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Perception of hard of hearing children and adolescents and their families about the use and benefit with hearing devices

Percepção de crianças e adolescentes com deficiência auditiva e de suas famílias sobre o uso e benefício com dispositivos auditivos

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ABSTRACT

Purpose: To analyze the self-perception of hard of hearing children and adolescents and their families about the daily use of hearing devices, comparing the referred use with data logging, as well as knowing the self-reported benefits with hearing aids. **Methods:** Cross-sectional, observational, descriptive-analytical study, with quantitative and qualitative analysis, approved by the Research Ethics Committee. Adapted Questionnaires were applied to 38 children and adolescents and their families, additionally, the data logging of their devices was collected. Descriptive and comparative analysis were performed, using the Kappa coefficient between data logging and the use reported by users and families, in addition to qualitative analysis of their perception about the devices. **Results:** Children, adolescents and their families overestimated, respectively, on average 5.3 and 2.5 hours per day, the time of hearing aids use, compared to the data logging measure. They r eported benefits from using hearing aids, although the use and the handling of remote microphones were the biggest identified challenge , both for the users and for their families. **Conclusion:** There was disagreement between the number of hours reported by users and their families , as well as between them and the data logging measure. Families reported the need for more guidance about remote microphones, which points to the importance of personalized intervention aimed at the empowerment of these family members, children and adolescents, with the involvement of the school team and support network, identified by the families as essential for the effective use of hearing devices.

Keywords: Hearing loss; Hearing aids; Daily living activities; Self report; Treatment adherence and compliance

RESUMO

Objetivo: Analisar a autopercepção de crianças e adolescentes com deficiência auditiva e de suas famílias quanto ao uso diário dos dispositivos auditivos, comparando o uso referido com os dados de *data logging*, bem como conhecer os seus benefícios autorrelatados. **Métodos:** Estudo transversal, observacional, descritivo-analítico. Aplicados questionários a 38 famílias e seus filhos com deficiência auditiva, bem como coletado o *data logging* com o número de horas/dia de uso dos aparelhos auditivos. Realizada a análise descritiva e comparativa, por meio do coeficiente de Kappa, entre o *data logging* e o uso referido pelos usuários e famílias, além da análise qualitativa sobre a percepção de ambos com relação aos dispositivos. **Resultados:** As crianças, adolescentes e suas famílias superestimaram, respectivamente, em média, 5,3 e 2,5 horas por dia o tempo de uso, em comparação à medida de *data logging*. Os usuários referiram benefícios com o uso dos equipamentos, embora o uso e o manuseio dos microfones remotos tenham sido o maior desafio identificado, tanto para eles como para as suas famílias. **Conclusão:** Houve discordância entre o número de horas relatadas pelos usuários e famílias entre si, bem como entre eles e a medição do *data logging*. As famílias referiram a necessidade de mais orientações quanto aos microfones remotos, o que aponta para a importância da intervenção personalizada voltada ao empoderamento desses familiares, crianças e adolescentes, com o envolvimento da equipe escolar e rede de apoio, identificadas pelas famílias como essenciais para o uso efetivo dos dispositivos auditivos.

Palavras-chave: Deficiência auditiva; Auxiliares de audição; Atividades diárias; Autorrelato; Adesão terapêutica

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INTRODUCTION

Considering the therapeutic model centered on individuals with hearing loss, self-perception measures are important tools in the speech-language therapy clinical routine. When patients are children or adolescents with hearing loss, evaluating their perception and that of their family about the daily use of electronic devices and the benefits perceived by them with the use of these resources is essential for the paradigm shift and for the organization of interventions that address their needs[1-3].

Thus, from the stage of adaptation of the devices, speech-language therapist is responsible for analyzing the data of benefits and limitations that affect the quality of life of children and adolescents with hearing loss, through clinical observation and the application of questionnaires with them and their responsible[4].

In addition to evaluating the needs and benefits perceived by children, adolescents, and their families with electronic hearing aids, the speech-language therapist must offer to listen and support for the good management of these resources, so that patients can achieve the expected gains for their development[5].

However, despite the importance of evaluating self-perception and benefits with the devices reported by children, adolescents, and their families, the number of studies that evaluate the benefits of auxiliary resources to hearing in childhood and adolescence is small[6].

