Measures of quality of life in children with cochlear implant: systematic review

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Abstract

The use of cochlear implant (CI) in children enables the development of listening and communication skills, allowing the child’s progress in school and to be able to obtain, maintain and carry out an occupation. However, the progress after the CI has different results in some children, because many children are able to interact and participate in society, while others develop limited ability to communicate verbally. The need for a better understanding of CI outcomes, besides hearing and language benefits, has spurred the inclusion of quality of life measurements (QOL) to assess the impact of this technology.

Objective: Identify the key aspects of quality of life assessed in children with cochlear implant.

Method: Through a systematic literature review, we considered publications from the period of 2000 to 2011.

Conclusion: We concluded that QOL measurements in children include several concepts and methodologies. When referring to children using CI, results showed the challenges in broadly conceptualizing which quality of life domains are important to the child and how these areas can evolve during development, considering the wide variety of instruments and aspects evaluated.

Keywords: child; cochlear implants; hearing loss; quality of life; rehabilitation of hearing impaired.

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INTRODUCTION

Several studies have reported that children with severe and/or profound hearing loss (HL) may substantially benefit from using a cochlear implant (CI), together with proper auditory rehabilitation. These children have greater likelihood of acquiring oral language and being integrated in regular schools, extending their chances of participating in activities and being part of the world of sounds.

To perform activities and participate in the auditory world means to communicate and, consequently, communication is directly related to socializing, since social interactions occur by means of verbal communication. The social aspect is one of the most important parts of a child’s global development; it integrates the meaning of “quality of life”, as well as other issues associated with functionality, physical and mental well-being. Therefore, if the CI provides for hearing and language development and, consequently, the development of communication skills, such progress, because of CI use, would bring quality of life improvements for children with hearing loss.

However, although the CI can usually improve the quality of life (QL) of children, there is but a very limited number of studies in our field investigating such aspects. This is a surprising finding, since hearing interference has been well documented, especially in regards of social performance, self-esteem and acceptance at school; and these issues are even more relevant in children with severe and/or profound hearing loss.

Studies in this field evaluate aspects which are more associated with auditory, language and speech performance, school type, and analyze the cost-effectiveness of the CI treatment. More attention has been given to the measures carried through in image/behavior clinic/laboratory than the collection of information at the level of CI user’s functionality or other significant factors associated with their bio-psycho-social development. Concerning the progresses achieved in the field of Audiology, especially with the pediatric population using CI, healthcare professionals must consider that the factors affecting the results are so numerous, and only one part of them can be investigated by means of tests or other instruments used in clinical routine. Moreover, a detailed investigation concerning other aspects of life is not only relevant for the parents and physicians, but also for setting up healthcare policies, allowing for proper resource assignments to take care of the different social needs, service programs and specific interventions for this population.

Thus, to measure health-related quality of life (HRQL), which is a unique and personal perception of physical, mental and social well-being in diverse situations and activities, it is important to evaluate the multidimensional impact of hearing loss and cochlear implant use in the life of children, complementing the results of the clinical measures.

But, specifically in the pediatric population, to measure the HRQL is not an easy task. Numerous methodological issues permeate this type of evaluation, and to measure the state of health of a child requires choices concerning which health aspects are relevant, which preferences are of interest (child, parents, professors, doctors, etc.), the values that must be used, and an entire series of other contextual and psychometric issues that must be tended.

The challenge is in putting it within a comprehensive concept which HRQL aspects are important for the child, and how such aspects may progress during his/her development are determining factors in this type of assessment. For example, HRQL domains for a 5 year girl who is starting school can be different from those for an 18 year old who is just starting to drive. This fact directly reflects the choice of instrument to be used, since it must identify and evaluate all the relevant factors for the population being studied. Moreover, most of the time, HRQL questionnaires for children are frequently filled up by the parents or care-givers and studies have shown a poor correlation between the scores from the parents and the child vis-à-vis mental and social aspects, and a better correlation concerning physical domains. Thus, the interpretation of the HRQL results must take into consideration the questionnaire’s respondent and, when possible, the evaluation of the parents and that of the child must be done together.

