (10.81)*	
Emotional	5	0-4	0.81	0.79	76.33 (16.05)	-2.1 (-6.3;2.0)	71.81 (20.90)	75.71 (16.38)	
Social	5	0-4	0.71	0.88	<b>81.33 (15.56)</b>	<b>-8.76 (-12.6;-4.9)</b>	82.21 (16.33)	76.88 (21.48)	
School	5	0-4	0.68	0.74	<b>86.43 (14.57)</b>	<b>-7.63 (-11.2;-4.1)</b>	<b>69.57 (16.30)</b>	73.05 (15.30)	
Language skills									
Receptive language	67-70				84.70 (19.83) (n=53)		91.44 (18.68) (n=62)		
Expressive language	102-77				87.53 (14.05) (n=50)		94.02 (18.33) (n=62)		
Non-verbal intelligence	26				105.21 (13.40) (n=34)		101.18 (17.71) (n=60)		

SD, standard deviation; n, number of participants who completed the questionnaire or task; Mean difference and 95% confidence interval indicates differences (Bold= $p<0.05$ ) between participants and Dutch normative samples (Engelen et al., 2009; Schepers et al., 2017); †, no normative data available for parent-reported measures at this age; \* $p<0.05$  differences between parent- and self-reported data at Time 2. Language skills and intelligence are shown as standard scores (mean of 100 and SD of 15).

### Level of QoL differs according to sex and type of education

To appraise whether QoL of children with HL had changed after 7 years, linear mixed models were used with parent-report data. Based on these parents' reports, sex and the educational setting of children with HL influenced the level of QoL of these children at both time points. When controlled for age and time, linear mixed models showed that boys had a higher Total QoL and Social QoL than girls at both 4 and 11 years of age (coefficient of sex (boys=1 girls=0) for Total QoL = 5.88, [0.93, 10.83],  $p < 0.05$ ; coefficient of sex (boys=1 girls=0) for Social QoL = 13.27, [5.31, 21.22],  $p < 0.001$ ). When corrected for sex, age, IQ, and time, linear mixed models revealed that children who attended special education at one or at both time points had significantly and clinically lower Total QoL, School QoL, and Social QoL than children in mainstream education (Figure 1C and Table 4). Children with HL in mainstream education had similar levels of School QoL and Social QoL to children with NH at both time points.

**TABLE 3.** Changes of quality of life over time of children with hearing loss ( $n=62$ ) analyzed with linear mixed models.

	Time		Time	
	Uncorrected		Corrected for sex and age at Time 1	
	Coefficients	95% Confidence interval	Coefficients	95% Confidence interval
Total QoL	<b>-3.59*</b>	<b>[-6.47, -0.70]</b>	<b>-3.86**</b>	<b>[-6.74, -0.98]</b>
Physical QoL	0.60	[-2.60, 3.80]	0.39	[-2.82, 3.60]
Emotional QoL	0.10	[-5.21, 5.40]	-0.10	[-5.47, 5.27]
Social QoL	-4.19	[-9.54, 1.16]	-4.64	[-9.98, 0.69]
School QoL	<b>-13.49***</b>	<b>[-18.18, -8.80]</b>	<b>-13.73***</b>	<b>[-18.44, -9.02]</b>

**Bold** \* $p \leq 0.05$ , \*\* $p \leq 0.01$ , \*\*\* $p \leq 0.001$ ; Time: 0 = Time 1, 1 = Time 2; QoL, quality of life

**TABLE 4.** The association between hearing loss related factors and changes of quality of life over time of children with hearing loss (n=62) analyzed with linear mixed models.

Receptive language			Hearing device			Educational setting		
	Coeffi- cients	95% confidence interval		Coeffi- cients	95% confidence interval		Coeffi- cients	95% confidence interval
Total QoL	Receptive language	0.02	[-0.15, 0.18]	Hearing device	-3.92	Special education	<b>-7.79*</b>	<b>[-13.82, -1.77]</b>
	Time* Receptive language	0.05	[-0.10, 0.20]	Time* Hearing device	4.67	Switched from education	<b>-6.27*</b>	<b>[-11.54, -1.00]</b>
Physical QoL	Receptive language	0.02	[-0.16, 0.20]	Hearing device	-4.77	Mainstream education	0	
	Time* Receptive language	-0.04	[-0.21, 0.13]	Time* Hearing device	6.19	Special education	-5.22	[-12.15, 1.70]
						Switched from education	-4.38	[-10.43, 1.66]
Emo- tional QoL	Receptive language	-0.06	[-0.27, 0.16]	Hearing device	-3.22	Mainstream education	0	
	Time* Receptive language	<b>0.33*</b>	<b>[0.04, 0.62]</b>	Time* Hearing device	5.32	Special education	-1.07	[-9.66, 7.52]
						Switched from education	-6.64	[-14.15, 0.86]
						Mainstream education	0	

