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Family's perception of the quality of life of children using cochlear implants and of the capixaba hearing health service

Percepção da família sobre qualidade de vida da criança com implante coclear e sobre o serviço capixaba em saúde auditiva

Talita Falqueto Pereira[1], *Alessandra Brunoro Motta Loss*[1], *Aline Neves Pessoa Almeida*[1]

ABSTRACT

Purpose: To investigate, from the family's perspective, the quality of life of children using cochlear implants and correlate it with perceptions about the care received in hospital hearing health care, according to clinical and sociodemographic characteristics. **Methods:** Eighteen families of children with cochlear implants attended by Unified Health System Hospital Care Service completely responded to the *Kidscreen-10 index Proxy* and *Measure of Processes of Care-56* (MPOC-56) questionnaires, which, according to clinical and sociodemographic data, were statistically correlated. **Results:** The children's quality of life presented scores close to the maximum, with lower scores in emotional development, school performance and attention which improved with age. Satisfaction with the Service also presented a good rating, with Providing General Information being the Factor with the lowest score. Age and geographic location affected the families' perception of the children's quality of life and age, use of cochlear implant, therapy time and geographic location influenced the family's satisfaction with the Service. No statistically significant difference was observed in the correlation between the *Kidscreen-10 index Proxy* total score and the MPOC-56, however, there was a positive correlation in the effect size: weak between Factors 3 and 4 and moderate between Factors 1 and 5. **Conclusion:** The study of these variables can contribute towards the development of unique therapeutic planning and management in favor of quality of service.

Keywords: Correction of hearing impairment; Quality of life; Child; Speech; language and hearing sciences; Kinship network; Health centers; Health services; Health services for persons with disabilities; Cochlear implantation

RESUMO

Objetivo: Investigar, sob a perspectiva da família, a qualidade de vida de crianças usuárias de implante coclear e correlacionar com as percepções sobre o cuidado recebido na atenção hospitalar em saúde auditiva, conforme características clínicas e sociodemográficas. **Métodos:** Dezoito famílias de crianças usuárias de implante coclear atendidas por um Serviço de Atenção Hospitalar do Sistema Único de Saúde responderam aos questionários *Kidscreen-10 index Proxy* e *Measure of Processes of Care-56* (MPOC-56), os quais, conforme dados clínicos e sociodemográficos, foram correlacionados estatisticamente. **Resultados:** A qualidade de vida dessas crianças apresentou pontuações próximas ao máximo, havendo menores pontuações em desenvolvimento emocional, desempenho escolar e capacidade de prestar atenção - com melhora conforme aumento da idade. A satisfação com o Serviço apresentou pontuações elevadas, sendo Acessibilidade e Disponibilidade dos Serviços o Fator com menor pontuação. A idade e a localização geográfica afetaram a percepção das famílias quanto à qualidade de vida das crianças e a idade, o tempo de implante coclear e de terapia e a localização geográfica influenciaram a satisfação da família com o Serviço. Não foi observada diferença estatisticamente significativa em correlação da pontuação entre *Kidscreen-10 index Proxy* e MPOC-56, todavia, houve correlação positiva no tamanho do efeito: fraca entre os Fatores 3 e 4 e moderada entre Fatores 1 e 5. **Conclusão:** O estudo dessas variáveis pode impactar a elaboração do planejamento terapêutico singular e manejos em prol da qualidade do Serviço.

Palavras-chave: Reabilitação da deficiência auditiva; Qualidade de vida; Criança; Fonoaudiologia; Rede familiar; Unidade hospitalar de saúde pública; Uso de serviços de saúde; Rede de cuidados à pessoa com deficiência; Implante coclear

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Study carried out at Departamento de Fonoaudiologia, Centro de Ciências da Saúde, Universidade Federal do Espírito Santo – UFES – Vitória (ES), Brasil.

[1] Curso de Fonoaudiologia, Universidade Federal do Espírito Santo – UFES – Vitória (ES), Brasil.

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Corresponding author: Talita Falqueto Pereira. E-mail: talitafalqueto@gmail.com

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INTRODUCTION

Multiple biopsychosocial health determinants impact the path and development of children with hearing loss (HL), according to Brazilian public policies of the Care Network for People with Disabilities (RCPD) of the Unified Health System (SUS)(1). Environmental factors (e.g., family adherence, emotional status, and quality of the service), social factors (e.g., access to treatment and social participation), and personal factors (e.g., etiology, HL type and degree, time of auditory sensory deprivation, age, cognition, and language) affect the success of the intervention at the service and the quality of life (QOL) of the person with HL(2).

