

# The impact of hearing impairment on family relationships of schoolchildren who use individual sound amplification devices

## O impacto da deficiência auditiva nas relações familiares de escolares usuários de dispositivos eletrônicos de amplificação sonora

Cristiane Dellinghausen Valim<sup>1</sup> , Viviane Piber<sup>1</sup> , Eliara Pinto Vieira Biaggio<sup>1</sup> 

### ABSTRACT

**Purpose:** To analyze the impact of the diagnosis of hearing loss on the family relationships of schoolchildren who use hearing aids. **Methods:** The sample consisted of 26 parents from schools with hearing aid hearing aid users aged between 4 and 14 years, assisted in a public Hearing Health Program. Parents responded to an objective, prepared by the authors without prior validation, with seven questions on the subject. Inferential statistical analysis was performed whenever possible. **Results:** Most parents do not report having had personal difficulties and/or strain in family relationships with their hearing-impaired child. No association was found between the degree of hearing loss and the communication difficulties between both family groups. There was also no association between language modality and communication difficulty between the two groups, although in the broader family group the responses were not as unanimous as in the main family group. **Conclusion:** Parents did not report a significant impact on family relationships and communication with their children with hearing loss who use hearing aids, regardless of the degree of hearing impairment and language modality. Among the broader family group, there was also no significant association between the degree of hearing impairment or the language modality used and communication difficulties between the child and the family, even with more heterogeneous responses than in the main family group.

**Keywords:** Hearing loss; Family relations; Child development; Hearing aids; Communication barriers

### RESUMO

**Objetivo:** Analisar o impacto do diagnóstico da deficiência auditiva nas relações familiares de escolares usuários de dispositivos eletrônicos de amplificação sonora. **Métodos:** A amostra foi composta por 26 pais de escolares com deficiência auditiva, usuários de dispositivos eletrônicos de amplificação sonora, com idades entre 4 e 14 anos, atendidos em um Programa de Saúde Auditiva público. Os pais responderam a um questionário objetivo, elaborado pelas autoras, sem validação prévia, com sete perguntas sobre a temática. Realizou-se análise estatística inferencial sempre que possível. **Resultados:** A maioria dos pais não relatou ter apresentado dificuldades pessoais e/ou desgaste nas relações familiares com seus filhos deficientes auditivos. Não foi encontrada associação entre grau da deficiência auditiva e dificuldade de comunicação em ambos os grupos familiares. Também não se observou associação entre modalidade linguística e dificuldade de comunicação nos dois grupos, apesar de as respostas do grupo familiar mais amplo não terem sido tão unânimes como as do grupo familiar principal. **Conclusão:** Os pais não relataram impacto significativo entre as relações familiares e a comunicação com seus filhos com deficiência auditiva, usuários de dispositivos eletrônicos de amplificação sonora, independentemente do grau da deficiência auditiva e da modalidade linguística. No grupo familiar mais amplo, também não houve associação importante entre grau da deficiência auditiva ou a modalidade linguística utilizada e dificuldade de comunicação entre a criança e a família, mesmo com respostas mais heterogêneas do que no grupo familiar principal.

**Palavras-chave:** Perda auditiva; Relações familiares; Desenvolvimento infantil; Auxiliares de audição; Barreiras de comunicação

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<sup>1</sup>Programa de Pós-graduação (Mestrado), Universidade Federal de Santa Maria – UFSM – Santa Maria (RS), Brasil.

**Conflict of interests:** No.

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**Corresponding author:** Cristiane Dellinghausen Valim. E-mail: [cristiane\\_valim@hotmail.com](mailto:cristiane_valim@hotmail.com)

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## INTRODUCTION

Hearing is necessary and essential to human relationships, especially when related to the acquisition and development of oral language and learning. As a result, the diagnosis of childhood hearing impairment (HI) tends to have a significant impact on the daily lives of these children and their families<sup>(1-3)</sup>.

The early diagnosis of AD is associated with technological advances and the use of principles, such as cross-check, which is carried out through a set of electrophysiological, behavioral and physiological assessments used in a complementary way<sup>(3,4)</sup>. Appropriate conduct and adequate guidance have helped to better manage these cases. It should also be added that public hearing health programs serve as support and reference for the hearing impaired and their families, as it is through them that assistive hearing devices are granted.

In Brazil, since 2004, there has been the National Hearing Health Care Policy (NHHCP-PNASA)<sup>(5)</sup>, which guarantees audiological diagnosis, selection, adaptation and supply of electronic sound amplification devices (ESAD) and speech therapy to all users of the Unified Health System (UHS-SUS)<sup>(6)</sup>. Furthermore, this ordinance indicates the importance of establishing a comprehensive care approach that is applied at all levels of hearing health care. Therefore, offering interdisciplinary psychological support in coping with the diagnosis and supporting communication in the hearing qualification process is a relevant aspect of national hearing health programs.