Having all these issues associated with the measure of quality of life in children and trying to guide the bibliographic survey with high scientific evidence, we carried through a systematic revision of the literature in order to pinpoint quality of life of children with cochlear implants, and find out which are the main aspects assessed in this population and factors associated with quality-of-life measuring.

METHOD

As an essential principle of evidence-based studies, the investigated issue in this study was: “Which are the main quality of life aspects assessed in children using CI and the factors related with its results?”.

The search strategy used in the bibliographical revision was oriented by the combination of seven keywords indexed in the DecS (health keywords) in Portuguese and English, employing the keywords in groups with at least two keywords (Chart 1).

The chosen scientific databases for the search were: LILACS, MedLine, SciELO, Cochrane Library.
The choice of papers followed inclusion criteria based on confining the subject matters to the objectives of this paper. The adopted criteria were:

- **Participants**: Children with cochlear implants;
- **Intervention**: Cochlear implant;
- **Measured outcomes**: Quality of life by means of questionnaires;
- **Time**: Published in the last 11 years (2000-2011);
- **Language**: Papers written in Portuguese, English, and Spanish;
- **Types of studies**: Papers published in indexed journals with evidence levels 1a, 1b, 2a, 2b, 3a, 3b, and 4, in accordance with the criteria proposed by the American Speech Language Hearing Association (ASHA) \(^\text{18}\) (Table 1).

We took off those studies carried out with special groups of children with cochlear implant and other disorders, such as cerebral paralysis, auditory neuropathy, syndromes, auditory nerve hypoplasia, internal component re-implant, bilateral implant and other complications.

A total of 2,937 papers were identified in all the databases. In a pre-selection of these citations, based on reading the titles and summaries of all studies found in the electronic search, we took 2,853 studies off, 84 papers were selected and read in their entirety (Flowchart 1). At the end, 10 papers met the inclusion criteria \(^\text{3,7,11,17,19-24}\). Of these 10 papers included in this revision, 8 were classified as cross-sectional studies \(^\text{3,11,19-24}\), one was characterized as a high quality non-randomized controlled trial \(^\text{7}\), classified as level 2b according to the ASHA criteria, and one was a systematic revision \(^\text{17}\) (Tables 2 and 3).

A systematic review is described on Table 2 with the authors’ names, the year of publication, the journal chosen

### Chart 1. Search strategies in the databases.

<table>
<thead>
<tr>
<th>Search strategy - Keywords in portuguese</th>
<th>Search strategy - Keywords in english</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criança x Qualidade de Vida x Implante Coclear</td>
<td>Child x Quality of Life x Cochlear Implant</td>
</tr>
<tr>
<td>Criança x Implante Coclear x Perda Auditiva x Qualidade de Vida</td>
<td>Child x Quality of Life x Cochlear Implant x Hearing Loss</td>
</tr>
<tr>
<td>Criança x Qualidade de Vida x Implante Coclear x Avaliação de</td>
<td>Child x Quality of Life x Cochlear Implant x Outcome Assessment</td>
</tr>
<tr>
<td>Resultados</td>
<td>(Health Care)</td>
</tr>
<tr>
<td>Surdez x Criança x Qualidade de Vida x Implante Coclear</td>
<td>Deafness x Child x Quality of Life x Cochlear Implant</td>
</tr>
<tr>
<td>Reabilitação de Deficientes Auditivos x Criança x Qualidade de</td>
<td>Child x Quality of Life x Cochlear Implantation x Rehabilitation of</td>
</tr>
<tr>
<td>Vida x Implante Coclear</td>
<td>Hearing Impaired</td>
</tr>
</tbody>
</table>