In the auditory-oral approach, auditory rehabilitation integrates hearing by developing auditory skills that depend on biological maturation and facilitated sensitive experiences. They promote learning by providing opportunities for it and ensuring its maintenance and refinement, addressing audibility processes accessible through hearing technologies, such as cochlear implants (CI)(2). Early and individualized intervention with unique interprofessional goals and therapeutic plans is essential to reduce the negative impact of these biopsychosocial aspects during the development of individuals with HL and to increase the positive impact on this population's QOL.

QOL can be defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"(3). QOL analysis in chronic conditions, such as HL, demonstrates the impacts and consequences of biopsychosocial conditions on the individual and inseparably brings notions about conditions of social constitution and insertion in the community. Considering that people with disabilities (PWD) suffer harm in their full and effective participation in society(2), the intervention and involvement of interdisciplinary teams can positively impact the psychosocial needs of children with HL by developing intervention strategies focused on the family and the context in which they are inserted(4-6).

Family-Centered Care (FCC) or the Family-Centered Approach focuses on care in which the child and their family are at the center of all health care decisions. It ensures that the family participates in the intervention process and recognizes them as participants in care, so that, in an interprofessional context, the members of each family have individual access and the ability to define problems and solutions(7).

Estimates indicate that when the FCC is involved, the family not only engages more in the treatment but also better evaluates and transforms the service(8,9). It is important to know the perception of the Family-Centered Service, as it provides information about what it does and its real consequences, enabling improvement in the interdisciplinary team's skills, intervention strategies, and prognostic evolution of the cases(10,11).

Interprofessional clinical actions are increasingly strengthening family dialogue and engagement to encourage active participation, self-advocacy(12), and family involvement(13). Family guidance and counseling have directly and indirectly provided expanded and group family settings with information and opportunities for self-knowledge, reflection, and changes regarding their needs and satisfaction, enhancing aspects of parenting that support and nurture the child's development(2,10,14,15).

This study established an interface between QOL and satisfaction with the service, engaging, conceiving, and encompassing families in the care process. It highlighted the interprofessional context of the highly complex hearing health team, from the perspective of the hospital care network, with families of children with HL who use CI. Researching such evidence aimed to support public policies and inform and engage service strategies and multiprofessional interventions in unique therapeutic planning.

This study aimed to investigate, from the family's perspective, the QOL of their children with CI and correlate it with these families' perceptions about the care received in hospital hearing healthcare in Espírito Santo, Brazil, according to clinical and sociodemographic characteristics.

METHODS

This quantitative, cross-sectional, analytical, descriptive study integrated teaching, research, and outreach. It was conducted at the interface between the speech-language-hearing program at a federal public university, the Cochlear Implant and Bone-Anchored Hearing Aid Program at Cassiano Antonio Moraes University Hospital (HUCAM), accredited by the RCPD-SUS, and the Interprofessional Health Teaching Clinic of the Health Sciences Center at the Federal University of Espírito Santo (UFES).

The research was approved by the Research Ethics Committee of UFES' Health Sciences Center under protocol number 069863/2023 in September 2023.

Study participants

Families of children who underwent CI surgery in HUCAM/UFES' Cochlear Implant and Bone-Anchored Hearing Aid Program in the capital of Espírito Santo, a state in southeastern Brazil, were invited to participate in the research. The interdisciplinary team follows operating procedures according to instructions and ordinances authorized by the Ministry of Health(6).

All children who undergo CI surgery at this service remain with the team for some time for hearing rehabilitation. Priority is given to ensuring that all children receive weekly speech therapy near their homes, given that most live outside the metropolitan area where the service is located.

The HUCAM/UFES' Cochlear Implant and Bone-Anchored Hearing Aid Program performed 93 surgeries by the end of this 6-month data collection period, encompassing 78 patients, as some underwent more than one procedure due to sequential bilateral implant surgery. Of these patients, 39 were children who underwent CI surgery and were therefore eligible to participate in this study.