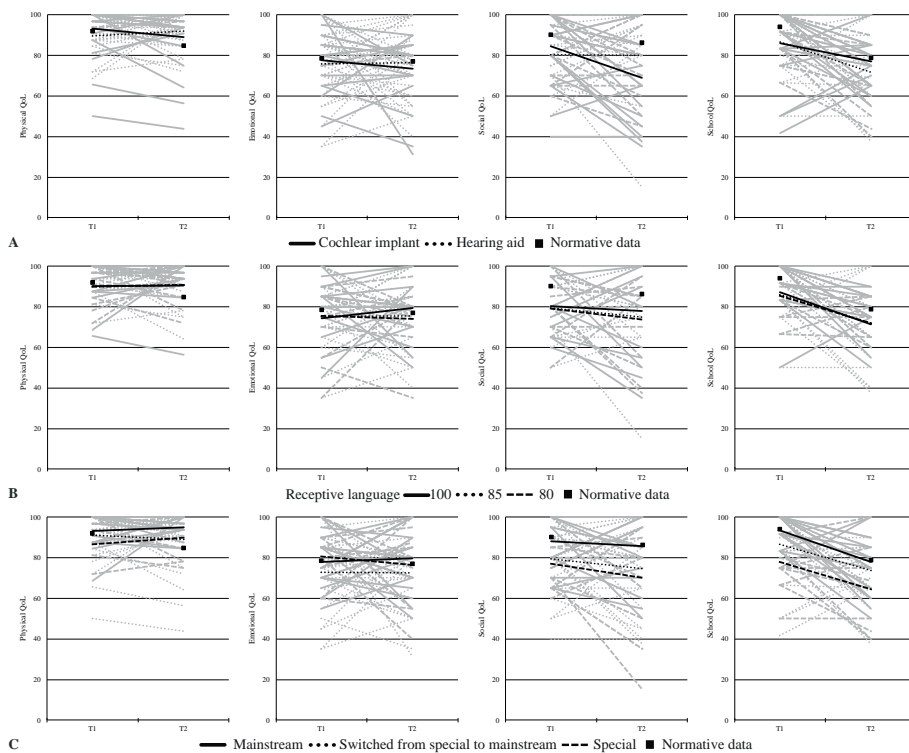
TABLE 4. Continued

Receptive language			Hearing device			Educational setting		
	Coeffi- cients	95% confidence interval		Coeffi- cients	95% confidence interval		Coeffi- cients	95% confidence interval
Social QoL	Receptive language	0.04	[-0.21, 0.30]	Hearing device	-6.73	Special education	<b>-12.99*</b>	<b>[-23.00, -2.98]</b>
	Time* Receptive language	0.15	[-0.13, 0.43]	Time* Hearing device	<b>14.04*</b>	Switched from education	<b>-8.83*</b>	<b>[-17.58, -0.08]</b>
School QoL	Receptive language	0.07	[-0.15, 0.30]	Hearing device	0.32	Mainstream education	0	
	Time* Receptive language	-0.11	[-0.37, 0.15]	Time* Hearing device	-6.10	Special education	<b>-14.22***</b>	<b>[-21.85, -6.59]</b>
						Switched from education	<b>-6.90*</b>	<b>[-13.55, -0.26]</b>
						Mainstream education	0	

**Bold** \* $p \leq 0.05$ , \*\* $p \leq 0.01$ , \*\*\* $p \leq 0.001$ ; Time: 0 = Time 1, 1 = Time 2; hearing device: 0 = cochlear implant, 1 = hearing aid; QoL, quality of life; All models are corrected for at least sex and age at Time 1, educational setting also for IQ.