### Table 1. Levels of scientific evidence according to criteria proposed by the ASHA \(^\text{18}\).

<table>
<thead>
<tr>
<th>Levels of evidence</th>
<th>Type of study</th>
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<tbody>
<tr>
<td>1a</td>
<td>Systematic review or high-quality metaanalysis of randomized controlled trials</td>
</tr>
<tr>
<td>1b</td>
<td>High-quality randomized controlled trials</td>
</tr>
<tr>
<td>2a</td>
<td>Systematic review or high-quality metaanalysis of non-randomized controlled trials</td>
</tr>
<tr>
<td>2b</td>
<td>High-quality non-randomized controlled trials</td>
</tr>
<tr>
<td>3a</td>
<td>Systematic review of cohort studies</td>
</tr>
<tr>
<td>3b</td>
<td>Individual cohort studies or low-quality randomized controlled trials</td>
</tr>
<tr>
<td>4</td>
<td>Studies from clinical outcomes</td>
</tr>
<tr>
<td>5a</td>
<td>Systematic review of a case-control study</td>
</tr>
<tr>
<td>5b</td>
<td>Individual case-control study</td>
</tr>
<tr>
<td>6</td>
<td>Series of cases</td>
</tr>
<tr>
<td>7</td>
<td>Specialists’ opinion without overt critical assessment</td>
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</tbody>
</table>
for publication, type of study, the age group included in the papers examined by the authors, the search string, the inclusion criteria for selecting the studies and the results found.

This set of papers was submitted to data evaluation, and the relevant information from each paper (number of participating subjects, age upon CI, duration of use, mean age of the subjects, object of the study, questionnaires used and conclusion), as well as classification vis-à-vis the degree of recommendation, gathered in tables to facilitate consultation and access during the presentation and result discussion (Table 3).

Table 2. Summary chart of the studies included in the systematic review.

<table>
<thead>
<tr>
<th>Author and title</th>
<th>Study’s objective</th>
<th>Methods/participants</th>
<th>CI information</th>
<th>Questionnaires utilized/ aspects assessed</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anmyr L. Olsson M., Larson K, Frejd A. Children with hearing impairment - Living with cochlear implants or hearing aids. International Journal of Pediatric Otorhinolaryngology. 2011;75(8):844-9.</td>
<td>Enhance knowledge on the daily activities of children with CI and ISAD, and their knowledge concerning their hearing and the behavior of others in relation to them.</td>
<td>- Cross-sectional study;</td>
<td>- Level of evidence ASHA 4;</td>
<td>Children who received the CI at 3 years and 10 months; Children who received the ISAD at 5 years and 3 months. No information regarding the CI/ISAD use duration.</td>
<td>Body Functions: Neck and shoulder pains were significantly more common among children with the ISAD than their CI counterparts; Activities: The children with ISAD use their devices less frequently than the children with CI. More children with CI use sign language than children with ISAD; Participation: More children with ISAD had auditory problems than children with CI while participating in sports and outdoor activities. Children from both groups reported situations in which they would like to hear better, in the classroom for instance, during talks with their families and when they needed to hear at distances; Personal and environmental factors: Many children with CI and ISAD did not find their hearing a problem.</td>
</tr>
</tbody>
</table>
Continued Table 2.


- Cross-sectional study; - ASHA 4 level of evidence; - 138 children using CI; - Age of the participants: 4 to 16 years; - Control group: No; - Children who answered the questionnaire.

- Cross-sectional study; - Received the CI at a mean age of 3.7 years; - Mean time using the CI: 5 years.

- Cross-sectional study; - ASHA 4 evidence level; - 216 parents from 222 children with CI (6 parents with two children users of CI); - Mean age of the children: 9.26 years; - Control group: No; - Parents who answered the questionnaires.

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To study which factors are associated with the EuroQol EQ-5D score in children with CI, and to explore the concepts of the parents on health-related quality of life (HRQL) and Quality of Life (QL).

- Mean age in which they received the CI: children: 4.3 years; Adolescents: 7.3 years; - Mean time using the CI: children: 6.3 years; Adolescents: 6.9 years.