The sample inclusion criteria were (a) families of children with HL, up to 11 years and 11 months old, who underwent CI surgery at the aforementioned service, and any family member could answer the questions in the interview instruments; (b) the family member answering the questions had to be able to hear, since the researchers would administer the instruments through directed oral questions. The exclusion criterion was the family's failure to complete the interview instruments.

Instruments

Child's clinical data: Identification form of the child with HL and data from the medical record, pedagogical didactic file of the speech-language-hearing supervised internship in partnership with the service, and post-CI surgery rehabilitation, with information on the general health of the child with CI. The study comprised the following variables: age, gender, etiology and type of HL, family members, education level, type of school (regular or bilingual), whether the child had a Brazilian Sign Language (Libras) interpreter at school, type of hearing aid (unilateral, simultaneous or sequential bilateral), time since the first CI, time of speech therapy, location where speech therapy with an emphasis on auditory rehabilitation was performed, and the family's place of residence.

Two instruments were applied to the participating families:

- Kidscreen-10 index Proxy-10 (Health Questionnaire for Children and Young People - Parent Proxy Version)(16), Brazilian Portuguese version. The Proxy version of the questionnaires, in which parents can respond about their perception of their children's QOL, aims to provide complementary and comparative information, assessing younger children and those cognitively unable to understand the construct(16,17). Children with HL may have cognitive-perceptual alterations that affect language comprehension, justifying the use of the Proxy version in this study(18).

The 10-item version of the instrument was feasible for this study because it assesses children's QOL from the family's perspective in a generic, single-factor approach and is a short time. The questions refer to the previous week, and the score is calculated on a 5-point scale ranging from "not at all" to "extremely." The total score is calculated by adding all items, ranging from 10 to 50 points.

- MPOC-56 (Measure of Processes of Care)(7), translated into Portuguese(10). It was created to assess the services provided by the rehabilitation center from the perspective of families of patients with disabilities aged 0 to 17 years. It was translated into Brazilian Portuguese with an emphasis on auditory-oral therapy(10). Its 56 questions are subdivided into five factors (Factor 1 – Enabling and Partnership, Factor 2 – Providing General Information, Factor 3 – Providing Specific Information about the Child, Factor 4 – Coordinated and Comprehensive Care for the Child and Family, and Factor 5 – Respectful and Supportive Care) that identify the extent to which health services assist in child rehabilitation, from the perspective of the family. They also allow the center to assess the extent to which its procedure leads to satisfactory or unsatisfactory results. The questions are grouped into two categories: questions about the people who work with the child and questions about the service where the child is rehabilitated. Questions are scored on a scale from 0 (not applicable) to 7 (very satisfied), and the scale score is calculated by averaging responses to each factor's topic. The score ranges from 1.00 to 7.00; the calculation does not include questions marked as "not applicable".

A 20-item short version was developed(8) and validated for Portuguese(9), but the full 56-item version is still recommended for research, which justifies its use in this study(8,19). The psychometric properties of the 56-item Brazilian version are not yet found in the literature.

Procedures

A list of patients who met the research inclusion criteria was obtained from the service's information system, as well as their telephone contacts and/or appointments for follow-up and/or therapy sessions when conducted at the service. Most participants were approached at the reception of the location where they had follow-up care (audiological evaluation, mapping, and other interprofessional procedures of the service) or speech therapy, being invited to participate in the project. Patients who met the inclusion criteria and did not attend the institution during the collection period were contacted by telephone and invited to participate remotely. The instrument application sessions were conducted with each family, either in person or remotely, for over 6 months, lasting approximately 30 minutes. The guardians of all families involved in the research signed an informed consent form.

The collected data were compiled into spreadsheets and analyzed using SPSS Statistics software, version 27.0 (IBM Corp., Armonk, NY, USA). Absolute frequency, relative frequency, and measures of central tendency and dispersion were calculated. In the inferential analysis, the correlation coefficient and p-value were calculated using Pearson's correlation test, and the statistical significance level was set at 5% ($p \leq 0.05$). In addition to statistical significance, the results were also interpreted based on effect size using the bias-corrected and accelerated bootstrap sampling method, based on 2,000 samples. The analyses involving duration of therapy excluded cases with intermittent adherence to therapy, and the analyses of education level and type of school excluded cases without school attendance due to the small sample size. The locations were grouped into two categories due to the similarities between the cities regarding access to healthcare: The metropolitan area, comprising the municipalities of Greater Vitória (including the municipality where the service is located), and inland Espírito Santo, comprising the remaining municipalities.

