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Evaluation of quality of life after paediatric cochlear implantation

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Background. Cochlear implantation (CI) is the main treatment method for deaf children. CI influences not only communication, but also psychosocial outcomes in children with severe to profound hearing loss. Focusing on issues specific to CI (e.g., self-reliance, social relations, education) may provide a more accurate and relative view of functional status of paediatric cochlear implant users. The objectives of this study were to translate into Lithuanian and adapt an international questionnaire of the quality of life after cochlear implantation and to evaluate parental perspectives regarding CI and the child's progress after a minimum of two years after surgery.

Materials and methods. The parental questionnaire *The Children with Cochlear Implants: Parental Perspectives CCIPP* was used to evaluate the quality of life following cochlear implantation. The questionnaire includes 74 items covering two main domains: decision-making (26 items) and the outcomes of implantation (48 items). Quality of life is estimated according to the scores of eight sub-domains: communication, general functioning, well-being, self-reliance, social relations, education, effects of implantation, and supporting the child.

Results. The paediatric sample consisted of 11 (39%) girls and 17 (61%) boys, whose mean age at the time of cochlear implantation was 2.41 ± 2.25 years, mean duration of the implant use 3.7 ± 1.3 years. All the grand means in the outcomes of implantation domain exceeded 3 on the 5-point scale, meaning that parents viewed the quality of life of their children as either average or better. Parents rated the sub-domains of communication (3.90 ± 0.77 points), social relations (4.05 ± 0.41), and supporting the child (3.89 ± 0.49) most positively.

Conclusions. According to parents, the quality of life improves after the cochlear implantation, especially in the fields of communication, social relations and supporting the child.

Keywords: cochlear implantation, hearing loss, quality of life, parental questionnaire

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INTRODUCTION

Since 1989, when USA Food and Drug Administration approved cochlear implants for children, this technology has developed so fast that today cochlear implantation (CI) is the treatment of choice for children diagnosed with sever-to-profound hearing loss in majority of developed countries (1–3). Numerous trials demonstrated advantages of CI: improved hearing, speech perception, and language development (4–7). A cochlear implant enables a deaf child to develop communication skills equal to those of the hearing peers, especially if the hearing impairment is diagnosed and CI performed early (8, 9). In addition to this, easier integration into mainstream education institutions is ensured along with better social adaptation, broader educational and professional opportunities, and social independency (10, 11).

A lot of publications concentrate on the clinical parameters (hearing thresholds, speech perception, and language skills) when assessing the benefit of CI. However, little attention is still being paid on health-related quality of life (QoL) – the real advantage of CI in general context: in child's everyday life in family, at school, and changes in social environment. World Health Organization defined health-related quality of life as a broad multidimensional concept that includes physical, mental, emotional and social functioning, concentrating on the effect health changes have on person's quality of life (12). Today, health-related quality of life questionnaires are becoming more popular in estimating efficiency of treatment, and CI is not an exception. It is well known that CI affects not only communication but socio-psychological well-being as well (11), besides, it has been noticed that the quality of life in paediatric population is not directly correlated to speech perception level (13). Reaching the best possible result of CI is the reason for the evaluation of CI-related quality of life of a child.

Life quality questionnaires are divided into generic and disease-specific. The latter are far more sensitive to positive and negative changes in QoL that are associated with the disease or its treatment; however, such questionnaires are few for paediatric CI users. In clinical practice, the most popular questionnaire is the one suggested by Archbold and colleagues (2002) *The Children with Cochlear Implants: Parental Perspectives CCIPP* (14). The CCIPP is a closed-set specific cochlear implantation questionnaire based on parental responses. As this questionnaire estimates responses of parents and not of children themselves, data about children of different age, including younger than 7 years of age, can be obtained (15). The CCIPP is widely used in CI centres and is described as a useful tool in scientific research and clinical practice (16).

Lithuania has been performing CI since 1998. In 2014, the Lithuanian government approved compensation of bilateral cochlear implants; therefore, medical care and possibilities of children born with hearing impairment in Lithuania are parallel to other developed countries. Nevertheless, CI-related quality of life of Lithuanian children has not yet been studied. Differences in social insurance, health care, education system and culture may have influence on QoL differences in various countries; therefore, studies performed in other countries do not necessarily represent changes in the Lithuanian population of children using cochlear implants. It is important to estimate how QoL of these children changes following surgery and implant fitting, and what challenges children and their families meet. Thus, the aim of this study is to: (1) translate the questionnaire *The Children with Cochlear Implants: Parental Perspectives CCIPP* into Lithuanian language and adapt it to the Lithuanian population; (2) use this questionnaire to examine families, raising children with CI, about QoL changes in child and family's life; (3) to find the main changes in QoL of children after CI, and compare these data to the results of other countries.