Therefore, there are still little data available on this topic. However, in the routine of auditory rehabilitation programs, difficulties with the effective use of these resources, especially in mild hearing losses[7] are usually observed.

It is important to emphasize that there is sufficient evidence to support the early and constant use of electronic hearing aids for the effectiveness of auditory, linguistic, and cognitive development, with impacts on other spheres of the children's and their families´ lives[8-11].

The consistency of this use is closely related to the involvement of parents since children with guardians who are more active in the intervention have better results in auditory access and, consequently, in language development[5].

Thus, familiar perception of electronic hearing aids can also determine their effective use by children and adolescents with hearing loss. The central role played by family members in enabling their children to hear, their awareness of the importance of constant use, and their ability to manage the use of hearing aids by children are essential for the optimal use of the devices in this population[12-14].

Regarding the perception of children, particularly those in school age and in adolescence[15], there is a need for contributions, especially in Brazil, that improve the understanding of their needs[4,16-18].

Thus, given the scarcity of studies and the relevance of hearing access for the full development in childhood and adolescence, this research aimed to analyze the self-perception of children and adolescents with hearing loss and their families regarding the daily use of auxiliary hearing electronic devices. Also, we compared the reported use with logging data and knowing the benefits and difficulties with the devices reported by patients and families, in different situations of their daily lives.

METHODS

This is a cross-sectional, observational, descriptive-analytical study, approved by the Research Ethics Committee of Universidade Federal do Rio Grande do Norte, Natal (RN), under protocol number 3,440,683.

The study included 38 children and adolescents with unilateral or bilateral sensorineural hearing loss with mild to severe hearing loss, between 5 and 17 years of age, and their respective families, totaling 76 respondents. Parents signed the Informed Consent Term (ICT) and the students signed the Informed Assent Term (IAT). All children and adolescents participated in individual speech-language therapy and interdisciplinary group therapies, as well as in psychological and social service support for the families. All were diagnosed and adapted in the same hearing rehabilitation service of the Brazilian Unified Health System (*Sistema Único de Saúde* - SUS).

The collection instruments were two adapted questionnaires, one of them called Assessment of HA (hearing aids) Benefit in Children and Young People[1], applied according to age group, to evaluate self-perception of children and adolescents regarding the use and benefits of the devices. The questionnaire comprised closed questions, and was divided into three parts: part A, about tasks performed at home; part B, school environment; part C, social issues.

Children and adolescents answered the questionnaire with the visual support of figures referring to daily situations and emojis related to the perception of benefits in specific hearing experiences with their devices. As to the time of use, the instrument delimits the options to part of the day, the whole day, and a few hours, so that these categories were related to the number of hours/day measured by the data logging of the hearing aid.

Those responsible for the children answered an adaptation of the Observation Diary questionnaire[19], with closed and open questions, which allowed the assessment of the families' perception of situations regarding the use of hearing devices in their daily lives.

All questionnaires were applied face-to-face when patients and families were in routine care at the rehabilitation service. The survey of children, adolescents, and families took place in a private room after their assent and/or consent. Children and families answered the questionnaires separately, at different times.

Both the application of the questionnaires and the data logging of children's hearing aids (HA) were collected in the same month.

Descriptive data analyzes were performed using graphics. The inferential analysis used Kappa coefficient[20], which determined the agreement between the perception of hours of use from the reports of patients and families and the objective information collected by data logging of hearing aids.

The qualitative analysis used was based on content analysis[21]. Thus, two researchers independently read the applied questionnaires, and following coded the results in Word® text editor.

For the synthesis of the categories resulting from the content analysis, a quantitative systematic analysis of the frequency of occurrence of certain themes and qualitative analysis by the repetition of the concordant content among the respondents was carried out. Charts show the results.

RESULTS

Data are presented considering the perspectives of children, adolescents, and their families, comparatively.

Figure 1 shows a comparison of the time of daily use of hearing devices reported by children, adolescents, and their families and that measured by data logging.

The analysis of the data logging of the number of hours/day of use show that patients and families overestimated, respectively, on average, 5.3 and 2.5 hours per day the time of use of hearing devices. Thus, 97.37% of the children overestimated the use of hearing aids, compared to what was reported in the objective measure.

