Factors that influence the participation of parents in the oral rehabilitation process of children with cochlear implants: a systematic review

Fatores que influenciam na participação dos pais de crianças usuárias de implante coclear na (re)habilitação oral: revisão sistemática

ABSTRACT

Purpose: To identify and analyze factors that influence the participation of parents in the rehabilitation process of children with cochlear implants (CI). Research strategy: Question formulation and articles selection in three databases using the following keywords: cochlear implant (implante coclear) and parents (pais). Selection criteria: Complete original articles published in Brazilian Portuguese or English, with direct participation of parents of children with CI. Data analysis: Articles were fully read. Data regarding characterization of the centers, research methodology and content were analyzed. Results: Thirteen articles were selected based on the established criteria. The types of studies were cross-sectional and case-control (interview technique). The following influential factors were identified: pre-CI surgery factors (knowledge about CI, quality and quantity of information, specialist’s advices, ethical and biomedical aspects, rehabilitation engagement, contact with experienced families, social service support and overall costs); rehabilitation aspects (CI use, oral communication modality, regular school, other disabilities, social and demographic aspects and rehabilitation program’s effectiveness); other important influential processes (communication modality, auditory and language development, second oral language learning, as well as parent’s behavior and satisfaction). Conclusion: The engagement of parents in the rehabilitation process of children with CI depends on several distinct influential factors which audiologists should understand and consider when elaborating a rehabilitation program.

RESUMO

Objetivo: Identificar e analisar os fatores que interferem na participação dos pais de crianças usuárias de implante coclear (IC) no processo (re)habilitação aurioral. Estratégia de pesquisa: Formulação da pergunta da pesquisa, levantamento e seleção dos estudos em bases de dados, com os descritores cochlear implant (implante coclear) e parents (pais). Critérios de seleção: Artigos originais e completos publicados na língua portuguesa brasileira ou inglesa, pais de crianças usuárias de IC como participantes diretos da pesquisa. Análise dos dados: Leitura dos artigos na íntegra e extração de dados para a caracterização dos centros, da metodologia e conteúdo das pesquisas. Resultados: Treze artigos foram selecionados, dos tipos transversal e caso-controle (técnica de entrevista). Foram identificados os fatores sobre a tomada de decisão em realizar ou não a cirurgia (conhecimento prévio sobre IC, expectativas dos resultados, qualidade e quantidade de informações, encaminhamentos realizados, aspectos biomédicos e éticos, inserção na reabilitação, contato com outros pais, apoio social e custos); os fatores preditivos relacionados aos resultados da reabilitação (tempo de uso diário do IC, modalidade aurioral, escola regular, comprometimentos associados, aspectos sócio-demográficos e efetividade do programa); os fatores relacionados aos benefícios e limitações do IC (modalidade comunicativa, evolução das habilidades auditivas e linguísticas, o aprendizado de uma segunda língua oral), bem como o grau de satisfação dos pais. Conclusão: O engajamento dos pais de crianças usuárias de IC na (re)habilitação aurioral depende de fatores relacionados a diferentes domínios, os quais os fonoaudiólogos devem compreender e considerar na elaboração do programa de intervenção.
INTRODUCTION

The oral pediatric rehabilitation aims to develop the spoken language and improve conversational fluency of children with hearing loss through hearing, directing the children toward independence and integration into the hearing community\(^{(1-3)}\). In the case of a child with severe and/or profound bilateral sensorineural hearing loss, after complete evaluation by a multidisciplinary team, the cochlear implant (CI) might be the electronic device selected.

This effective clinical resource is a technologically sophisticated prosthetic that is surgically inserted into the cochlea in order to partially replace the functions of the organ of Corti. It provides electrical impulses to direct stimulation of the remaining cochlear nerve fibers allowing access to speech sounds\(^{(4)}\).

The variability of the CI results in children is associated with several factors, such as etiology, age of CI activation, amount of residual hearing prior to surgery, duration of sensory deprivation, number of electrodes inserted into the cochlea, daily time of device usage, and parental participation in the process of auditory rehabilitation\(^{(5-7)}\).