## Chapter 5



**FIGURE 1.** Changes in the quality of life (QoL) over time of children with HL as reported by their parents ( $n = 62$ ). Individual trajectories are in grey and group differences are plotted in black. Note. Normative data = Time 1 parent-reported data and Time 2 self-reported data of Dutch children with normal hearing (Engelen et al., 2009; Schepers et al., 2017). **A.** Children with cochlear implants showed a clinical decrease in their Social QoL at the second time point, while children with hearing aids had similar Social QoL levels at both time points. No significant difference was found between children with cochlear implants and hearing aids in the other subscales of QoL. **B.** Children with HL with adequate receptive language skills (e.g. 100) at age 4 showed a significant increase in their Emotional QoL over time which was not clinically different ( $>4$  points). When receptive language skills were below average (e.g. 80), the Emotional QoL decreased slightly over time. Receptive language skills did not influence the other subscales of QoL. **C.** At both time points, children with HL who attended special education ( $n = 24.2\%$ ) and who switched from special to mainstream education ( $n = 46.8\%$ ) had a clinically lower Social QoL and School QoL than children with HL in mainstream education ( $n = 29.0\%$ ). There were no differences between these educational groups in the Physical and Emotional domain.

## DISCUSSION

This longitudinal study examined how type of hearing device and type of education were associated with changes in the QoL of children with HL over a 7-year period. We used the PedsQL™ questionnaire, which includes assessments of Physical, Emotional, Social, and School functioning. The outcomes of this study confirmed that the Emotional QoL and Physical QoL of 4- and 11-year-old children with HL were similar to the QoL of their peers with NH. The Social QoL and School QoL of children with HL in mainstream education were also on par with these measures in children with NH. However, compared to children with and without HL in mainstream education, children with HL who were in special education or who switched from special to mainstream education had lower levels of Social and School QoL. Regarding changes in the QoL, children with HL who had at least average receptive language skills at 4 years of age had statistically but not clinically improved emotional QoL at 11 years of age. In line with findings in children with NH, School QoL decreased between the ages of 4 and 11 years. Social QoL also declined over time, but only for children with CIs; in contrast, the Social QoL of children with HAs did not differ at both assessment times. These findings were all of clinical importance and can be used to modify and improve personalized care for children with HL by creating a focus on their social interactions and school activities.

### QoL of children with and without HL

Our findings confirmed those of the meta-analysis by Roland et al. (Roland et al., 2016), in that we found that the Emotional QoL and the Physical QoL of children with HL were similar to those of children with NH at the ages of 4 and 11 years. A novel finding in group differences was the similar level of Social and School QoL of children with HL in mainstream and children with NH at both ages.

### Social and School QoL of children with HL in different educational settings

Children in special education and children who switched from special to mainstream education had lower Social QoL and School QoL than children with HL in mainstream education and children with NH at both time points. This is in line with previous studies which found that children with HL in special schools, as opposed to children in mainstream schools, have more problems due to their difficulties with language and communication and presumably some additional non-auditory disabilities, all of which may contribute negatively to their QoL (Hintermair, 2011; Keilmann et al., 2007; Schick et al., 2013; S.C.P.M. Theunissen, Rieffe, Kouwenberg, et al., 2014; Wakil et al., 2014; Zaidman-zait et al., 2017).

Almost half of the children with HL in this study had adequate language skills in the range of children with NH, which enabled them to transfer from special to mainstream education. Therefore, this study is the first to investigate the impact of a school transition on the QoL of children with HL. The Social QoL and School QoL of children who switched from special to mainstream education were lower at both time points compared to children with HL in mainstream education. At the first assessment time point, 4-year-old children with HL were in special education and had to catch up due to language and communication delays (McCreery et al., 2015). It is likely that social interactions and school activities were more challenging at that age (Keilmann et al., 2007; Schick et al., 2013). Seven years later, children with HL who switched to mainstream education may have struggled with the demands of a faster teaching pace and/or with the less favorable acoustics of mainstream classrooms (Hintermair, 2011). Furthermore, due to the level of (extra) noise, children with HL regularly misperceive information in class and social situations, which can lead to feelings of exclusion (A. E. Geers et al., 2013; McCreery et al., 2015; Nitttrouer et al., 2013; Picard & Bradley, 2001; Rieffe et al., 2018; Wolters et al., 2011). These feelings of exclusion might even be enhanced since children with HL in mainstream settings are often the only ones wearing hearing technology in a hearing classroom. This can affect their self-perception, social development, friendships, and eventually their QoL (I. W. Leigh & Leigh, 1999; Rieffe et al., 2018; Xie et al., 2014). Based on the results of this study, it is important to consider specific and long-term guidance regarding school activities and social interactions for children with HL who switch from special to mainstream education.