RESULTS

Of the 20 families that agreed to participate in the research, 10% (2) were excluded from the sample because the family member (grandmother) was unable to complete the questionnaires, and the interview was interrupted without any response from the family.

The final sample of this research consisted of 18 families, of which 14 children (77.78%) underwent hearing rehabilitation at the service, and four children (22.22%) underwent rehabilitation elsewhere, such as a community health center, non-governmental organization, or private service. There was no difference between genders in the sample. The family members interviewed were predominantly biological mothers (66.67%), although biological fathers and grandparents were also interviewed. No children in the sample attended bilingual schools, and nine (50%) children had a Libras interpreter as a resource in their regular school. The characterization of clinical and sociodemographic data is presented in Table 1.

Table 1. Characterization of clinical and sociodemographic data of children with cochlear implants

Variables	Values
Age (years)	
Mean (SD)	6.31 (1.99)
Median; min-max	6.04; 3.50-11.33
Location	
Metropolitan area - n (%)	11 (61.11)
Inland Espírito Santo - n (%)	7 (38.89)
Etiology of hearing loss	
Idiopathic - n (%)	11 (61.11)
Congenital - n (%)	4 (22.22)
Ototoxicity - n (%)	2 (11.11)
Waardenburg syndrome - n (%)	1 (5.56)
CI type	
Unilateral	15 (83.33)
Sequential bilateral	3 (16.67)
Time since first implant (months)	
Mean (SD)	28.33 (19.91)
Median; min-max	31.50; 1.00-60.00
Time since the beginning of therapy	
Since hearing aid - n (%)	8(44.44)
Since CI - n (%)	7 (38.89)
Over 1 year since CI - n (%)	1 (5.56)
Intermittent - n (%)	2 (11.11)
School characteristics	
Regular school - n (%)	8 (44.44)
Regular school with a Libras interpreter - n (%)	9 (50.00)
Not attending school - n (%)	1 (5.56)
Education level	
Elementary school - n (%)	9 (50.00)
Preschool - n (%)	8 (44.44)
Not attending school - n (%)	1 (5.56)

Subtitle: n = number of participants; % = percentage; SD = standard deviation; min = minimum value; max = maximum value; CI = cochlear implant; Libras = Brazilian Sign Language

Family members perceived high scores, close to maximum, for their child's QOL and general health. The items perceived as worst by families were, "Was your child well at school?" and "Was your child able to pay attention?", followed by "Did your child feel sad?" and "Did your child feel lonely?". Families also evaluated the service positively, with lower averages on MPOC-56 Factor 2, which addresses the provision of general information in the intervention program (Table 2).

There was no statistically significant difference between the variables assessed by the questionnaires. However, there was a weak positive correlation (small effect size) between MPOC-56 Factors 3 and 4 and the total Kidscreen-10 Index Proxy score, and a moderate positive correlation (medium effect size) between MPOC-56 Factors 1 and 5 and the total Kidscreen-10 Index Proxy score. These results indicate that the better the service's assessment of these Factors, the better the family's perception of the child's QOL. No statistically significant difference or relevant effect size was observed between the total Kidscreen-10 Index Proxy score and the MPOC-56 Factor 2 score (Table 3). Greater dispersion among the population was observed in MPOC-56 Factor 2 in relation to the Kidscreen-10 Index Proxy when compared to the other Factors (Figure 1).

No statistically significant correlation was observed between age, time of CI use, time of therapy, perception of QOL, and family members' satisfaction with the service. However, age was positively correlated (moderate effect size) with the overall Kidscreen-10 Index Proxy score and the MPOC-56 Factor 1. Furthermore, age was negatively correlated with MPOC-56 Factor 2 (strong effect size) and Factors 5 and 3 (moderate effect size). There was also a negative correlation (moderate effect size) between implant time and MPOC-56 Factors 2 and 5 and between time of therapy and MPOC-56 Factor 4 (Table 4).