One of the most important factors that affect such development is the involvement of parents as it is directly related to the results of language and communication skills assessment of children with hearing loss. Parental involvement can be characterized by the following behaviors: to ensure that the child regularly uses the CI; to ensure that the CI is working properly; to provide auditory stimulation and consistently speak to the child providing a good language model in all environments; to stimulate speech production of the child; to engage the child in conversation; to maintain regular contact with the teacher; to participate in the development and implementation of the intervention program; and to attend therapy sessions. All of these behaviors can be classified on a scale in order to characterize their quality\(^{(2,5)}\).

In this scenario, a consensus exists with regard to how the participation of parents should be held in the habilitation and rehabilitation program. However, professionals who work with these parents need to consider and provide appropriate conditions for parents to satisfactorily perform all these tasks.

Health professionals should be aware that soon after diagnosis of hearing loss, the parents, who in the vast majority have no experience on the subject, need support as they adjust to this new and unexpected situation. At the same time, they need to actively participate in the entire process - i.e., contribute to the multidisciplinary team to ensure that the proposed target is reached\(^{(8)}\). These are moments in which parents go through many conflicts and must be active at the same time.

OBJECTIVES

The purposes of this study are to identify and analyze the factors that influence the participation of parents of children with cochlear implants (CI) in the oral rehabilitation process by describing the methodological aspects and the results of published studies.

RESEARCH STRATEGY

The first step consisted of formulating the research question: Which factors related to parental participation affect the results of oral rehabilitation of children with CI?

For the selection of studies, a search in national and international journals that are relevant to the topic was carried out in the following electronic databases: Medline, LILACS and SciELO. Articles published between January 2010 and June 2011 in electronically available journals were considered. The restriction in the stipulated period (18 months) was selected considering the emphasis of the study in detailing the identification of factors that influence the participation of parents at different stages of the rehabilitation program.

The following descriptors in English and Portuguese found in *Descritores em Ciência da Saúde* – DeCS (Medical Subjects Headings – MeSH) were used: cochlear implant (*implante coclear*) and parents (*pais*).

The selection of studies was performed in three steps: 1) selection of articles with cited and crossed (and/or) descriptors published between January 2010 and July 2011 in these electronic databases; 2) selection of articles which titles and abstracts were related to the proposed theme; 3) complete analysis of the articles.

SELECTION CRITERIA

The articles identified by the initial search strategy were independently assessed by the two authors following the inclusion and exclusion criteria. The following inclusion criteria were established: parents of children under the age of 12 users of CI as direct participants; primary type of collected data (the authors collected the data); articles published in Brazilian Portuguese or English; and full original articles.

Taking into account the classification of scientific evidence levels\(^{(9-11)}\) – according to the methodology of different types of research - articles consisting of case studies (evidence level 5), expert opinion (evidence level 6), abstracts from conference proceedings, theses and dissertations were excluded.

DATA ANALYSIS

The selected articles were read in full. For such, the following data was analyzed: characterization of the research centers and study methodology; name of authors; year of publication; journal in which the article was published; country and institution where the research was conducted; sample size; instrument used; and type of research.

The following data regarding the content of studies was collected: purpose of the study and conclusions reached. Next, subtopics of the studies were identified. After analysis of results and conclusions, the identification of factors that professionals should consider when requesting parental involvement at different times of the oral rehabilitation were identified.

The selected studies were analyzed according to the following aspects\(^{(12,13)}\):
RESULTS

Selection of studies

A search with the proposed descriptors yielded 220 citations in the three databases – 213 in MEDLINE, four in SciELO and three on LILACS. After sorting the articles for the stipulated period, 111 articles were excluded. The titles and abstracts of 109 studies were analyzed. Eighty-one articles were not related to the proposed topic, resulting in 28 articles. In the next step, a full reading of articles was performed and 15 articles were excluded because the title and summary did not properly clarify the methodology used. In total, 13 articles were selected and analyzed in this systematic review (Chart 1).