MATERIALS AND METHODS

This prospective cohort study was performed in Vilnius University Hospital Santaros klinikos (VUH SK) Hearing Implantation Centre. An approval of the bioethics committee was obtained (number 158200-15-786-298). The sample consisted of parents of children using at least one cochlear implant due to congenital sever-to-profound hearing impairment. Thirty families, who signed up the consent form, were asked to complete the questionnaire on the internet. Inclusion criteria were: (1) cochlear implantation performed to the child at VUH SK, (2) more than two years passed from CI fitting,

(3) spoken language is taught for speech and hearing rehabilitation. Exclusion criteria: (1) cognitive, (2) visual, or (3) developmental delay. The manufacturer of the cochlear implant or the mode of implant use (unilateral, bilateral, or bimodal) did not influence the inclusion into the study.

A validated parental questionnaire assessing QoL after CI – *The Children with Cochlear Implants: Parental Perspectives CCIPP* (Archbold et al., 2002) was used to collect data. After receiving permission from the authors, it was translated into Lithuanian and adapted to the Lithuanian population. The questionnaire comprises 74 statements covering two main stages of cochlear implantation: decision-making (26 statements) and the outcomes of implantation (48 statements). The decision-making domain is subdivided into ten items assessing decision making, and 16 items assessing the process of implantation. The domain of the outcomes of implantation is subdivided into eight sub-domains: communication (5 items), general functioning (5), well-being (5), self-reliance (4), social relations (8), education (8), effects of implantation (6), and supporting the child (7). The 74 statements are presented randomly throughout the questionnaire, therefore the results obtained are objective and not influenced by nearby questions of similar theme. Parents are asked to rate their response based on 5-point Likert scale ranging from *strongly agree* to *strongly disagree*. When analysing the data, the ratio of the parents who “strongly agreed” or “agreed” to the items presented was counted. In addition to this, items in the questionnaire are divided into positive and negative ones: 46 are presented in a positive format (e.g., “*She is keeping up well with children of her own age at school*”), and 28 in negative (e.g., “*She does not have a close relationship with her grandparents*”).

Families, included into the study were asked to complete the questionnaire on the internet anonymously and independently. The sex of the child was recorded, but the remaining individual data (the age at cochlear implantation and implant fitting, duration of cochlear implant use) remained unknown.

The data obtained were processed using MS Excel program, statistical analysis was done using SPSS 18.0. The data of eight sub-domains in the domain of the outcomes of implantation (communication, general functioning, well-being, self-reliance, social relations, education, effects of implantation, and supporting the child) were used for statistical analysis. Statements presented in the negative format were reversed so that a higher value corresponded to a more positive response. Non-responses were classified as missing values. Firstly, a domain mean for each participant was yielded. These individual domain means were combined to receive a grand mean for each domain, including all participants and all items or this domain. The grand mean is essential to compare the domains and search for correlation despite different number of items in different domains. The percentage of different responses was calculated for each item as well as means, standard deviation, maximum and minimal values, Spearman correlation between different items from the outcomes of implantation domain. In order to estimate the relation between different sub-domains in the outcomes of implantation domain, Spearman correlation coefficient was calculated too. Statistical significance was accepted at the $p < 0.05$ level.

RESULTS

Thirty families raising children using cochlear implants were asked to complete the questionnaire *The Children with Cochlear Implants: Parental Perspectives CCIPP* on the internet. Twenty-eight questionnaires were completed. The demographic data of 28 children using cochlear implants, whose parents participated in the research, are presented in Table 1. This study included families of 17 (61%) boys and 11 (39%) girls. All of these children underwent cochlear implantation before 12 years of age, and the implant was used for at least two years. Seventy-seven per cent of children attend mainstream education institutions and 23% receive special education.

