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Cochlear implant and quality of life: a study with parents and families of deaf children

Implante coclear e qualidade de vida: estudo com pais e familiares de crianças surdas

Implante coclear y calidad de vida: un estudio con padres y familias de niños sordos

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Abstract

Introduction: The cochlear implant is a hearing solution implemented in the Brazilian scenario, becoming a viable strategy for auditory rehabilitation for severe and profound hearing loss. However, despite the great technological advancements and the excellent results obtained and described in the literature, having an implanted child can compromise the quality of life of the families involved in the process. Objective: Compare the quality of life of a group of parents and families who have children users of cochlear implants, before and after implantation. Method: This is a cross-sectional clinical study. The participants were 30 individuals that were submitted to the WHOQOL- Bref questionnaire before surgery

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Authors' contributions:
AR elaboration of the research project, data collection and analysis, writing of the manuscript.
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and after six months of implant activation. The overall score and the data for the four areas covered (physical, psychological, environmental and social relations) were analyzed and described. Results: There was a significant positive change to the scores of environmental and social relationships domains of the instrument. There was no significant difference in the overall score or on the physical and psychological domains. Conclusion: It was possible to compare the quality of life of a group of parents of children using CI before and after the surgical process and device activation. The implantation has generated significant improvement in the environment and social relationships areas, showing an improvement in the quality of life of the interviewed parents.

Keywords: Deafness; Cochlear implant; Quality of life; Child.

Resumo

Introdução: O implante coclear é uma solução auditiva concretizada no cenário brasileiro, constituindo-se uma estratégia viável de reabilitação auditiva para perdas auditivas severas e profundas. Porém, apesar dos grandes avanços tecnológicos e dos excelentes resultados obtidos e descritos na literatura, ter um filho implantado pode comprometer a qualidade de vida dos familiares envolvidos no processo. **Objetivo:** Comparar a qualidade de vida de um grupo de pais e familiares que possuem filhos usuários de implante coclear, antes e depois da implantação. **Método:** Trata-se de um estudo clínico descritivo transversal. Participaram 30 indivíduos que foram submetidos ao questionário WHOQOL-Bref antes da cirurgia e depois de seis meses de ativação do implante. O escore geral e os dados relativos aos quatro domínios abrangidos (físico, psicológico, meio ambiente e relações sociais) foram analisados e descritos. **Resultados**: Houve mudança positiva significativa para os escores dos domínios de meio ambiente e relações sociais do instrumento. Não houve diferença significativa no escore geral e nos domínios físico e psicológico. **Conclusão:** Foi possível comparar a qualidade de vida de um grupo de pais de crianças usuárias de IC, antes e depois do processo cirúrgico e ativação do dispositivo. A implantação gerou melhora significativa nos domínios: meio ambiente e relações sociais, evidenciando que houve melhora da qualidade de vida dos pais entrevistados.

Palavras-chave: Surdez; Implante coclear; Qualidade de vida; Criança.

Resumen

Introducción: El implante coclear es una solución auditiva concretizada en la escena brasileña, que se constituye como estrategia de rehabilitación auditiva viable para la pérdida de audición severa y profunda. Sin embargo, a pesar de los grandes avances tecnológicos y los excelentes resultados obtenidos y descritos en la literatura, tener un niño implantado puede comprometer la calidad de vida de las familias involucradas en el proceso. **Objetivo:** Comparar la calidad de vida de un grupo de padres y familias que tienen niños usuarios de implantes cocleares, antes y después de la implantación. **Método:** Se trata de un estudio clínico descriptivo transversal. Se incluyeron 30 individuos que se sometieron al cuestionario WHOQOL Bref antes de la cirugía y después de seis meses de la activación del implante. La puntuación global y los datos para los cuatro dominios cubiertos (físico, psicológico, medioambientales y relaciones sociales) fueron analizados y descritos. **Resultados:** Hubo un cambio positivo significativo de las puntuaciones en los dominios de las relaciones sociales y medioambientales del instrumento. No hubo diferencia significativa en la puntuación total y en los dominios físico y psicológico. **Conclusión:** Fue posible comparar la calidad de vida de un grupo de padres de niños que utilizan IC, antes y después del proceso quirúrgico y activación del dispositivo. La implantación ha generado una mejora significativa en los dominios medioambientales y relaciones sociales, demostrando una mejora en la calidad de vida de los padres entrevistados.