Analysis of methodological aspects of studies

Data base results

The journals of the two national publications in Brazilian Portuguese located at SciELO database were Psychology Theory and Research and International Archives of Ototorhinolaryngology (Chart 1).


Among the various participating countries, Australian researchers showed a higher number of publications, European, Chinese and North-Americans represented the other participants. It is noteworthy that in six publications, participants were recruited from more than one CI center, and one of the studies was developed by researchers from three different countries (Germany, Italy and Austria) (Chart 1).

Sample size

The sample of studies located in the Medline database ranged from 63 to 247 participants within a quantitative approach, and between 13 and 27 in qualitative studies. In the SciELO database, the samples consisted of eight parents in the qualitative-quantitative and ten parents in the qualitative approach (Chart 1).

The sample size heterogeneity of these different studies indicates the difficulty of selecting participants with similar characteristics. The intersection of three factors could explain such difficulty: number of variables that can affect the performance of a child with CI to compose a homogeneous group (socio-demographic characteristics, etiology, duration of sensory deprivation, among others); the consent and availability of parents to participate in the study; and restriction of a single institution to develop the study.

Research design

There are more quantitative approach studies (six) available than studies with hybrid approach or qualitative-quantitative (five). Studies that have a qualitative approach (two) are less frequent. Even though different in nature, these scientific approaches complement each other. The qualitative approach made possible the knowledge of values, beliefs and specific opinions of each participant. This information is very important for clinical practice especially for the area of oral rehabilitation where numerous variables are encountered. The quantitative approach evidenced trends observed by groups of parents that might assist in the establishment of perspectives of development of children with IC.

There was a predominance of cross-sectional studies (11). Two studies were case-control (Chart 1).

The interviews were predominantly structured (seven), followed by unstructured (four) and, in two studies, both types of interviews were conducted. The most commonly used instrument in the interviews was the questionnaire (eight), followed by the form (three). In two studies, both instruments were used.

Materials

In several studies, questionnaires and forms were used in unstructured interviews and arranged for collection of: socio-demographic data; information that parents have about the CI; risks and restrictions involving the CI; expectations of parents before and after the child receives the CI; communication mode used by children and their parents; production of speech and language; behavior changes; relationship of the child with peers; independence; decision-making process; experiences and perceptions of communication, personal, social and educational results after cochlear implantation. These instruments allowed further analysis of the topic proposed by the authors, pointing out relevant details and sample diversity.

It is emphasized that socio-demographic information was used in most studies. Such information is considered a factor that influences the effectiveness of intervention programs. More specifically, the socio-demographic parameter emphasizing parental education is able to interfere on the results since accessibility to speech sounds, conquered after activation of the CI, must be integrated with the possibilities of stimulation available in the environment during the oral rehabilitation process.
The instruments used to collect data in structured interviews consisted of scales, questionnaires and forms frequently referenced in publications and with psychometric properties that have been previously analyzed (Chart 2). In international papers, structured interviews were conducted with several different instruments, but most of them have not been translated and adapted to Brazilian Portuguese. These instruments are: Revised Category of Auditory Performance (CAPR); Kindl-R Questionnaire, Children’s Communication Checklist (CCC-2) and LittleEARS Questionnaire (LEAQ).

Authors reported the results of auditory and linguistic performance of children with CI with the use of direct measurements (collected by the researchers) and information obtained from the parents. An agreement between the results obtained in clinical assessment and those obtained from information from parents was reported in all studies, suggesting that parents are good informants\(^\text{15,16,24}\).