- Mean age at which they received their CI was 3.2 years; - Mean time of use: 5.9 years.

To study the subjective perceptions of the children regarding their quality of life with the CI, measured by the report of benefits and problems associated with the device and check to see if the CI at an early age could predict their QL perception with their CI.

- Mean age at which they received their CI was 3.2 years; - Mean time of use: 5.9 years.

They found that the EQ-5D validity construct is variable, although it was capable of discriminating among the children with certain levels of auditory performance, not capable of discriminating among the children who differ in other ways. Moreover, since most of the parents reported that their child had the same score before and after the implant on a VAS, they inferred that most of the parents rejected the notion that hearing loss was a question of HRQL.


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- Age they received the CI: 108 children: < 4 years; 114 children: > 4 years; - CI time of use: 110 used < 4 years; 112 with > 4 years of use.

Aimed at studying the HRQL of school-aged children.

- Mean age in which they received the CI: children: 4.3 years; Adolescents: 7.3 years; - Mean time using the CI: children: 6.3 years; Adolescents: 6.9 years.


Using both questionnaires: 1 - KINDLR (Generic HRQL assessment). Covers the following: Physical well-being: emotional well-being; Self-esteem; Family; Friends; School. 2 - One specific for CI, created by the authors. Covering the following aspects: Satisfaction with the CI; Physical well-being; friends; school; self-esteem; social aspects.

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Younger children (4-7 years) and using the CI for less time had a more positive HRQL assessment than older children in the KINDLR questionnaire. In the CI-specific questionnaire, the younger group (4-7 years) had a more positive score than the older children. Chronological age differences showed in the CI module in the items associated with friends, school and self-esteem. The issue about the difficulty in hearing the teacher had the opposite effect, in which the younger children reported the worst score. The group of children between 12-16 years was more regular and reliable in their answers.

The children reported considerable benefits with the CI regarding improvements in their hearing and communication skills and in fields such as social interaction and academic performance. The child has few problems with the CI, especially the conflict with the parents when they do not want to use their CI. Although age at the implant did not predict benefits or problems associated with the CI, the age at which the amplification started predicts the QL score. This implies that early confirmation of the HL and the ISAD use contributes to a positive result in HRQL.
Continued Table 2.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Details</th>
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<tbody>
<tr>
<td>Loy B, Warner-Czyz AD, Tong L, Tobey EA, Roland PS.</td>
<td>The children speak: An examination of the quality of life of pediatric cochlear implant users. Otalaryngology-Head and Neck Surgery. 2010;142(2):247-53.</td>
</tr>
<tr>
<td>Warner-Czyz AD et al.</td>
<td>Parent versus child assessment of quality of life in children using cochlear implants. International Journal of Pediatric Otorhinolaryngology. 2009;73(10):1423-9.</td>
</tr>
<tr>
<td>Huttunen K et al.</td>
<td>The present study aims at exploring the quality of life of Finish children and families after the CI surgery using a validated questionnaire. International Journal of Pediatric Otorhinolaryngology. 2009;73(16):1762-94.</td>
</tr>
<tr>
<td>Incesulu A, Vural M, Erkam U. Children With Cochlear Implants: Parental Perspective. Otolaryngology &amp; Neurotology. 2003;24(4):605-11.</td>
<td>To assess parents’ views on the parents’ views on the quality of life of their children 2-3 years after cochlear implantation.</td>
</tr>
</tbody>
</table>
Although the generic instruments of health-related quality-of-life evaluation are much too general vis-à-vis the investigated aspects, which cannot enable the investigation of issues of particular interest for a given condition (for instance, telephone use), some studies currently show that these bear enough sensitivity, given the ample impact that the hearing loss has on the life of a child. Another advantage of this type of instrument is the ability of being able to compare the multidimensional aspects that make it, in different groups of children.