Palabras clave: Sordera; Implantación coclear; Calidad de vida; Niño.

Introduction

Etymologically, the term quality derives from *"qualis"* [Latin] which means the characteristic way of being of something, both considered in itself, and related to another group, thus being able to assume both positive and negative characteristics. However, when one speaks of quality of life, it is generally believed that it refers to something good, dignified and positive[1].

General or holistic approaches are based on the premise that the concept of quality of life is multidimensional, presents a complex and dynamic organization of its components, differs from person to person according to its environment/context and even between two people inserted in a similar context[2].

According to the area of interest, the concept of quality of life is adopted as a synonym of health, happiness and personal satisfaction, living conditions, lifestyle among others, and its indicators range from income to satisfaction with certain aspects of life. Due to this complexity, the quality of life presents itself as a subject difficult to understand and require certain delimitations that enable its operationalization in scientific analyzes[3,4].

Satisfaction with life or a sense of subjective well-being depends on the individual's assessment of his abilities, environmental conditions and quality of life based on personal criteria combined with society's values and expectations at that time. The Quality of Life Group of the World Health Organization (WHO)[5] defines quality of life as "the individual's perception of his position in life in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards and perceptions."[6]

One of the factors that most impact the quality of life of the people is to have in the family a member with a disability that generates dependence and insecurity about the future. When the deficiency affects children, it is common, in the functioning of the family, to occur changes in the dynamics of the couple and distancing among its members[7].

It is known that hearing loss, in general, limits the oral communication process of people, reducing the possibility of interaction with their social environment, which leads to educational and socioeconomic consequences that affect the individual and society. Hearing impairment, depending on severity, may cause harm in the acquisition of spoken language and cognitive development in children, especially if it begins in the first years of life. At all ages and in both genders, it can cause significant social problems, especially isolation and stigmatization[8].

This obviously creates a detrimental impact on the quality of life of deaf individuals and their family members[9], since the deaf, because of the communication difficulties they face often isolate themselves from family and social life. An alternative that allows people with severe and profound hearing loss to have access to the sound world is the cochlear implant (CI)[8].

Early restoration of the auditory input through the CI allows the communicative skills of children to improve substantially, although with quite varied results[10]. While most children with CI become fit to attend regular school, others present significant limitations in their verbal communication skills and require specialized attention[11].

According to Tavares *et al*[12], the vast majority of studies on the impact of CI have been focused on the clinical evaluation of their effectiveness measures (hearing and speech skills, hearing thresholds). However, these measures represent only a fraction of the effect of treatment with CI. The efficacy of the device should be evaluated considering not only structured evaluation tests but also using instruments that analyze the ease of daily communication, social relations, well-being and other constituents of the quality of life[13]. Thus, the need to measure results more comprehensively has stimulated interest in using quality of life measures in the evaluation of the impact of the device[14].

In this sense, the present study aims to compare the quality of life of a group of parents and family members who have children with CI for at least one year in a service accredited by the Brazilian Unified Health System (SUS).

Methods

This is a descriptive cross-sectional clinical study, an integral part of the project "Evaluation and conduct in patients using implantable hearing aids," approved by CEP 047/2009.

The research was developed in a speech therapy clinic in the city of Curitiba and data were collected from January 2012 to November 2015.

The sample consisted of 30 family members of children with CI who voluntarily agreed to participate in the study and signed the informed consent form.

The study included fathers, mothers or other relatives of CI users, listeners and able to respond to the proposed protocol, whose children used the device for more than 12 months and attended the speech therapy clinic for auditory rehabilitation. Those responsible for institutionalized children and relatives of children with less than six months of CI were excluded.

All the implanted children, whose parents and relatives participated in this study, had a profound prelingual hearing loss.

The cause of deafness was: 36% cause unknown; 12% congenital infection (rubella and cytomegalovirus); 18% genetic; 10% meningitis; 10% jaundice; 14% others.

Regarding the age of implantation, it was verified that: 12% implanted between 1.6 and 2 years; 54% between 2 and 3.6 years; 34% more than 4 years. The mean age of the children at the time of the interviews was 3.3 years. The minimum was 2.3 years and the maximum was 5.1 years.