### Chart 1. Academic and scientific information of the studies

<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>Journal (Country)</th>
<th>Number of institutions</th>
<th>Approach (n)</th>
<th>Research design</th>
<th>Interview</th>
<th>Instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Qt</td>
<td>Ql</td>
<td>CS</td>
<td>CC</td>
</tr>
<tr>
<td>Mota et al. (2011)(^\text{14})</td>
<td>Arq Int Otorrinolaringol. (Brazil)</td>
<td>1</td>
<td>✓ (CG=4;RG=4)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ramirez-Inscoc; Moore (2011)(^\text{15})</td>
<td>Ear and Hearing. (United Kingdom)</td>
<td>1</td>
<td>✓ (CG=25;RG=23)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Teschendorf et al. (2011)(^\text{16})</td>
<td>Otol Neurotol. (Germany)</td>
<td>1</td>
<td>✓ (93)</td>
<td>✓ (27)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Wang et al. (2011)(^\text{17})</td>
<td>Otol Neurotol. (China)</td>
<td>7</td>
<td>✓ (177)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hyde; Punch (2011)(^\text{18})</td>
<td>Am Ann Deaf. (Australia)</td>
<td>3</td>
<td>✓ (247)</td>
<td>✓ (27)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hyde et al. (2010)(^\text{19})</td>
<td>Am Ann Deaf. (Australia)</td>
<td>3</td>
<td>✓ (247)</td>
<td>✓ (27)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hardonk et al. (2010)(^\text{20})</td>
<td>Am Ann Deaf. (Belgium)</td>
<td>1</td>
<td>✓ (13)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hyde et al. (2010)(^\text{21})</td>
<td>J Deaf Stud. and Deaf Educ. (Australia)</td>
<td>3</td>
<td>✓ (247)</td>
<td>✓ (27)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Huttunen; Välimaa (2010)(^\text{22})</td>
<td>J Deaf Stud and Deaf Educ. (Finland)</td>
<td>1</td>
<td>✓ (18)</td>
<td>✓ (18)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>May-Mederake et al. (2010)(^\text{23})</td>
<td>Int J Pediatr Otorhinolaryngol. (Germany; Italy; Austria)</td>
<td>7</td>
<td>✓ (63)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Percy-Smith (2010)(^\text{24})</td>
<td>Cochlear Implants Int. (Denmark)</td>
<td>1</td>
<td>✓ (168)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Loy et al. (2010)(^\text{25})</td>
<td>Otolaryngol Head Neck Sug. (USA)</td>
<td>2</td>
<td>✓ (CG=918;RG=88)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Yamanaka et al. (2010)(^\text{26})</td>
<td>Psic Teor e Pesq. (Brazil)</td>
<td>1</td>
<td>✓ (10)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Note: ✓= Yes; Qt = quantitative; Ql = qualitative; CS = cross-sectional; CC = case-control; S = structured; NS = non-structured; Qs = questionnaire; n = number of parents; CG = control group; RG = research group.

### Analysis of results of studies

The most addressed subtopics were “auditory and/or linguistic performance of children with CI” (six articles) and “perspectives and/or expectations of parents on the IC before surgery” (four articles). With just one article each, the other subtopics addressed were “educational aspects”, “program effectiveness” and “quality of life”.

#### Perspectives and/or expectations of parents on the CI before surgery

It is known that the process of deciding whether or not to implant is difficult for parents. For most of them, the decision making process was less than three months long whereas for others the process took between three and six months. Expectations, hopes and beliefs of parents about the CI may more accurately reflect the parent-child relationship in search
of doing the best for their children (21).

The aspects that interfere with the decision of parents and that were at several moments associated with the urgency in having their child implanted can be classified as: referrals and guidance that parents received from professionals; biomedical aspects (risks in surgery; device; post-surgical care; rehabilitation and ethics – opinion on definition of disadvantage; surgery in very young children; life threatening; views of the child; deaf identity); quality, quantity and diversity of information on the full program; knowledge on the device care; rehabilitation process; previous experience with deaf individuals; social support; and costs involved in the process (20).

In a national survey, the CI was described by parents as a solution not only to the deafness of their children, but also as a possibility of a better future in school, at work and in relationships, independence and a hope of quality of life improvement. Most parents somehow already knew about the CI before reaching the CI center – this information was obtained from several sources. Parents were aware that the CI could cause difficulties for both the child (in adapting to the use of the external unit), and for the family (witnessing a new situation that generates anguish and despair). On the other hand, they believed there would be benefits from improved communication to the possibility of the child to listen and speak (26).