Table 2. Descriptive values of measures related to family members' satisfaction with the service and perception of the child's quality of life

Variable	Mean	SD	Median	Min.	Max.
MPOC-56					
Factor 1 - Enabling and Partnership	6.64	0.33	6.78	5.88	7.00
Factor 2 - Providing General Information	5.69	1.60	6.22	1.00	7.00
Factor 3 Providing Specific Information about the Child	6.86	0.33	7.00	5.80	7.00
Factor 4 - Coordinated and Comprehensive Care for the Child and Family	6.62	0.31	6.64	6.00	7.00
Factor 5 - Respectful and Supportive Care	6.80	0.33	7.00	5.89	7.00
Kidscreen-10 index Proxy					
Total score	46.06	3.92	47.00	36.00	50.00
Overall health	4.33	1.02	5.00	1.00	5.00

Subtitle: SD = standard deviation; Min. = minimum value; Max. = maximum value; MPOC-56 = Measure of Processes of Care-56

Table 3. Correlation analysis between scores on the Measure of Processes of Care-56 and the Kidscreen-10 index Proxy

MPOC-56	Kidscreen-10 Index Proxy	
	Coef. [95% CI]	*p-value
Factor 1 - Enabling and Partnership	0.474†† [-0.174. 0.753]	0.091
Factor 2 - Providing General Information	0.047 [-0.340. 0.561]	0.837
Factor 3 - Providing Specific Information about the Child	0.240† [-0.171. 0.841]	0.542
Factor 4 - Coordinated and Comprehensive Care for the Child and Family	0.292† [-0.144. 0.601]	0.137
Factor 5 - Respectful and Supportive Care	0.340†† [-0.150. 0.890]	0.355

*Statistically significant value at the 5% level ($p \leq 0.05$); †small effect; ††medium effect

Subtitle: Coef. = coefficient; CI = confidence interval; MPOC-56 = Measure of Processes of Care-56