### Changes in QoL over time

According to parents, the School QoL and Social QoL of children with HL changed over time. All children with HL experienced a decline in School QoL after 7 years, which is in line with findings among children with NH (Engelen et al., 2009; Schepers et al., 2017). This decrease may have been related to their developmental stage of adolescence and concomitantly a more demanding educational curriculum for older children, which the children must learn to cope with.

In contrast to our expectations, the receptive and expressive language scores of 4-year-old children with HL did not clinically contribute to the development of QoL. The absence of a clear relation between language skills and QoL in children with HL was also found in other studies on language skills and social emotional functioning (Beitchmen et al., 1986; Constantinescu-Sharpe et al., 2017; Horwitz et al., 2003; Netten et al., 2015, 2018). They found that communication skills and not language skills are more important for social

functioning which in turn can affect the wellbeing of children with HL. Language skills such as vocabulary are learned by professionals in schools and are important to develop communication skills (Moeller et al., 2007; Netten et al., 2015). Yet, the social rules are learned in a more indirect way by observing and communicating with others outside of school or at the playground. Understanding a joke for example requires the understanding behind the vocabulary and relies on the pragmatics within communication. It is therefore more important that children with HL learn to use their language capacities in the right way.

### Children with HAs or CIs

Except for Social QoL, changes in the QoL of children with CIs did not differ from changes in children with HAs. The parents of children with HAs reported similar Social QoL when their children were 4 and 11 years old, whereas parents of children with CIs reported a decrease in Social QoL after 7 years. This finding should be interpreted with care due to the difference in group size (the CI group was three times smaller than the HA group) and the difference in degree and etiology of HL between groups. However, three plausible explanations could be suggested for the change in Social QoL over time for children with CIs. First, children with CIs participated in intensive rehabilitation programs in their early years. Such programs gave them access to speech therapists, psychologists, qualified teachers for children with HL, and other professionals. However, for older children with CIs, the frequency of rehabilitation services usually decreases to once a year and children must be more self-reliant which can result in a lower QoL. Second, the decrease in Social QoL could be a consequence of the fact that parents of children with CIs may expect their child to be like children with NH and social problems in their 4-year-old child may go unnoticed (A Zaidman-Zait & Most, 2005). When the children with CIs are 11 years old, they can express themselves concerning their difficulties with social interactions and parents of children with CIs may be, therefore, more aware of the difficulties. Third, regarding the educational settings of these two groups, 75% of children with CIs, but just 37% of children with HAs, switched from special to mainstream education between the two time points. This greater number of children with CIs who switched educational settings may have had more of an impact on their social development than explained previously.

### Strengths and limitations

One of the strengths of this study is its longitudinal design. It provides a unique, and valid perspective on QoL changes in children with HL over a period of 7 years, from pre-school to pre-adolescence. It would be informative to follow this cohort into adolescence, when the demands of social interactions and school become even greater. This third time point

would provide more information regarding causal relationships and could further validate our findings. In addition, children in this study were born in the implementation phase of the Newborn Hearing Screening preventing us from drawing conclusions concerning the age at detection or the age at first amplification and QoL. However, factors like audibility, early access to amplification, and family counseling have been proven to influence language skills in children with HL and should therefore be integrated in future studies when studying QoL in this group (J. B. Tomblin et al., 2015). The study had three main limitations. First, the QoL of children with HL was compared to normative QoL data instead of being compared to data from a control group of children with NH. Second, compared to the 4-year-old children who only participated at the first time point, 4-year-old children with HL who participated at both time points had a higher Total QoL as rated by their parents and had mothers with a higher educational degree. These differences together with the response rate of 30.4% may have potentially led to selection bias. From a statistical point of view, the linear mixed models used address this problem if the missing data is missing “at random”, i.e. the reason for missing data can be explained by the covariates in the model. As we have included sex and age in the model, we believe that important sources of bias have been considered. This being said, the possibility of bias cannot be eliminated. Third, this study used a generic health-related QoL questionnaire to compare the QoL of children with and without HL and to examine the development of QoL over time for children with HL. Despite the relative positive findings concerning the generic QoL of the children with HL in our study, children with HL could still have hearing-specific problems and consequently a lower hearing-specific QoL (Clark et al., 2012; Rachakonda et al., 2014; Umansky et al., 2011). Future studies should therefore take the development of hearing-specific QoL into account for children with HL.