THE DECISION-MAKING DOMAIN OF THE CCIPP QUESTIONNAIRE

When analysing the process of cochlear implantation, it was found that 78% of parents were very stressed when waiting for the results of the assessment before implantation and 71% agreed that taking the decision to proceed with the implantation was the most difficult part. Forty-seven per cent of respondents chose CI so that their child

Table 1. Demographic data of the paediatric sample

Demographic index	Mean	SD	Range
Child age at the time of cochlear implantation, years	2.41	2.25	1.1–11.1
Duration of cochlear implant use, years	3.7	1.3	2.3–7.6
Child age at the time of the research, years	6.1	3.3	3.5–18.7

SD – standard deviation

"would have a change to become part of the hearing world." All parents expressed a wish to receive all possible information and advice before the CI procedure, therefore 78% of these families would like to meet and consult other families that had a child with an implant. Three quarters (74%) claimed that the process of implantation was not more intrusive than they had expected, nonetheless, all (100%) respondents feared the implant might break down and were concerned about the need to constantly check the processor. All parents agreed that Implant Centre staff should visit the child at home or at school at least once a year.

THE OUTCOMES OF IMPLANTATION DOMAIN OF THE CCIPP QUESTIONNAIRE

First of all, the relative distribution of answers to each statement was estimated in order to better understand the effect cochlear implantation had on the changes in different spheres in the life of the child and family. Then, the grand means of each of eight sub-domains were calculated to represent CI-related QoL in general. Estimating the answers, positive changes in communication were observed (Table 2): communication of children and speech improved, children found it easier to talk when not seeing the face of the interlocutor, and parents noticed that their children became more talkative and engaged others in conversation. Positive strong correlations were found between different items in the communication sub-domain: parents, who claimed their child became more talkative and engaging others in conversation after CI, tended to agree with the statements: "*I find it easier to communicate with her by speaking than by signing*" ($r = 0.621$; $p < 0.01$) and "*We can now chat even when she cannot see my face*" ($r = 0.701$; $p < 0.01$).

After analysing the sub-domain of general functioning, the fact was confirmed that majority of children (92.9%) had no benefit from hearing

Table 2. Distribution of answers in the communication sub-domain of the CCIPP questionnaire

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Communication is difficult even with people she knows well	3.7	7.41	11.11	**51.85**	25.93
The quality of her speech gives me cause for concern	10.71	42.86	14.29	**25**	7.14
We can now chat even when she cannot see my face	0	0	3.7	**40.74**	55.56
I find it easier to communicate with her by speaking than by signing	0	0	13.04	**47.83**	39.13
Her use of spoken language has developed greatly	0	0	3.7	**59.26**	37.04
Now she is talkative and engages others in conversation	0	3.7	14.81	**51.85**	29.63

Note: the distribution in per cent is presented in the table. Most dominant answers (with the highest score) are given in bold.

aids used before CI; what is more, after the surgery many children (63%) relied on their implant, it became easier to function normally in the surrounding environment full of sounds: to hear when accosted (100%), to amuse oneself listening to music or watching TV (93%), or playing outside (57.2%). In addition to this, parents noticed positive changes in self-reliance: even though only 46.4% of parents claimed that their child was totally reliant on the implant, 75% agreed that confidence of the child improved greatly after the CI. Besides, although the majority of parents were still afraid to leave their child to do something on her own (only 39.7% of parents did that), as many as 67.9% agreed that their child was as independent as most other children of her age. In addition to this, respondents who agreed with the statement "*She is totally reliant on her implant all the time*" tended to estimate the potential of the child to cope with new situations more positively ($r = 0.534$; $p < 0.01$); the ones who claimed their child was able to amuse herself listening to music or watching TV agreed more frequently that "*She knows when I want her attention because she can hear me call*" ($r = 0.61$; $p < 0.01$).

An overwhelming majority of parents (96.5%) claimed their child remained as happy as she used to be. More than half of the respondents noticed an improvement in behaviour and argumentation of the child since getting the implant (respectively 64.3% and 67.8%); however, they disagreed with the statement that CI influenced frustration of the child. Families stating "*Her behaviour has improved since she had her implant*" tended to agree more with the statement "*She is less frustrated than before she had the implant*" ($r = 0.728$; $p < 0.01$).

Analysis of the social relations sub-domain revealed that as many as half of the respondents (50%) thought their child was not socially isolated even before CI, was able to make friends easily outside the family, was sociable within the family, communicated with family members, and was in close relationship with the grandparents (respectively, 75%, 92.9%, 71.4%, and 78.6%). Parents, who agreed with the statement "*She takes part in family relationships on an equal footing with other members*", were more prone to state their child was sociable within the family ($r = 0.588$; $p < 0.01$), and she did not find it difficult to make friends outside the family ($r = 0{,}559$; $p < 0.01$).