However, the reflection of the discovery of hearing impairment and the need to use hearing aids bring changes in behavior among children and their families, from mourning for not having an ideal child to the establishment of linguistic exchanges. The way the diagnosis is conducted and guided points family members to new and different perspectives on emotional and relationship issues between them<sup>(1,2)</sup>.

The wide use of hearing aids, with the effective use of ESAD, whether or not associated with the use of the Frequency Modulation System (FM), helps in the good prognosis and development of language, communication and learning in these children<sup>(3,7)</sup> and it is known that, for the effective use of these devices, it is necessary for the family of the child with HI to understand the entire process.

Such factors are influenced and/or influence the family relationships of this population<sup>(1)</sup> and are the focus of this study. Based on the above, the objective was to analyze the impact of the diagnosis of hearing impairment on the family relationships of schoolchildren who use ESAD.

## METHODS

This is an observational, descriptive, quantitative and cross-sectional study, approved by the Research Ethics Committee of the Federal University of Santa Maria, under CAAE number 23081.027862/2021-65 and report 055748. All biosafety and ethical rules were adopted and Resolution 466/12 of the National Health Council was fully respected. Those responsible for the children were informed about the objectives of the study and received the Free and Informed Consent Form (FICF) for reading and awareness and their signature was a necessary condition for participating in the research.

The initial sample was composed of 60 parents of children/schoolchildren with HI, treated in a SUS Hearing Health Program. Initially, the data of the students, aged between 4 and 14 years old, were located in a database and contact was made via telephone to schedule a return to the program and an interview to carry out this research.

The inclusion criteria for the study were: parents of students with symmetric bilateral sensorineural HI of different degrees, enrolled in public schools in the city where the study was developed; parents of students who used ESAD (oral and/or bilingual) and who were willing to respond to a questionnaire previously prepared for this research. The exclusion criteria were defined as follows: parents of students with multiple disabilities; parents who did not present visible cognitive conditions, as no protocol was applied to validate this information, and parents who did not respond to the questionnaire in its entirety.

As a research procedure, a questionnaire developed by the authors was applied, without prior validation, to the parents of students with HI who used ESAD and who were part of the aforementioned Hearing Health Program. The questionnaire contained seven objective questions, in addition to the participants' identification data and information regarding their hearing history (degree of HI, type of device used and therapies performed). The questions were multiple choice, dealing with family relationships and hearing impairment, addressing aspects of the emotional impact of the diagnosis of this disability, difficulties in family communication, the strain on family relationships and the routine after diagnosis (Chart 1).

When applying the questionnaire, those responsible were asked to score the questions according to their experience in the process from diagnosis to prosthetization. For statistical analysis purposes, the questionnaire responses were considered according to the occurrence of the situations investigated: more than 50% of the occurrences, when the responses were referred to as "always" or "almost always", and less than 50% of the occurrences, when the answers were "sometimes/often", "rarely" or "never". The questionnaire was filled out by the researchers, who read each of the questions to the sample subjects. This research took place in the waiting room, while the students were undergoing hearing rehabilitation therapy and/or receiving assistance for adjustments to hearing aids.

The development of the research questionnaire aimed to standardize responses between the topics covered in understanding family relationships in the face of their children's HI diagnosis. Thus, it was sought to understand the perception of the subjects questioned regarding the impact of HI on their daily lives and also to infer possible weaknesses and potentialities in this process.

After applying the eligibility criteria, parents of 26 schoolchildren with HI aged between 4 and 14 years old effectively participated in this study. Of the total number of participating subjects (26 parents), 16 were female and ten were male, with an average age of 37 years and 8 months, ranging between 27 and 50 years old. Regarding education, 17 (68%) parents/guardians had secondary education, seven (28%) had higher education and one (4%) had primary education.