### Conclusion

In this longitudinal study, the Physical and Emotional QoL levels of children with HL were in line with those of children with NH at the ages of 4 and 11 years. Half of the children with HL in this study had appropriate language skills, which allowed them to switch from special to mainstream education. However, for good clinical practice, they should receive extra guidance and long-term support for school activities and social interactions. In particular, school-aged children with CIs may need extra guidance for their social functioning. It is our expectation that these findings can be used to improve personalized guidance for children with HL.

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**SUPPLEMENTARY TABLE.** Demographic characteristics of the children with hearing loss who participated in the follow-up study and who did not.

	Participants of follow-up study (n=62)	Drop-outs (n=142)
Age at first study		
Mean, years; months(SD)	4;5 (0;9)	4;4 (1;0)
Range, years; months	2;6-6;0	2;6-6;2
Sex, <i>n</i> (%)		
Male	40 (64.5)	79 (55.6)
Hearing amplification type, <i>n</i> (%)		
Hearing aid	50 (80.6)	94 (66.2)
Cochlear implant	11 (17.7)	34 (23.9)
Bone-anchored hearing aid	1 (1.6)	8 (5.6)
Missing	0	
Degree of hearing loss, <i>n</i> (%)		
<40 dB (mild)	7 (11.3)	15 (10.6)
41-60 dB (moderate)	28 (45.2)	41 (28.9)
61-80 dB (severe)	14 (22.6)	42 (29.6)
>80 dB (profound)	13 (21.0)	38 (26.8)
Missing	0	6 (4.2)
Mean age at detection, months(SD)	13.40 (16.2)	12.55 (14.4)
Age range at detection, months	0-50	1-60
Mean age at amplification, months(SD)	21.44 (15.0)	18.93 (14.8)
Age range at amplification, months	2-55	1-60
Education, <i>n</i> (%)		
Mainstream	20 (32.3)	36 (25.4)
Special	42 (67.7)	56 (39.4)
Missing	0	50 (35.2)
Preferred mode of communication, <i>n</i> (%)		
Oral language only	32 (51.5)	48 (33.8)
Spoken and sign-supported	18 (29)	37 (26.1)
Sign and/or sign-supported	5 (8)	23 (16.2)
Spoken, sign, and sign-supported	3 (4.8)	4 (2.8)
Missing	4 (6.5)	20 (14.1)

SUPPLEMENTARY TABLE. Continued

	Participants of follow-up study (n=62)	Drop-outs (n=142)
<b>Maternal education, n(%)*</b>		
Primary/lower general secondary education	4 (6.4)	26 (18.3)
Secondary vocational education	20 (32.3)	49 (34.5)
Higher general secondary education	6 (9.7)	8 (5.6)
College/university	32 (51.6)	55 (38.7)
Missing	0	5 (3.5)
Pediatric Quality of Life Inventory 4.0, Mean (SD)	n=61	n=130
<b>Total score*</b>	84.4 (10.8)	80.8 (12.2)
<b>Physical*</b>	90.5 (12.9)	85.7 (18.3)
Emotional	76.3 (16.1)	73.9 (14.6)
Social	81.3 (15.6)	79.7 (16.8)
School	86.4 (14.6)	81.9 (17.6)
Language skills, Mean (SD)		
Receptive language	84.70 (19.83)(n=53)	82.0 (15.6)(n=95)
Expressive language	87.53 (14.05)(n=50)	83.8 (15.2)(n=85)
Non-verbal intelligence, Mean (SD)	105.21 (13.40)(n=34)	101.9 (16.9)(n=51)

**Bold** \*p≤0.05, \*\*p≤0.01, \*\*\*p≤0.001