In this study it was complicated to draw conclusions on the education sub-domain: some of the questions accentuate changes at the school level, whereas part of the children was of a younger age. Due to that, a lot of missing values were noticed in the statistical analysis. Nonetheless, after summarizing the answers it was noticed that children were reliant on their implant at school, half of the respondents claimed their children kept well with children of their own age at school (Table 3). Children in 39.3% of families were still of pre-school age; however, 75.9% of parents whose children attended school were happy with the child's progress in education. Families that agreed with the statement "*She is keeping up well with children of her own age at school*" tended to think the mainstream schooling was not too difficult for their child ($r = 0.733$; $p < 0.01$).

Table 3. Distribution of answers in the education sub-domain of the CCIPP questionnaire

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
She is totally reliant on her implant at school	**0**	**0**	**8**	**64**	**28**
She is unable to cope with mainstream schooling	**3.85**	**15.38**	**26.92**	**50**	**3.85**
She is keeping up well with children of her own age at school	**11.11**	**14.82**	**18.52**	**51.85**	**3.7**
The local school and support services adequately meet all our needs concerning the use of her implant at school	**8**	**16**	**16**	**48**	**12**

Note: the distribution in per cent is presented in the table. Most dominant answers (with the highest score) are given in bold.

Around two-thirds of the respondents (60.8%) stated that progress after implantation exceeded their expectations, as much as 82.4% constantly fear the implant will break down, and majority (82.1%) of parents are sure their child will not blame them for the decision to implant the device. Three quarters noticed they had more time for themselves because of increased independence of the child. In addition to this, 92.9% thought that parents' help to children became more productive after CI. Majority of parents agreed that progress after implantation was not that fast, the child required more help after the surgery, and parents needed to wait for the effect patiently (Table 4). However, 75% agreed that efforts put in immediately after implantation would result in reduced need to help later. Parents who agreed with the latter statement were prone to agree with the following statements as well: "*The help I give her has become more productive now she has her implant*" ($r = 0.455$; $p < 0.05$) and "*I get more time to myself because of her increased independence*" ($r = 0.491$; $p < 0.01$).

Comparison of different sub-domains of the CCIPP questionnaire

The grand mean of each sub-domain exceeded 3 on the 5-point scale, therefore, parents saw the quality of life of their children to be average or better after the implantation. The best scores were given to the communication (3.90 ± 0.77 points), social relations (4.05 ± 0.41), and supporting the child (3.89 ± 0.49) (Fig. 1). Self-reliance (3.30 ± 0.27) and effects of implantation (3.16 ± 0.46) scored the least.

Spearman correlation coefficient was counted to find the correlation between different sub-domains of the questionnaire (Table 5). The most significant correlations were found between communication, self-reliance, and social relations. Communication significantly correlated with general functioning, self-reliance, social relations, education ($p < 0.01$), and supporting the child ($p < 0.05$). Significant correlation was found between self-reliance and communication, general functioning, social relations ($p < 0.01$), education, and effects of implantation ($p < 0.05$). Social relations were significantly related to communication, general functioning, self-reliance, supporting the child ($p < 0.01$), and education ($p < 0.05$).

Due to anonymous answers we had no opportunity to estimate the correlation between scores of the questionnaire and duration of the implant use or age at the time of the surgery. No significant correlation was found between the children's sex and the grand means of different sub-domains of the CCIPP questionnaire.

DISCUSSION

Although this research on the quality of life of Lithuanian paediatric cochlear implant users is the first, data in the world literature on the changes in the quality of life of children after CI are increasing. Most of the researchers rely on the questionnaire by Archbold and colleagues *The Children*

Table 4. Distribution of answers in the sub-domains of effects of implantation and supporting the child of the CCIPP questionnaire

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Immediately after implantation her ability to communicate was poorer	11.11	44.44	14.82	25.93	3.7
Progress during the first few months seemed very slow	14.29	**42.86**	14.29	25	3.56
She has needed more help from me since she received her implant	0	21.43	14.29	**46.42**	17.86
A parent of a child with an implant needs to be patient as benefits may take time to show	0	0	3.57	**53.57**	42.86

Note: the distribution in per cent is presented in the table. Most dominant answers (with the highest score) are given in bold.