Moreover, currently few specific and standardized HRQL assessment tools are available for the pediatric population with hearing loss. It was only in December 2011 that a tool intended for the assessment of quality of life in children with hearing loss was published, called “Hearing Environments and Reflections on Quality of Life (HEAR-QL)”\(^\text{19}\). This questionnaire was not translated into Portuguese until the final analysis of this study.

Thus, we recommend that these two types of assessment should be used in order to perform a HRQL assessment in children with hearing loss, as complementary to the clinical results. The two instruments are needed to completely understand the CI impact instead of compartmentalizing this intervention into an auditory phenomenon only\(^\text{20}\).

In relation to the analysis of the quality-of-life measure-related factors in children and youngsters with CI, one of the evaluated aspects was the child’s age upon surgery. The qualitative analysis of the studies which ran this analysis made it possible to consider that children who were submitted to surgery in earlier ages make a more positive analysis of their quality of life.

Although each study evaluated children at different ages, research in this field show that children implanted earlier reach a better auditory perception, better, incidental language acquisition and better speech intelligibility\(^\text{15}\). The early development of these skills can improve the children's communication with their parents and at school, thus bringing about better social performances, reflected on quality of life assessments.

As to the duration of use, of the three studies that ran this analysis, two found a positive correlation between the total HRQL score and the duration of the CI use, and those children using it longer had a more positive assessment of their HRQL. This aspect has also has been relevant in the results obtained from children\(^\text{26}\). Children using it longer and more effective may have a better speech perception and intelligibility performances; and just like the age upon implantation, the more effective communication may bring about benefits for other aspects of life.

Thirty children using CI for a period of 10 to 14 years were assessed in a prospective and longitudinal study as to their speech perception and intelligibility. The results showed that 87% of the children used the implant effectively, and after 10 years of use, 60% could speak on the telephone, and 77% developed speech intelligibility near that of their normal hearing counterparts\(^\text{27}\).

Some studies\(^\text{1,8,19,21}\) found a significantly inverse correlation between the child’s chronological age and the HRQL evaluation, in which the younger children made a more positive classification of their HRQL than the older children. The groups of children evaluated in these studies had ages varying between 4 and 16 years and, in the three studies, the younger children had been submitted to the CI surgery earlier than the older children, and these findings can be justified vis-à-vis quality of life.
This early identification and prevention of the hearing loss may have provided for a faster and more complete acceptance, recovery of hearing and, consequently, of the CI in the lives of the younger children. That is, the CI use within the children’s day-to-day activities enables them to embody the device as part of themselves, instead of being something that distinguished them from their normal-hearing colleagues.

Both for children and their parents, the speech perception results were correlated with quality of life, and these findings may indicate that their perceptions regarding the well-being of the CI users are influenced by factors that go beyond hearing and communication capacity. Moreover, today, advances in the CI hardware, software and speech processing technology have had a direct impact on the performance and success associated with speech understanding, and such factors should be always considered, since they may in such a way impact the QL results.

As to the differences in quality-of-life evaluations among children using the CI, their parents and children with hearing, the data did not allow for conclusions in relation to these comparisons.

In some fields, such as auditory rehabilitation - where the problems are of complex and intervention cannot be done in definitive groups (control group versus case group), it is possible to include in the systematic review studies with limited methodological characteristics, at least for the methodological standards adopted by high scientific evidence studies. Consequently, these studies could be susceptible to a restricted analysis, but they should not be discarded.

We must consider the different ages at which the surgery was carried out, and the duration of CI use in each study must be considered a limitation, given the well-established association between the development of hearing and language skills and these variables and, therefore, the heterogeneity of these factors may result in a population with broad results vis-à-vis language skills.

**FINAL REMARKS**

Further studies must be done, using HRQL assessment tools which enable result comparison among clinics and countries, and which may lead to a better understanding of the criteria used to select candidates for the surgery, the needs for rehabilitating children with CI, besides enabling access to the clinics, allowing the children with CI to develop their true potential in all aspects of their lives.

**REFERENCES**