To better understand the sample group, it was chosen to characterize the profile of the children of the researched subjects (for whom the term "schoolchildren" was adopted in the present study) in terms of age: from 4 years old (one subject) to 14 years old (with an average age 8 years, 8 months); regarding the degree of HI: 11 had a severe degree, 14, a moderate degree and one, a mild degree; regarding the

**Chart 1.** Questionnaire on family relationships in the diagnosis of hearing impairment prepared by the authors

Block A: Family Relations	Always (1)	Almost always (2)	Sometimes (3)	Rarely (4)	Never (5)
1. After your child was diagnosed with hearing impairment, did the family feel helpless?					
2. Soon after your child's hearing impairment diagnosis, did you have difficulties in establishing the best form of communication (main family nucleus)?					
3. Upon receiving the diagnosis, did the family feel unprepared to deal with the situation?					
4. Has the diagnosis of your child's hearing loss caused strain on the family relationship?					
5. Due to the diagnosis of your child's hearing impairment, was it necessary to change the family's routine?					
6. Have you noticed difficulties in your relationship with your child after the hearing impairment diagnosis?					
7. Did the family (uncles, grandparents, cousins) have difficulties communicating with their child at home, immediately after the hearing impairment diagnosis?					

main form of communication: six were bilingual and 20 used orality as their main form of communication; regarding the use of assistive listening devices: of the 26 ESAD users, ten used the FM System, only in a school environment. It is worth noting that the children in this group, in their entirety, had bilaterally symmetric AD and were included in school in the city where the study was carried out. Regarding speech therapy for auditory rehabilitation, all students, at some point, were treated in the specific sector. The therapeutic approach adopted in the service where the present study was carried out is based on the stimulation of auditory and linguistic skills, through multisensory stimulation. Therapy time and frequency in this process were not variables analyzed.

For descriptive analysis and characterization of the sample group, the data collected were entered into a spreadsheet, so that all information obtained was presented in summary form for subsequent inferential statistical analysis. Categorical variables were presented in percentage form and, when quantitative, in the form of mean and standard deviation. To analyze the association between difficulty in family communication and the degree of hearing impairment of the child, the Fisher's Exact statistical test was used, as well as to analyze the linguistic modality and difficulty in family communication. A 5% level of significance was considered for all statistical tests and the IBM SPSS software, version 25, was used.

**RESULTS**

The different responses from parents regarding the impact of the hearing loss diagnosis on family relationships and the frequency of occurrences reported by each family are shown in Figure 1.

Based on these data, it was observed that the majority of parents did not report having personal difficulties in their relationship with their hearing-impaired children, or that the disability had caused strain on the family relationship.

Based on this information, some data underwent statistical analysis and the responses were divided into two groups: more

than 50% of occurrences (always and almost always) or less than 50% of occurrences (sometimes/often, rarely or never).

Thus, the association between the degree of HI and the difficulty in establishing the best form of communication immediately after the diagnosis of hearing loss was analyzed, both in the main family nucleus and in the broader family group.

Of the parents who answered the questionnaire, 25 (96.15% of the sample) reported that they did not have difficulties in establishing the best form of communication within the main family nucleus (father, mother and siblings), regardless of the degree of hearing impairment.

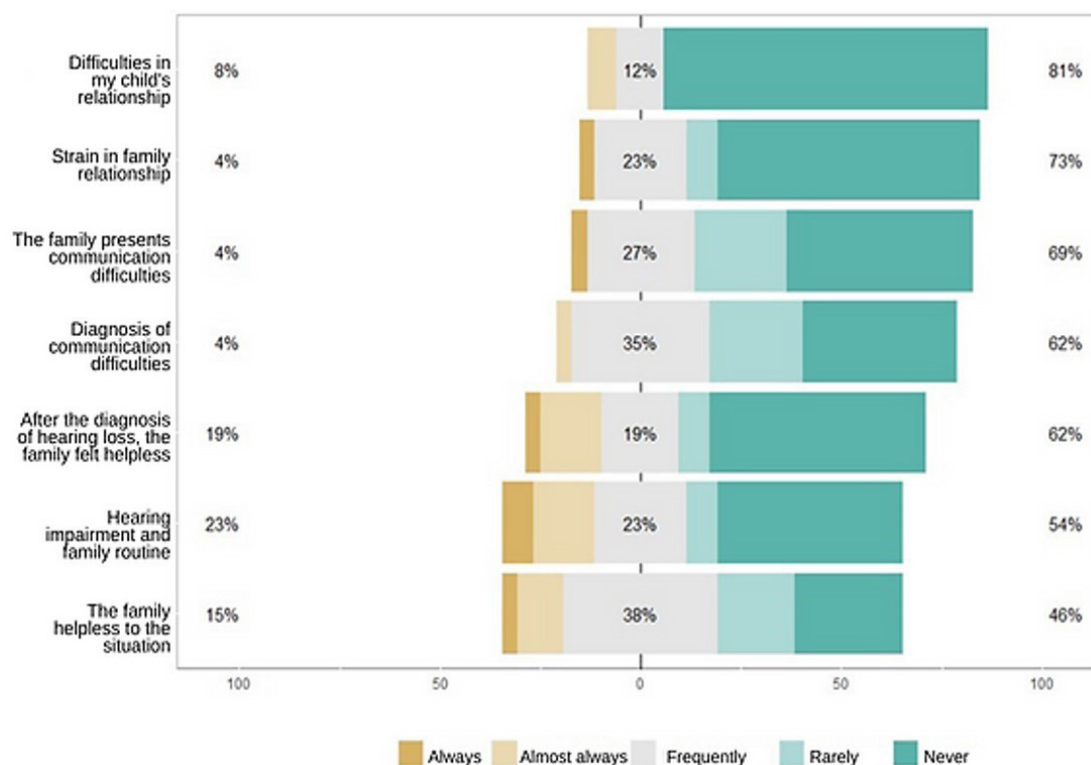
In the broader family group, composed of uncles, grandparents, cousins, among others, the responses were more varied and we sought to analyze the association of these responses with the degree of the child's hearing impairment, using the Fisher's Exact statistical test (Table 1).