Inserted into the CI or oral rehabilitation program, parents can use a range of information sources to answer their questions and aid on the decision on whether or not their child should receive the CI. Australian researchers have identified that one of the major sources of information was the very staff of the CI center: audiologists (40.9%) and otolaryngologists (23.1%). Thirteen other possible sources of information were also cited by parents. Of these, the most important were: other families with children with CI, children users of CI, and teachers. Only a few contacted the Deaf community and Deaf organizations. Parents reported knowledge of the negative opinion about the CI of the members of such community. The decision was stressful for parents. However, they believed that the CI could be “the only option” for the child to develop listening and speaking and to communicate in the same mode with others family members (21).

There is a high degree of consistency between expectations of parents and experiences after the surgery. In one study, the quantitative results indicated that most parents before surgery believed the CI was a positive step in the lives of their children and subsequently high levels of satisfaction in the post surgery results were achieved. The authors also considered the differences in responses in the qualitative analysis: some parents did not demonstrate satisfaction with the results of communication, social and academic skills of their children; they were parents whose children had other associated commitments that prevented the full benefit from the implant (19).

**Auditory and/or linguistic performance of children with CI**

Parents reported that children using CI benefited from access to speech sounds and hence the likelihood of developing spoken language in shortest time interval was greater when compared with those using hearing aids (23).

The reports from parents about the auditory performance of children with CI provide a functioning measure in real life. Chinese researchers developed a study to investigate the predictors of satisfactory auditory performance and identified the following factors: hours of device use per day (16-24 hours); the communicative mode (oral/aural) at home and school; educational approach (regular classroom); and absence of associated conditions. The authors concluded that the perception of parents should be examined during the entire process - from

![Table 2. Instruments used on structured interviews](data:image/png;base64,iVBORw0KGgoAAAANSUhEUgAAA...)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Instrument</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyde et al. (19,21)</td>
<td>Questionnaire with 33 items, divided in five subscales to measure expectation of mothers</td>
<td>Communication and social abilities, academic achievement, future changes, and rehabilitation demands. Parents should evaluate the agreement level between their expectations before and after their children received the cochlear implant.</td>
</tr>
<tr>
<td>Percy-Smith (24); Wang et al. (177)</td>
<td>Revised Category of Auditory Performance (CAPR)</td>
<td>Standardized measure in which the lowest level describes unawareness to environmental sounds (zero) and the highest level (nine) describes the ability to speak with an unknown person on the phone.</td>
</tr>
<tr>
<td>Mota et al. (140)</td>
<td>Language Development Survey</td>
<td>Registry of the number of words of different categories that are spontaneously produced by the child</td>
</tr>
<tr>
<td>Loy et al. (25)</td>
<td>KINDL-R Questionnaire measures quality of life – child version (between 8 and 11 years of age) and parent version</td>
<td>24 questions equally distributed into 6 subscales: physical wellness, psychological wellness, self-esteem, family, friends and school</td>
</tr>
<tr>
<td>Ramirez-Incoe; Moore (152)</td>
<td>Children’s Communication Checklist (CCC-2)</td>
<td>Screening instrument that identifies children who are at risk for language disorder</td>
</tr>
<tr>
<td>Teschendorf et al. (145)</td>
<td>Student Oral Language Observation Matrix (SOLOM)</td>
<td>Questionnaire that evaluates the competence of the child in his/her first language</td>
</tr>
<tr>
<td>Percy-Smith (24)</td>
<td>Speech Intelligibility Rating (SIR)</td>
<td>Measures speech intelligibility in the conversation with different individuals</td>
</tr>
<tr>
<td>May-Mederake et al. (271)</td>
<td>LittleEARS (LEAQ)</td>
<td>Tests the receptive, expressive, and semantic linguistic ability in response to auditory input</td>
</tr>
</tbody>
</table>
decision making on implantation to follow-up after surgery\(^{(17)}\).