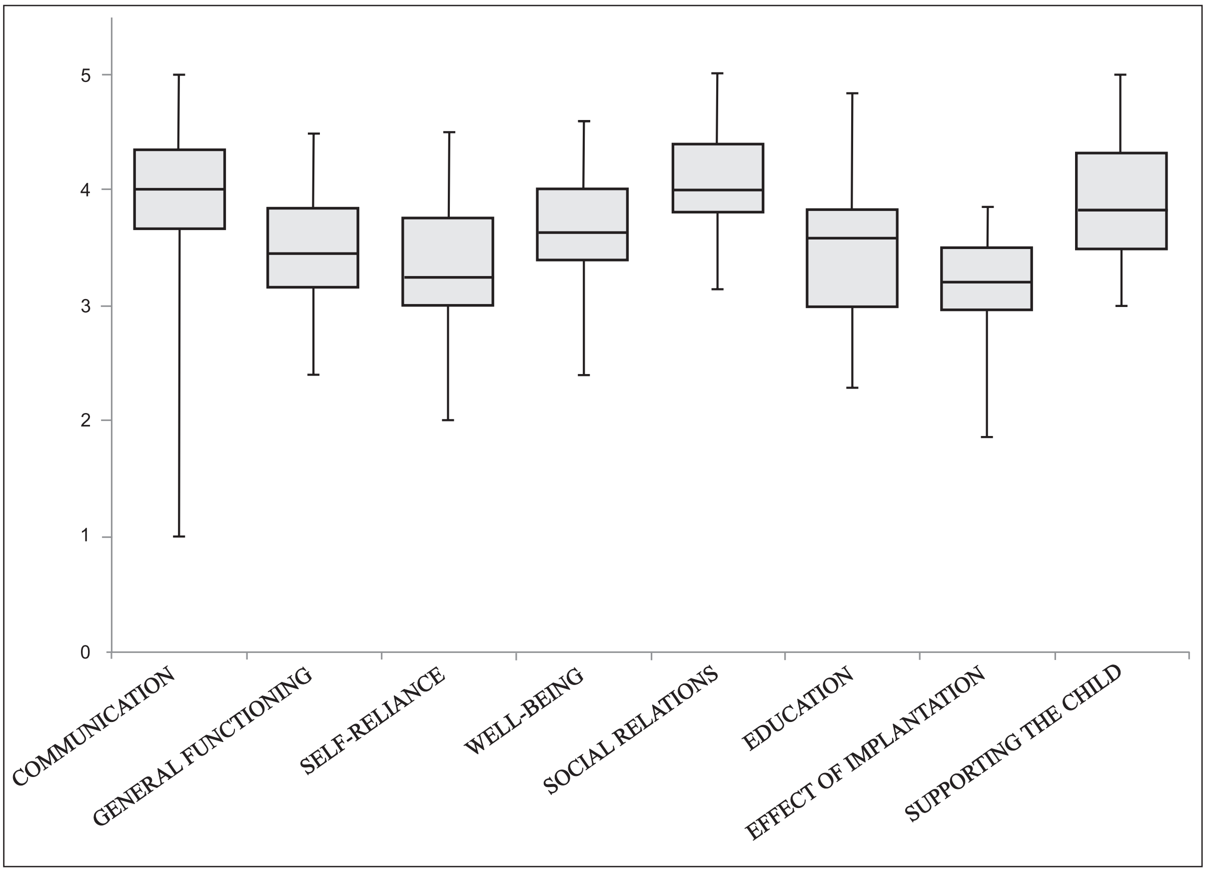

Fig. 1. Quality of life of children with cochlear implants, parental view. The X axis represents eight psycho-social sub-domains of *The Children with Cochlear Implants: Parental Perspectives CCIPP* questionnaire. The Y axis displays the quality of life of children with cochlear implants based on their parents' rate (in scores). The highest score – 5 – represents the most positive response. The line in the middle of the box shows the grand mean of each sub-domain, the bottom and top of the box each represent the 25th and 75th percentile, respectively, and the whiskers stand for maximum and minimum values

Table 5. Spearman correlation between different sub-domains of the CCIPP questionnaire

	General functioning	Selfreliance	Well-being	Social relations	Education	Effects of implantation	Supporting the child
Communication	**0.585****	**0.703****	0.329	**0.572****	**0.581****	0.247	**0.447***
General functioning		**0.642****	**0.448***	**0.501****	0.113	0.084	0.373
Self-reliance			0.167	**0.563****	**0.464***	**0.405***	
Well-being				0.232	0.127	0.003	**0.477***
Social relations					**0.432***	0.14	**0.509****
Education						**0.440***	0.246
Effects of implantation							−0.136

Note: *statistically significant correlation when $p < 0.05$; ** statistically significant correlation when $p < 0.01$.

with Cochlear Implants: Parental Perspectives CCIPP, others use the questionnaire "The HEAR-QL: quality of life questionnaire for children with hearing loss" that assesses the quality of life of children suffering from all kinds of hearing loss, or open-answer interviews and generic quality of life questionnaires for children. Evaluation of the quality of life of children is a specific field (related to young age, underestimation of situation, misunderstanding of questions), therefore target populations of researches differ: some researches assess parental (or teachers') opinion about changes in their child's life, others focus on the opinion of children themselves, or even compare parents' and children's answers to the same questions.