All the children were in speech therapy, but it was not possible to determine the modality. Although the service provided guidance on the need to work with orality, 16% of the children also received content in Brazilian sign language.

With regard to data collection, a survey was first carried out to identify the interviewees with a view to the sociodemographic characterization of the sample. Further, for the evaluation of the quality of life, the WHOQOL-BREF[15] was used, which consists of two general questions and 24 questions covering four domains (physical, psychological, social relationships and environment).

The questionnaire was applied to the respondent, in the form of an interview, in two moments: 1) before the child underwent HF surgery; 2) After at least six months of effective use of the device, during the third speech-language follow-up visit.

The study respected the design of the instrument and the responses, after being tabulated, were analyzed based on a scale of values from 1 to 5, wherein each response corresponds to a specific score (Fleek, 99). For purposes of analysis, questions 3, 4 and 26 had their scores reversed as a function of 1=5, 2=4, 3=3, 4=2, 5=1.

The following variables were considered: physical aspect (issues related to pain, discomfort, fatigue, sleep, mobility and ability to perform tasks); psychological aspect (questions related to reasoning, learning, concentration, memory, feelings and spirituality); environment (issues related to the environment of the home and work, participation, recreation and leisure); relationship (interpersonal relationship issues).

The general and per domain values were established, and the higher the score, the better the quality of life. For the purpose of data comparison, the Student's t-test was used, at a significance level of 0.05%.

Results

The results regarding the characterization of the sample are shown in Table 1, and the results obtained from the WHOQOL-BREF instrument are shown in Table 2.

From the data in table 1, it is possible to establish the sociodemographic profile of the sample, formed in the majority by women between 26 and 30 years old, secondary education, married and with income between 3 and 5 minimum wages.

Considering the level of significance of 0.05, there was a significant difference for the environmental domains and social relations, that is, there was a significant improvement in the quality of life in these two aspects.

Table 1. Sample characteristics (n = 30)

Variable	N	%
GENDER		
Female	27	90
Male	03	10
AGE IN YEARS		
18 to 25	02	6.6
26 to 30	23	76.6
31 to 36	04	13.3
>37	01	3.3
EDUCATIONAL LEVEL		
Primary	05	16.6
Secondary	18	60.0
University degree	07	23.3
MARITAL STATUS		
Married	27	90
Divorced/widow(er)	03	10
INCOME IN MINIMUM WAGE		
1 a 3	08	26.6
3 a 5	11	36.6
5 a 10	07	23.3
>10	04	13.3
Total	30	100

Table 2. Comparison of the mean scores, by domain, before and after the CI surgery (n= 30)

Domain	Before IC		After IC		p
	n	Standard deviation	n	Standard deviation	
General	3.3	0.8	3.6	0.7	0.2114
Physical	3.2	0.5	3.2	0.5	0.4771
Psychological	2.8	1.0	2.9	0.6	0.3258
Environment	2.7	0.5	3.4	0.4	0.0011*
Social relationships	2.5	0.6	3.2	0.3	0.0045*

Statistical test: Student's t-test.
Significance level of 0.05%

Discussion

In the present study, 30 relatives, parents or caregivers of deaf children with CI were interviewed, 90% of which were female relatives (mothers, aunts and grandmothers) with the age group with the highest concentration between 26 and 30 years old (76.6%). These data highlight the fact that the care and health care of children continue to be functions performed by women[16], although they have entered the labor market more intensely and lead the household, with or without male presence[17,18].

The majority of the respondents defined themselves in a stable civil union, which contributes to the organization of structured homes and results in a situation that interferes in a positive way for the development of a child with special needs[19].

Although the studied population comes from the SUS, more than 84% of the sample studied, at least, high school, which favors the mastery of knowledge about the CI. A similar study conducted in the city of Porto Alegre showed that 52.6% of the interviewees never studied or did not complete elementary school[15]. It is important to emphasize that the CI is a powerful technological resource at the service of human communication and this, demand for knowledge and scientific deepening, for professionals and family members of the child using the device, because these people are part of the therapeutic process[13].

The contemporary world and globalization, the new technologies and the speed of transformation mean that the individual has to learn (or at least try) to deal with totally new situations during his life.