In a Danish study\(^{(24)}\), parents scored on a scale the level of auditory, linguistic and communication skills of their children. The results indicated that 81% of children who were CI users were able to at least comprehend common phrases in daily life situations without facial reading and, in some cases children were able to comprehend a known speaker on the phone after three years of CI use. Information from parents about the speech intelligibility of children indicated that most children (69%) were comprehended by anyone in daily life situations.

However, the observations are not necessarily always exact. For example, parents might report the different behavioral changes in their children at different times (before and after activation of the CI). In one study, parents completed the questionnaire six months and then annually (one to five years) after activation. The results suggested that the development of auditory skills – after access to speech sounds promoted by CI - enabled 77% of children a significant improvement in the use of speech between the first and second year after activation, change in communicative mode, as well as greater facilitation for the child to communicate with parents and siblings. The authors also found that there was a decrease in the use of signs and dependence on eye contact. They also observed several socio emotional (self-confidence, security, expansion in social life) and behavioral (child is calmer) benefits. After five years of activation, the majority of parents were satisfied with the auditory and linguistic development of their children\(^{(22)}\).

Advanced language skills, including learning a second spoken language, are possible for children with CI living in bilingual homes. However, the results of a study conducted in Germany\(^{(16)}\) suggested that such performance is the exception and not the rule for the childhood population with CI. The authors found that children exposed to one language (German) exhibited better results on the test than children in the bilingual group at the five time points tested (up to 36 months) after CI activation.

The improvement in programs of hearing loss detection in the neonatal period and early intervention in infants created the need for tools to monitor the development of auditory skills of young children, including those with other associated disabilities. European researchers\(^{(23)}\) using the battery test LittleEARS (LEAQ) conducted a longitudinal study of children with CI up to the second year of life and compared the results with a group of normal hearing children. The results showed that children with CI under the age of 12 months were significantly better than the older age group (between 12 and 36 months). All children with CI achieved the maximum possible score in LEAQ, on average, at 22 months of hearing age. Three children with special needs showed slower growth over time, but also benefited from the early indication of the CI.

A large variability of results is observed in the clinical practice. Not all children show satisfactory results as described above. In this literature review, one study drew attention to this issue. A comparison of the performance of two groups of children with CI was performed. One group had typical language development and the other had disproportionate language development (DLI). In addition, there were two groups of normal hearing children that were composed by siblings of children of the CI groups. The results indicated that the difficulties in language development are not only determined by deafness and/or features of the device, but also by the same hereditary and environmental factors that influence language development in normal hearing children. Most normal hearing brothers of the DLI group also showed atypical language development\(^{(15)}\).

**Other subtopics**

An important predictive factor that must be considered for achieving successful results is the quality of service provided by the rehabilitation program and time (number of sessions) necessary to achieve the goal, i.e. the effectiveness of a program. This conclusion was evident in a national study\(^{(14)}\), with two groups of parents: one who attended orientation sessions and another who did not. Quantitative analysis showed that four orientation sessions for parents – covering topics on language and auditory skills – were not sufficient to observe a significant change in the number of words spontaneously produced by children. However, qualitatively, the average number of words acquired by children in the group of children whose parents participated in the sessions was higher than in the group of children whose parents did not participate.

The studies are not only focused on clinical outcomes, but also in the social life of the child with CI. New studies focusing on psychosocial behaviors and adjustments have emerged – i.e. studies of the quality of life of children and their families. American researchers\(^{(25)}\) examined the results of the questionnaire on quality of life related to the health of children with cochlear implants and compared findings with those of normal hearing children (matched for age) and their parents. The authors found that the quality of life (QoL) rating of the group of children with CI was less positive (mean score of 72.6) than the group of normal hearing children (mean score of 83.98). Children with CI tend to report more positive QoL in the areas of emotional wellbeing and self-esteem. Comparisons between children with CI and their parents showed similar results in all subscales and total score. Therefore, it was proved that parents are reliable reporters in areas where they can observe the behavior of their children and that the CI seems to have a positive effect on certain psychological domains not creating serious global psychological problems.