All studies unanimously conclude positive changes in the quality of life of children with cochlear implants. In our research, all sub-domains in the field of the outcomes of CI scored 3 or more according to parent's view, which means that parents saw quality of communication, general functioning, well-being, self-reliance, education, social relations, effects of implantation, and supporting the child as average or better. the same results are presented by other authors who used CCIPP in their research: in different studies, all eight sub-domains in the field of outcomes of implantation were rated ≥3 points (17–21). Consequently, cultural, social, and economic differences have no significant influence on the general tendency – every parent notices positive changes in their child's quality of life after CI. It can be stated that improved objective clinical indices important to specialists (hearing thresholds, hearing, speech perception, and language skills) are reflected in the changes in the quality of life (both the child using a cochlear implant and the family) assessed subjectively by parents. As hearing and speech are essential in everyday situations, it is not surprising that changes, more or less positive, are picked by parents in all spheres that are associated with the child and the family in general. In addition to this, it was noticed that children with cochlear implants rate QoL very high compared to their hearing peers: no significant difference was found between QoL ratings between normally-hearing and implant-using children in studies conducted in the USA (22, 23) and Portugal (24). Therefore it can be concluded that a timely CI not only ensures that hearing and speech perception levels and communication skills of children with congenital deafness are the same as those of their hearing peers, but also conditions that this diagnosis would not have any influence on the quality of life in the context of healthy peers.

In our study, the quality of life of the children was estimated based on their parents' opinion as the majority of the children were still too young to adequately answer the questions. According to the authors who interviewed both parents and children, no significant differences between answers of parents and children were found, therefore it is assumed that parents can provide health professionals with valuable information about children and describe socio-emotional and physical state of the child. Results of some studies differ: based on their data, school-aged children with cochlear implants tend to rate QoL slightly worse than their parents (21, 22), whereas younger children using cochlear implants assessed QoL significantly better compared to their parents ($p = 0.03$) (25) and compared to older children using cochlear implants (23). Parents of children aged 12–16 years with cochlear implants rated school results much better than the children themselves (68.20 ± 15.52 points compared to 56.07 ± 19.85). Also, the children tend to rate school- and friends-related quality of life worse compared to their hearing peers (22). However, these differences between children's and parents' answers are small and observed in only few spheres. The fact that results of many studies demonstrate similar evaluation of QoL by parents and children suggests that the data of our research reflect QoL of children after CI quite accurately, and parents can be seen as valuable in providing information about QoL of their children and in estimating the whole process of implantation.

Despite the fact that CI is a treatment of choice in most of developed countries in the case of congenital severe-to-profound hearing loss, the decision of whether to implant or not still remains with the parents: as many as 71% of families that participated in our research claimed it was the most difficult decision during the whole implantation process. The question remains if the mode of implantation – unilateral or bilateral CI, simultaneous or sequential – had any influence on that decision, but we did not have such data about children. However, after interviewing parents raising children with sequential cochlear implantation, Fitzpatrick and colleagues noticed that majority of parents found it much easier to decide on the second cochlear implant, and one family even described it as “effortless” (24). It might be influenced by several factors: (1) after the first CI is performed, obscurities associated with the implantation procedure and the post-operative period disappear and no fear remains about what is going to happen, (2) it is possible that parents had already noticed objective and subjective changes brought about by the use of the cochlear implant, thus they want their child to have a second implant for better results. Seventy-eight per cent of respondents noted it was very stressful to wait for the results before the CI. This is a much bigger number of parents compared to a study arranged in Australia (48% of parents described this period as very stressful) (2), but smaller compared to the Turkish population (91% of parents remembered perioperative period as very stressful) (26). It is a very important factor that should be considered by the implantation team: to pay enough attention not only to the child and technical or medical aspects, but to parents as well by providing them with all exhaustive information and answering all questions. Doubts and fear might be associated with lack of information or lack of attention towards parents. In the research performed by Yorgun and colleagues, even 90.1% of parents told they lacked information and recommendations before CI (26). In our study, the majority of parents also agreed that it would have been great to receive as much information as possible and to have a possibility to communicate with families raising children with cochlear implants.