When analyzing the data, it was evident that there was no association between the degree of hearing impairment and the difficulty in communicating between the child and the family, as everyone reported complaints in different proportions (p=0.462) (Table 1).

The association between the linguistic modality used for communication (oral/speech, LIBRAS - Brazilian Sign Language or bilingual - speech and LIBRAS) and the difficulty in establishing the best form of communication after the diagnosis of hearing impairment in the main family nucleus was also analyzed, as well as in the family in general (uncles, grandparents, cousins, among others).

In this way, the 26 families, the entire sample, reported that they did not have difficulties in establishing the best form of communication within the main family nucleus, regardless of the language modality.

In the broader family group, it was possible to use a statistical test to measure the association of the linguistic modality used by the children (oral or bilingual) and the difficulties that the family, in general, presented or did not present in communication. Thus, there was no association between the language modality and communication difficulties on the part of the family, in general (p=1) (Table 2).



**Figure 1.** Parents' response to the impact of hearing loss diagnosis on family relationships and the frequency of occurrences reported by each family  
**Subtitle:** % = Percentage of occurrence of responses

**Table 1.** Association between the degree of hearing impairment and communication difficulties among the family group in general (n=26)

		> 50%	< 50%	Total	p value
HI degree	Moderate	1 (100%)	11 (44.0%)	12 (46.2%)	0.462*
	Severe	0 (0%)	14 (56.0%)	14 (53.8%)	
Total		1 (100%)	25 (100%)	26 (100%)	

\*Statistically significant values (p≤0.05) - Fisher's Exact Test

**Subtitle:** HI = Hearing impairment; > = Greater than; < = Less than; % = Percentage of response occurrence

**Table 2.** Association between linguistic modality and communication difficulties among the family group in general (n=26)

		> 50%	< 50%	Total	p value
Linguistic Modality	Speech	1 (100%)	21 (84%)	22 (84.6%)	1.0*
	Bilingual (Speech and LIBRAS)	0 (0%)	4 (16%)	4 (15.4%)	
Total		1 (100%)	25 (100%)	26 (100%)	

\*Statistically significant values (p≤0.05) - Fisher's Exact Test

**Subtitle:** > = Greater than; < = Less than; % = Percentage of response occurrence

## DISCUSSION

In the present study, the data that stood out most were that parents did not report having personal difficulties in relating to their hearing-impaired children, or that the disability had caused strain on the family relationship. Regarding communication, parents, almost all of them, reported that they did not have any difficulties in establishing the best form of communication within the main family unit, regardless of the degree of hearing impairment and the language modality used. In the broader family group, there was no association between the degree of hearing

impairment and communication difficulties between the child and the family, nor was there a significant association between the linguistic modality used and communication difficulties on the part of the family, despite responses are more heterogeneous than those of the main family group.

The lack of significant reports regarding difficulties in family relationships as a result of HI (Figure 1) may have as a possible justification the way in which the diagnostic process is conducted by professionals from the Hearing Health Program in question, which reinforces the importance of assistance to hearing impaired and their family during the process of diagnosis and language monitoring of children with hearing

impairment<sup>(3,8)</sup>. This finding was also presented in a recent study<sup>(1)</sup>, in which parents and family members did not report significant complaints associated with the relationship between children with HI and their families, as they consider that the diagnosis of HI, in itself, does not impact the relationship between the child development and family life.

It is worth noting that perhaps the impact of the HI diagnosis was smaller than initially imagined, due to the access and quality of care in the Hearing Health Program, in which this study was developed. However, the provision of NHHCP-PNASA services and the scope of diagnostic support for families is uneven across the country<sup>(6,9)</sup>. The Brazilian extension and concentration of hearing health services (especially cochlear implants and speech therapy for auditory rehabilitation) in the Southeast and South Regions must be considered, according to the number of services registered in the National Registry of Health Establishments in Brazil, per inhabitants<sup>(9)</sup>. It would be interesting to replicate the present study in different regions of Brazil to visualize the effect of access to the Hearing Health Program at a national level.