Usually the first goal of parents and professionals in the rehabilitation of children with CI is granting enough access to speech stimuli for the child to develop listening skills and, consequently, oral language. However, there is the possibility of using a bilingual approach. There are centers that provide services where parents can choose different communication modes for their children – i.e., oral and sign language approaches. To understand how children with CI deal with these two communicative modalities, Australian researchers\(^{(18)}\) examined from the perspective of parents a group of children of different ages who were users of both speech and sign language. They found that 87% of the parents choose the CI for their children as a means to develop communication through listening and speaking, 12% indicated that they wanted their children to use a combination of speech and signs. Of the 27
The analysis of studies that investigated the different areas of parental involvement in oral rehabilitation programs for children with CI becomes necessary so that Audiologist and Speech-Language Pathologists understand the engagement of parents. It is also important to promote access to clinical instruments to identify the expectation of parents and to analyze their observations. These actions will enable building a therapeutic plan and improving the quality of Speech and Language services provided to parents.

The integration of information from all the 13 studies enabled the identification of the main subtopics “auditory and/or linguistic performance of children with CI” and “perspectives and/or expectations of parents on the CI before surgery”. The interpretation of the results, whether positive or negative, considered: the conditions of parents during the decision making process; different predictors of development; benefits and limitations to access to speech sounds with the CI; and the degree of parental satisfaction.

This literature review presented some limitations. The restriction on the selection of articles published in Brazilian Portuguese and English on the first phase of article selection and the period selected for data collection – 18 months – probably generated a smaller scope of the research developed on this topic. The systematic review proposed in this study did not intend to focus and deepen into an aspect of parental involvement in the CI program, but to identify and understand the extent of the influence of parents at different stages of rehabilitation.

Further investigations are needed for evidencing the identified factors and adaptation and validation to Brazilian Portuguese of questionnaires and forms that are internationally recognized. The development of multicenter studies with larger samples and the continuity of studies with rigorous level of scientific evidence are necessary.

**CONCLUSION**

The systematic review proposed in this study indicated that the topic of participation of parents of children with CI is studied worldwide, including Australian, European, American, Chinese and Brazilian researchers with studies available in the SciELO, Medline and Lilacs databases.

There was a predominance of cross-sectional and case control studies with qualitative and/or quantitative interviews. It is noteworthy that studies with larger number of participants consisted of researches which samples were obtained from more than one CI program center.

Different factors were identified in the present literature review: factors related to decision on implantation (prior knowledge about CI, expectations of outcomes, quality and quantity of information, referrals, ethical and biomedical aspects, inclusion in rehabilitation, contact with other parents, social support and costs); predictive factors related to rehabilitation outcome (daily use of CI, oral modality, regular school, associated conditions, socio-demographic aspects, and program effectives); factors related to the benefits and limitations of CI (communication mode, development of auditory and linguistic skills, possibility of learning a second oral language); as well as the degree of parental satisfaction with the results related to quality of life.

* MIVC was responsible for the conception and design of the theme, data collection and analysis, writing of the manuscript, and final approval. ACMC contributed to the methodology of the study, analysis, critical review of the

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**Chart 3. Synthesis of factors that interfere in the participation of parents on the CI program**

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision making process</td>
<td>- Knowledge of parents about the CI</td>
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<td>- Rehabilitation insertion</td>
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<td>- Contact with other parents, users of CI, Deaf</td>
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<td>- Social support</td>
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<td>Predictive factors</td>
<td>- Daily use of the CI</td>
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<td>- Communication mode</td>
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<td>- Effectiveness of intervention program</td>
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<td>- Possibility of a second oral language</td>
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<td>- Socio-emotional and behavioral benefits</td>
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<td>Satisfaction</td>
<td>- Quality of life</td>
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Parents and the cochlear implantation program

content, and conclusion of the findings, writing of the manuscript, and final approval.

REFERENCES