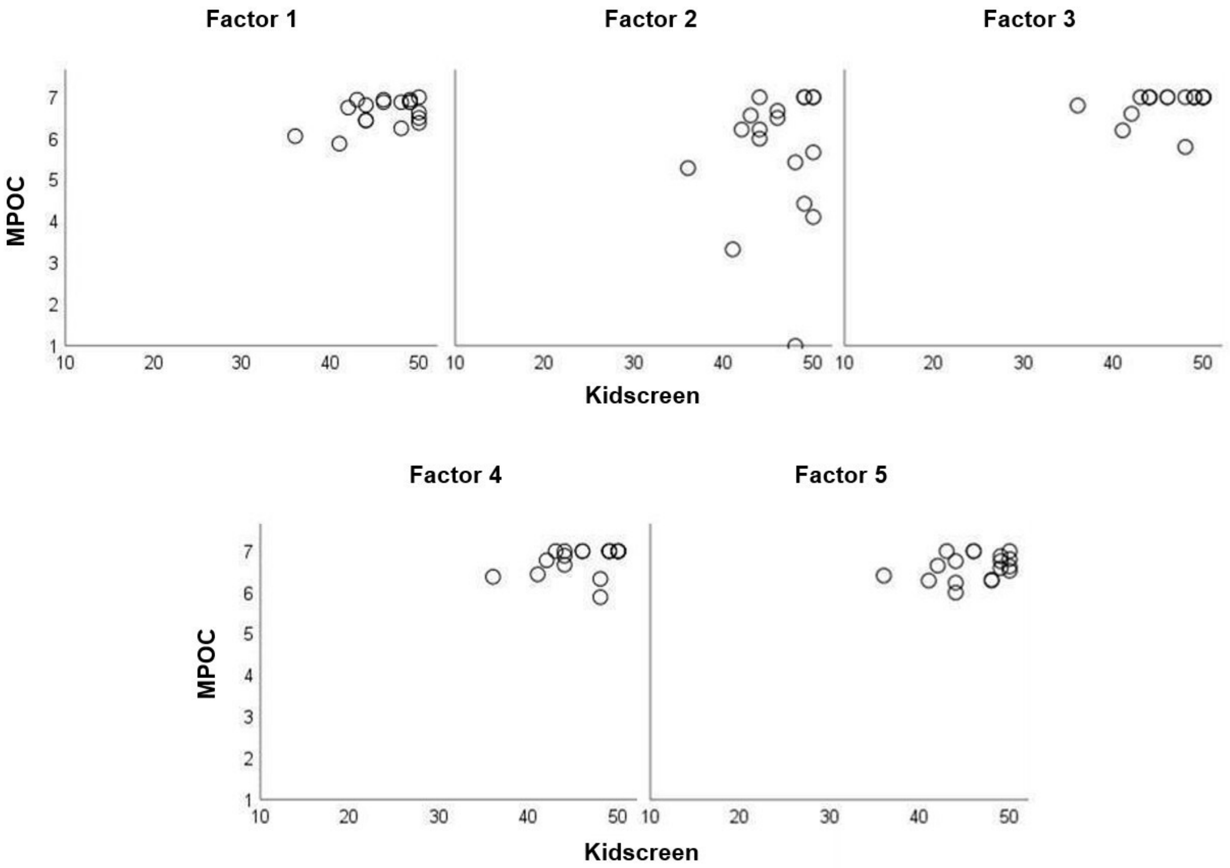

Figure 1. Dispersion of scores for each factor of the Measure of Processes of Care-56 as a function of the total score on the Kidscreen-10 index Proxy

Table 4. Correlation analysis between scores on the Measure of Processes of Care-56 and Kidscreen-10 index Proxy and age, time since implant, and therapy time

Questionnaires	Age		Time since implant		Therapy time	
	Coef. [95% CI]	p-value	Coef. [95% CI]	p-value	Coef. [95% CI]	*p-value
Kidscreen-10 index Proxy – Total score	0.388†† [-0.104. 0.724]	0.053	0.271† [-0.143. 0.723]	0.250	0.228† [-0.250. 0.662]	0.263
MPOC-56 - Factor 1 - Enabling and Partnership	0.317†† [-0.263. 0.727]	0.174	0.142† [-0.452. 0.628]	0.519	-0.033 [-0.586. 0.406]	0.894
MPOC-56 - Factor 2 - Providing General Information	-0.518††† [-0.861. 0.261]	0.072	-0.426†† [-0.732. 0.106]	0.077	0.083 [-0.386. 0.645]	0.759
MPOC-56 - Factor 3 - Providing Specific Information about the Child	-0.450†† [-0.836. 0.438]	0.202	-0.257† [-0.658. 0.359]	0.369	0.079 [-0.456. 0.614]	0.810
MPOC-56 - Factor 4 - Coordinated and Comprehensive Care for the Child and Family	0.077 [-0.479. 0.665]	0.766	0.119† [-0.401. 0.608]	0.644	-0.416†† [-0.736. 0.065]	0.094
MPOC-56 - Factor 5 - Respectful and Supportive Care	-0.383†† [-0.839. 0.630]	0.283	-0.354†† [-0.727. 0.378]	0.137	-0.057 [-0.522. 0.418]	0.809

*Statistically significant value at the 5% level ($p \leq 0.05$); †small effect; ††medium effect †††large effect

Subtitle: Coef. = coefficient; CI = confidence interval; MPOC-56 = Measure of Processes of Care-56

Satisfaction with the service and children's perceived QOL were positively assessed by both the families of children attending regular schools and those of children attending regular schools with a Libras interpreter. However, the group without a Libras interpreter had higher scores. When comparing questionnaire scores with geographic location, participants from inland Espírito Santo rated their satisfaction with the service higher on MPOC-56 Factors 2, 3, 4, and 5 and the Kidscreen-10 index proxy.

DISCUSSION

National and international literature scarcely investigates the perception of family members about the QOL of children with HL, correlating it with the satisfaction with the service. Hence, this research presents a positive contribution.

Family satisfaction with the service was mostly positive. Factors with lower scores, which have a potential for improvement, have also been observed in other studies, such as access to social needs and information received(20). A review assessed the application of the MPOC-56 over the 20 years since its creation and found that Factor 5 (Respectful and Supportive Care) was the best-rated, followed by Factor 1 (Enabling and Partnership) and Factor 4 (Coordinated and Comprehensive Care for the Child and Family)(19). In the present sample, Factors 5 and 1 also presented the best averages; however, Factor 3 (Providing Specific Information about the Child) had the highest score. One hypothesis for this occurrence is the characterization of the service with auditory rehabilitation intervention, which generates more specific data on each child's clinical condition and development, allowing professionals to gain greater insight into these issues and promoting a better assessment of this factor from the families' perspective. Likewise, the service's interprofessionality allows all team members to discuss information, making it easier for them to remember important information for the user and their family, possibly impacting the families' perception.