An international study<sup>(10)</sup>, with a very representative sample, investigated the impact of having a child with HI on the lives of parents and families, showing that children's HI, in itself, did not present a significant relationship with emotional/ mental health issues of the parents. The authors highlight that cases of children diagnosed with multiple disabilities are much more challenging when thinking about communication and family well-being/mental health.

The search for therapeutic support to the demands of children with hearing impairment, as well as other disabilities, is important and its frequency tends to reduce the impact of the disability on family dynamics and the possible strain on this relationship, as pointed out in a recent study<sup>(2)</sup>.

Parents reported not having communication difficulties, regardless of the degree of hearing impairment (Table 1), possibly due to the positive change in communicative interactions after the intervention program between children with HI and their families<sup>(8,11,12)</sup>. It is worth noting that the family members who responded to the questionnaire have also participated, together with their children, in intervention sessions on hearing rehabilitation in the Hearing Health Program in question, as already mentioned.

The language used by these children, most of whom are spoken and/or bilingual, did not prove to be relevant when associated with the difficulty in communication between the HI and his family. Such data may be related to family dynamics constructed in a way that contributes to this good mutual linguistic development. The parents' low level of stress may have also influenced this good linguistic relationship<sup>(13-15)</sup>.

It can also be mentioned that the families investigated did not point out communication barriers, as initially imagined. These families probably adopted a communicative model that inserted the child with HI into the family context, even considering their own linguistic pattern. Throughout child development, early exposure to spoken language in the family group, through the use of auxiliary devices, made communication between the child with HI and their family members adequate to the parents' perception<sup>(16)</sup>.

It is noteworthy that this sample came from a public hearing health service and from families with little education, for the most part, in which the linguistic standard tends to be less demanding and, perhaps, communicative difficulties are

more visible only to those teachers and/or people with less social interaction<sup>(17)</sup>. In this aspect, a limitation of the present study was the fact that a validated protocol was not used to evaluate the family reaction to the child's speech<sup>(18)</sup>; perhaps the questionnaire prepared by the authors was not sensitive enough to better investigate communication between the family and the child with HI. For example, the Intelligibility Scale in Context: Portuguese (ICS)<sup>(18)</sup> could, in a better way, analyze how much the child's speech is understood by teachers and/or people who are strangers/unknown to the family.

Another limitation of this study was the low sample size and the relationship with the COVID-19 pandemic, as data collection took place during a period of social restrictions, in which few families and their children had returned to speech therapy services in person. Another factor that may have influenced the findings is related to speech therapy, a point not investigated in the present study. It is known that the therapeutic model adopted, the time of insertion in qualification programs and the adherence of families in this process are determining factors in the good prognosis of language development and consequent communication of children with HI<sup>(8,11,12)</sup>, such as the positive influence of professionals who have accompanied these families over the years, specifically those in Speech Therapy, who, in general, adopt assertive behaviors when managing children with HI<sup>(19)</sup>.

An aspect not addressed in the present study was the time since diagnosis of HI/time of use of ESAD, but, when applying the questionnaire, those responsible were asked to score the questions according to the experience they had at the time of diagnosis (remembering the experiences lived at that time). The age of the children whose parents and/or guardians participated in this research was between 4 and 14 years old. Thus, this variable was heterogeneous and would be challenging to consider, but this was not one of the purposes of the study. Furthermore, each family has its own chronological time and time to face the impact of HI and, therefore, access to the hearing health services discussed above is essential. The objective, through these services, is to align strategies for coping with HI, increase motivation for the use of ESAD and inclusion in auditory habilitation therapy programs, including emotional support for families<sup>(20)</sup>.

The present study proved to be relevant, as it highlighted important aspects related to the diagnosis of hearing loss in children and their family relationships in a positive way, reinforcing the influence of monitoring by health teams for these families throughout the process, from diagnosis to monitoring of the use of auxiliary and/or therapeutic devices. It would also be interesting to investigate the issues addressed here in public services in different regions of Brazil, private services and at a non-pandemic time.

## CONCLUSION

Parents reported no significant impact on family relationships and communication with their children with HI, ESAD users, regardless of the degree of hearing impairment and language modality.

In the broader family group, there was also no important association between the degree of hearing impairment or the language modality used and communication difficulties between

the child and the family, even with more heterogeneous responses than those of the main family group.

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