Talking about separate spheres associated with the quality of life, we observed the most prominent changes in communication (grand mean – 3.9 ± 0.77 points) and social relations (4.05 ± 0.41), which is in line with the data presented by other authors: parents marked communication and social relations as spheres that had improved the most (17–21). It could be associated with the fact that these are the spheres mostly related to the child herself: improved hearing, speech perception, and spoken language directly influence easier communication and social adaptation outside the family or in extreme situations, therefore these are the changes first observed by parents. The data about the spheres that scored the least differed. In our study, parents gave the lowest score to self-reliance (3.3 ± 0.27 points) and effects of implantation (3.16 ± 0.46), whereas other authors described effectiveness of cochlear implantation (18, 20, 21) and supporting the child (17, 20, 21) as the lowest-scored. The fact that effectiveness of cochlear implantation scored the least both in our and foreign researches suggests that families have unfounded expectations before the surgery, therefore slower than expected progress of skills, slower changes in hearing and speech have a negative influence on the evaluation of QoL changes associated with the effectiveness of CI. The idea is supported by the research conducted in Australia. Fifty-six families raising children with cochlear implants were interviewed: one year after CI, 54% of parents were satisfied with the progress of their child, and several years later this number increased to 67% – therefore, it takes time for parents to notice effect of CI (27). In addition to this, 5–20% of parents claim their expectations were not met after CI (2, 11, 14, 28). Unrealistic and later unmet expectations are also associated with lack of information received by parents before the surgery. Therefore it is possible that this sphere (effectiveness of CI) of QoL could be rated higher after improved communication between the family and the implantation team.

Communication was the best-rated sphere of QoL. In our research, more than 80% of parents noticed their child become more talkative and showing initiative in the conversation. Spoken language became the language of choice compared to sign language and over 90% of the respondents marked improvement in child’s spoken language and communication when not seeing the face of interlocutor. Similar results are presented by other authors: 70–90% of parents notice obvious improvement in communication skills, easier communication in spoken language and when not seeing the face of interlocutor (14, 20, 26). Nevertheless, a study that included parents, children, and their teachers revealed that some children with cochlear implants manifested a “social deafness” phenomenon, when it was hard to communicate with others (to pick up details and nuances) in a noisy environment or a bigger group of people: 20% of parents and even 48% of teachers noticed it was hard for children with cochlear implants to keep the conversation in a group of people (2). It is worth mentioning that in a study in which parents and teachers were interviewed directly, teachers estimated work in class and school results lower compared with parents. Nevertheless, parents realized that progress in communication is much harder to achieve at school compared with home environment: majority of respondents in the study by Huttunen noticed an improvement in communication within the family after half a year, whereas communication progress at school was noticed only after a year (10). Statistical analysis of our data revealed that communication was the sphere to mostly correlate with other sub-domains: general functioning, self-reliance, social relations, education, and supporting the child. It is obvious that the ability to communicate without seeing the face of the interlocutor or to express one's thought in spoken language rather than using signs, the courage to initiate a conversation are all directly related to positive changes in school, self-confidence, and easier cultural adaptation.

According to parents, social relations are the second highly rated sub-domain of QoL. More than three quarters of parents noticed their child becoming an equal member of the family, joining in the family life, keeping in touch with grandparents, and being able to find friends easily outside the family. The sphere of social relations was positively rated by parents raising children with cochlear implant in other studies as well (17–21). In the research by Archbold et al. (which included all children despite developmental disorders or adjacent diseases), parents rated changes in social relations even better: 96% of parents claimed their child was sociable within the family; 80% that their child took part in family life on an equal footing with other members; and as many as half of the respondents noted an improvement in the child's relationships with brothers and sisters (14). Punch noticed that problems of social adaptation and emotional challenges usually arise for older children who have to adapt to and integrate into the surrounding social environment (2). Though the lack of demographic data did not allow us to calculate this correlation, it is possible that when the child grows and her independence and social responsibilities increase, the quality of life related to this sphere deteriorates compared to younger children. Despite that, improved speech and hearing skills, and communication progress assures better relations with both family members and other people, thus social adaptation improves together with QoL related to it.