In the literature, Factor 2 (Providing General Information) is typically the one with the worst evaluation in the MPOC-56(19). In the present study, Factor 2 was also the one with the lowest family evaluation. This Factor assesses satisfaction with aspects related to the center, rather than the professionals, evaluating the provision of general information that strengthens the knowledge of family members (e.g., multimedia reports and information on external services and the community in which the family is inserted), and mediating connections with other parents and other experts on the subject who can help them face the challenges related to HL(14).

These findings outline an area in which the service can focus efforts to improve care, such as providing guidance and counseling, health education, reception, and other health actions with specialists and an interprofessional team. It can also systematically update websites and social media and train groups of guardians in person (mediated by team professionals in expanded settings) and through social media (with informative and educational materials and information). Providing specific and general information, counseling, and guidance are part of the intervention process and promote the autonomy and self-advocacy of family members in the FCC. Speech-language-hearing guidance for individuals with HL is considered effective and an intervening agent in enhancing the child's development(1).

Family members perceived the children's QOL as good, with mean and median scores close to maximum, reporting that the children are happy, healthy, and satisfied with their family life, peers, and school life. Furthermore, most evaluated the children's general health as "very good" and "excellent." Participants indicated lower scores on items related to the children's emotional characteristics, school performance, and ability to pay attention. It is known that parents perceive a lower overall QOL in children with CIs than in those with normal hearing, as well as lower academic and social performance scores(21). Cognitive development is commonly delayed in deaf children(18), which can impact school performance. However, their auditory and linguistic skills and the acoustic conditions of the environment also affect their communication and autonomy at school(12,21), either improving or worsening academic performance, depending on their development. Thus, CI and early intervention can improve academic performance, as they optimize communication skills in verbal-oral language and cooperation with the school.

Family members who scored highly on MPOC-56 Factors 1 and 5 (Enabling and Partnership, and Respectful and Supportive Care) had better scores on the Kidscreen-10 Index Proxy, demonstrating that feeling involved in therapy and being the center of care led to a better perception of the child's QOL. Family involvement was a strong predictor of children's development and better QOL(12). Hence, the FCC can impact family members' perception of children's QOL, as it is based on engaging the family in intervention.

Age had an impact on family members' perception of the child's QOL, with older children achieving higher scores. Several factors can impact the perceived QOL of children and adolescents with CI, such as early implantation and intervention, hearing and chronological age, correct use of the hearing device, auditory skills, and language skills. Reviews have found conflicting data on the correlation of chronological age with QOL, depending on the participants' characterization of these multiple conditions. The various research instruments, the heterogeneous samples, direct or proxy assessment, and the subjective, multifactorial, and multidimensional nature of QOL often generate conflicting results regarding these variables, preventing a more assertive comparison between studies(22,23).

Older age also positively impacted MPOC-56 Factor 1 (Enabling and Partnership), indicating that the older the child, the more involved their guardians felt in the therapeutic process. Conversely, older age also negatively impacted MPOC-56 Factors 2 (Providing General Information), 3 (Providing Specific Information about the Child), and 5 (Respectful and Supportive Care), showing that family members of older children considered the service less efficient in providing general and specific information about the child and in providing FCC. After early childhood, development begins to generate more complex demands that require assistance beyond the context of therapy, and the child's social environment expands beyond the primary settings, which can lead to the perception of new difficulties, such as isolation and social exclusion, reading and writing development, and insertion into cultural environments where the service is not prepared to receive the child with HL(2,24). The emergence of these new needs can create new expectations for family members about what the service needs to cover, which can be one of the sources of frustration and consequent dissatisfaction with the factors mentioned. On the other hand, the development of a language, greater attention span, and interaction with family members in this age group can make them feel more engaged in the therapy, leading to a positive assessment of these factors and of QOL, although there is no consensus on this in the literature(22,23).

The time since the first implant negatively impacted MPOC-56 Factors 2 and 5, indicating that the longer the time since implantation, the less satisfactory families considered the service in providing general information and FCC. Families of children with longer hearing rehabilitation time rated the service as unsatisfactory in relation to Factor 4 (Coordinated and Comprehensive Care for the Child and Family). The process of discovering a child with a disability is complex and permeated by several aspects, such as frustration, creation of coping strategies, and realignment of expectations that impact family organization and life(4,25), requiring constantly adjusted expectations. A longitudinal study found that the impact on family life decreased after CI surgery and after 3 years of CI use, while parental expectations decreased after CI surgery but returned to pre-implantation high levels after 3 years of CI use(26). Therefore, the parents' high expectations long after beginning the therapy and/or surgery may also impact family satisfaction with the service, requiring further studies to investigate its correlation.