Research shows that people with lower levels of schooling and education tend to stay on the margins of society and benefit less from innovation, whether in the home or work environment[20].

The Brazilian Institute of Geography and Statistics (IBGE)[21] divides income and social classes into five groups: A, B, C, D and E; In this research, class "C" prevails with 36% (income between three and five minimum wages), different from the research of Jorge[22] with income between a salary and a half and that of Jackson *et al*.[23] where the family income is considerably higher because the majority of the sample holds an undergraduate degree.

From the perspective of the parents, the use of CI improves the life condition of their children[24]. The evaluation of results has shown that the device improves their communicative abilities and this fact alone pleases and rewards the efforts of parents and other family members involved in the rehabilitation of the child[14,25]. The development of auditory and language skills acquired after CI can improve the children's communication with their parents and at school, and thus lead to a better social performance[9,26,27].

It is important to note that the interviews were carried out during the third speech-language therapy consultation and that the children were using the device for approximately six months. It is known that the auditory and language development responses gradually improve[28] with the device usage time and, consequently, the perceptions of the interviewees should also improve, but this was not the object of this study due to the time limitation for data collection.

The speech therapy also contributes to the development of auditory and language skills and helps parents and family members understand the demands of implanted children, improving family relationships and interaction[7]. All the children whose parents took part in the research are in speech therapy, certainly a moment of welcome and listening.

After the period following the discovery of deafness, of the CI surgery itself and of the preliminary results after CI, it was possible to verify with this study that there was an improvement in the quality of life of the respondents, considering the domains: environment and social relationships.

The domain social relationships involves the perception of social relations, the social (uphold) support, and the sexual activity itself. And the environment involves physical security and protection, home environment, financial resources, health and social care, opportunities to acquire new information and skills and recreation/leisure. Probably, this impact is due to the changes observed in children after implantation. Similar studies indicate that the use of CI interferes positively in the quality of life of users and their environment[28], expanding social relations and intensifying relationships within the family[14,23].

There was no significant difference in the scores of physical and psychological domains. The physical domain investigates issues related to pain, discomfort, fatigue, sleep, mobility and ability to perform tasks, and the psychological investigates questions related to reasoning, learning, concentration, memory, feelings, and spirituality. Most likely, these domains will be impacted by the use of CI and the future development of children[22], a fact to be investigated when the experience with the device is greater and the child is more independent and grown up. It is worth mentioning that the mean age of the children whose parents were interviewed was 3.3 years, the stage where the child still depends heavily on caregivers' attention[7] and impacts the physical aspect investigated by the WHOQOL-BREF.

Hearing-impaired children generate demands and situations that intensify conflicts in the intersubjective relationships of all members of the family[19]. The fact that the child needs a surgical procedure for the CI, the fact that the parents have the responsibility of deciding whether or not to do the surgery, the lack of guarantees about the benefits, among other things, affect their quality of life.

Feelings of sadness, guilt, loss, and anxiety mark the parents of deaf children[29], however, to the extent that good results are verified and the intensity of these feelings diminishes. A study[30] with 52 mothers and 42 fathers of children with CI, found high levels of distress and reduced quality of life, however, during the habilitation of the child, there were improvements due to the adaptive process of these parents.

There are many variables that contribute to the CI to generate good results (or not) both in the implanted child, with regard to the development of hearing and language, socialization, education and emotional aspect, as in families that create expectations and feel rewarded by the achieved results. Among them, we can mention the cause and the time of the hearing loss installation (pre- or post-lingual), comorbidities associated with deafness[10], daily use time of the CI[8], and adherence to therapy[14]. In this study, the cause of deafness is still unclear in most cases (36% of children), which generates anxiety and insecurity in the family, a fact that may have impacted the psychological aspect investigated by the WHOQOL-BREF.

Parents and family members of implanted children need continuous emotional support, which evidences the need for constant counseling and guidance from the professionals who make up the interdisciplinary team in the specialized CI services.

Conclusion

It was useful to evaluate the quality of life of a group of parents of children with CI, before and after the surgical process and the device activation.

The implantation generated a significant improvement in the domains: environment and social relationships, evidencing that there was an improvement in the quality of life of the parents interviewed.

There was no significant improvement in the physical and psychological domain scores.

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