Unfortunately, due to completely anonymous answers we were unable to evaluate whether changes in QoL were influenced by any kind of demographic factors (the only factor we knew was the children's sex): duration of the implant use, child's age at the time of CI or at the time of research. Both our and other researches confirmed that sex had no influence on the quality of life of children using cochlear implants. When evaluating the influence of demographic factors, many authors observe the influence of age on QoL: younger age is associated with better QoL as rated by the child herself. In addition to this, a younger age at the time of implantation is associated with a better quality of life after CI (2, 23, 25). The result of this research is, first of all, the QoL questionnaire *The Children with Cochlear Implants: Parental Perspectives* that was translated into Lithuanian and adapted to the Lithuanian population. It can be used in everyday practice of the CI team: (1) to plan rehabilitation goals individually for each child, (2) to analyse general results of cochlear implant users, (3) to analyse work of the implant team, and (4) to foresee changes that should be introduced by the CI team to improve the service for the child and family.

CONCLUSIONS

The data of this research lead to the conclusion that for the children with severe-to-profound hearing impairment cochlear implantation followed by successful postoperative rehabilitation provides the ability to hear and speak and thus become an equal member of the hearing world and has a positive influence on the related QoL of children and their families in Lithuania. Parents noticed positive changes in child's communication, general functioning, self-reliance, and social relations. In the process of CI, parents are responsible for the main decisions, maintain close relations between the child and the CI team, and are essential in the rehabilitation process and everyday life of the child. Parents' opinion represented in this research is valuable, firstly, to the CI team in order to better understand the changes in the child and family life after CI and to find out shortages of the service. In addition, this information is useful for the specialists in health care and education system, in order to better understand the needs of parents raising children with a cochlear implant.

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VAIKŲ GYVENIMO KOKYBĖS PO KOCHLEARINĖS IMPLANTACIJOS VERTINIMAS

Santrauka

Tikslas. Įvertinti tėvų nuomonę apie jų kurčių vaikų gyvenimo kokybę po kochlearinės implantacijos.

Medžiaga ir metodai. Atliekant tyrimą naudotas gyvenimo kokybę po kochlearinės implantacijos vertinantis uždaro tipo klausimynas tėvams – „Vaikai su kochleariniais implantais: tėvų nuomonė VKITN“ („*The Children with Cochlear Implants: Parental Perspectives CCIP*“). Siekta išsiaiškinti tėvų nuomonę apie vaikų gyvenimo kokybę ir pažangą po kochlearinės implantacijos. Klausimyną sudarė 74 teiginiai, suskirstyti į dvi dalis: sprendimų priėmimas (26) ir kochlearinės implantacijos rezultatai (48). Vaikų gyvenimo kokybei po kochlearinės implantacijos įvertinti buvo skaičiuojami kochlearinės implantacijos rezultatų dalies balai pagal kategorijas: bendravimas, bendras funkcionavimas, gera savijauta, pasitikėjimas savimi, socialiniai santykiai, ugdymas, implantacijos veiksmingumas, parama vaikui. Tyrimas atliktas Vilniaus universiteto ligoninės Santaros klinikų Ausų, nosies ir gerklės ligų centre. Tyrime dalyvavo 28 šeimos, auginančios vaikus su įgimtu kurtumu, kuriems buvo atlikta kochlearinė implantacija.

Rezultatai. Tiriamąją vaikų grupę sudarė 11 (39 %) mergaičių ir 17 (61 %) berniukų, jų amžiaus vidurkis siekė 6,1 ± 3,3 metų, vidutinis amžius kochlearinės implantacijos metu – 2,41 ± 2,25 metų, vidutinė implanto naudojimo trukmė – 3,7 ± 1,3 metų. Sprendimas atlikti kochlearinę implantaciją buvo daugiausiai įtampos keliantis laikotarpis tėvams, taip pat iki šiol visos šeimos nerimauja dėl implanto priežiūros ir galimo prietaiso gedimo. Kochlearinės implantacijos rezultatų dalies skirtingų kategorijų vidurkiai viršijo tris balus penkiabalėje skalėje, vadinasi, tėvai savo vaikų gyvenimo kokybę vertino kaip vidutinę ar geresnę. Geriausiai tėvai įvertino bendravimo (3,90 ± 0,77), socialinių santykių (4,05 ± 0,41) ir tėvų paramos vaikui (3,89 ± 0,49) pokyčius.

Išvados. Kochlearinės implantacijos procese tėvai yra svarbūs tarpininkai tarp vaiko ir profesionalų, jie dalyvauja priimant sprendimus klausos reabilitacijos klausimais. Tėvų nuomone, vaikų gyvenimo kokybė po KI gerėja, ypač bendravimo, socialinių santykių ir tėvų paramos srityse.

Raktažodžiai: kochlearinė implantacija, kurtumas, gyvenimo kokybė, tėvų klausimynas