The program is a benchmark for hospital care for users from different parts of the state, despite being in the metropolitan area. Users from inland Espírito Santo obtained better scores on the questionnaires (except for MPOC-56 Factor 1) than those from the metropolitan area. Access to healthcare is one of the determinants of socioeconomic development and QOL. Brazil, like other developing countries, presents greatly unequal access between rural and urban populations(27), especially for the most vulnerable populations, such as PWDs, considering their need for specialized and hospital services concentrated in a few centers(28). Although geographic location interferes with the ability of rural populations to access healthcare, not all users report distance as a challenge, since this is true for other aspects of their lives, and many users consider that any effort is worthwhile to receive care, and waiting and distance are characteristics of the SUS(28-30). Effective care, welcoming, active listening to patients, provision of information that can increase autonomy and self-advocacy, professional performance, and bonding motivate them to create adaptive coping strategies and family reorganization to maintain follow-up in a service, despite the distance(28-30). Thus, the scarcity of these professional skills in the municipality of origin, combined with the effectiveness of care, welcoming, bond, and each family's beliefs may have led to greater satisfaction with the care and a better perception of QOL in the face of adversity.

The limitations of this study include its sample size, which challenges statistical analysis, considering the reliability of the influence of the results on the variables of interest (the multiple factors involved in rehabilitation). Challenges in accessing the service highlighted areas for improvement, such as the fact that some children were not undergoing rehabilitation within the network because they could not find professionals qualified to provide speech therapy to children with CIs. To this end, the university's role in teaching, research, and outreach, as a foundation for social demands, will certainly encompass strategies to ensure, for example, the ongoing training of professionals within the network and ensure that all children receive rehabilitation near their homes. Furthermore, engagement and dialogue with the schools these children attend are clearly necessary. Aspects related to the effects of academic performance and attention span depend on actions defined in cooperation at school, through specialized educational services within regular education, such as adjusting the acoustics of the environment and aligning team conduct with specific guidelines for each child/family and the technology used. The impact of the child's emotional and cognitive characteristics and access to healthcare also highlights the importance of the role of psychology and social assistance in expanded or individual settings for the child and their family, strengthening the interprofessional approach advocated by the FCC.

The impact of chronological age, implant time, and therapy duration on family members' perceptions raises questions about whether and how these perceptions may change throughout these individuals' childhood and adolescence. The perception of QOL by family members and the children themselves may differ, which may also have influenced the study findings. Therefore, further research is important to identify whether there are discrepancies between QOL and satisfaction with the service from the perspective of the family and the child/adolescent with CI (when cognitively capable) in the hospital network of the Espírito Santo RCPD. The instruments should be applied and reapplied continuously, not only because they allow longitudinal monitoring of users' and their families' perceptions of the service (as demands change throughout life) but also because they allow for self-awareness and reflection, considering that this is the context of a child with HL, involving changeable, dynamic, and chronic health determinants.

CONCLUSION

The study of these variables can impact the development of unique therapeutic planning and management in favor of the quality of the service.

Families of children with CIs rated their QOL positively and expressed overall satisfaction with the service. They identified the provision of general information as the Factor most in need of improvement within the RCPD-SUS CI service in Espírito Santo. The children's emotional characteristics, school performance, and attention span were the components that most negatively impacted family members' perception of QOL. Feeling involved in therapy and at the center of care improved the child's QOL. Age and geographic location influenced families' perception of children's QOL, and age, time since the implant, therapy duration, and geographic location influenced family satisfaction with the service.

The study clarified how the constructs relate to each other in the sample and proved relevant to the service, enabling adjustments to it and proposals for interventions based on the population's characteristics, needs, and expectations. It is expected that increasingly more services will apply these types of instruments, supporting the interprofessional team, so that well-informed and self-aware families can be more engaged, participatory, and motivated. Further research is needed to understand whether the family perception differs from self-reports of children and adolescents in this population and whether the study variables change throughout the participants' lives.

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