Kappa coefficient values for the agreement between the daily hours of use reported by patients versus the data logging measure was equal to 0 for both ears. As to family versus data, logging was 0.369 for the right ear and 0.316 for the left ear, considered, respectively, as a negligible agreement for patients and mild agreement for families.

Figure 2 shows a comparison of the perception of children, adolescents, and their families regarding the ability to listen with hearing devices.

When children and adolescents were asked about their daily activities with hearing devices, they highlighted that they heard well in most situations, in different environments (Figures 3 and 4).

When asked about the use of the Frequency Modulated System/Remote Microphone (FM/RM), only 13 participants, among children and adolescents, said they use it. Figure 5 shows their answers about how they use this device at school.

Children and adolescents in this study, until the time of the research, were adapted to Frequency Modulated Systems, suitable for their hearing aids. Considering the correctness of the nomenclature, the term FM System/Remote Microphone was used.

Regarding social activities with the use of devices, patients reported that they listened better with their devices in most situations and 35 of them (93.10%) reported that they played better using hearing aids. None of them reported difficulty listening to their friends when they were playing. Regarding liking the device, only one child (2.63%) declared disliking it and 5 (13.15%) said they liked it "more or less".

One question directed to parents was related to safety in handling the device. to which 20 of them (52.63%) answered that users felt safe when handling and taking care of hearing devices; 16 (42.10%) answered that they felt "more or less" safe and 2 (5.26%) reported insecurity in handling the devices.

In the quantitative analysis of these questions, we observed that 15 parents reported that children and adolescents used and liked to use hearing aids in all activities of the day; 21 of them answered that their children liked to use the device in activities

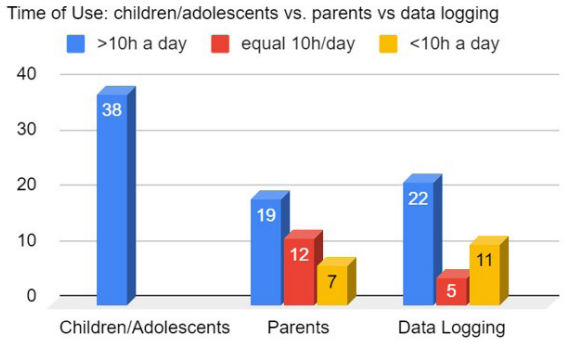

Figure 1. Comparison of the sample distribution regarding the time of use reported by children/adolescents and parents versus data logging measurement. Source: Author

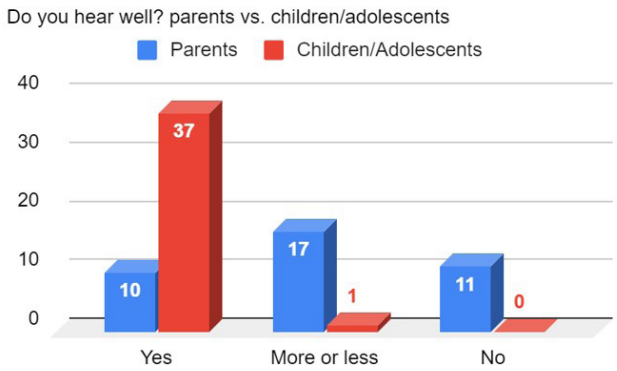

Figure 2. Comparison of the sample regarding the opinion of parents and children/adolescents on the question "Do you think you hear well using the hearing aids?". Source: Author

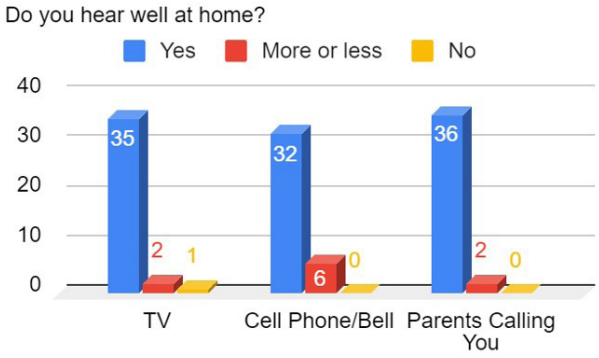

Figure 3. Part A: "at home", in which "do you hear well?" performing some of the activities with hearing aids. Source: Author

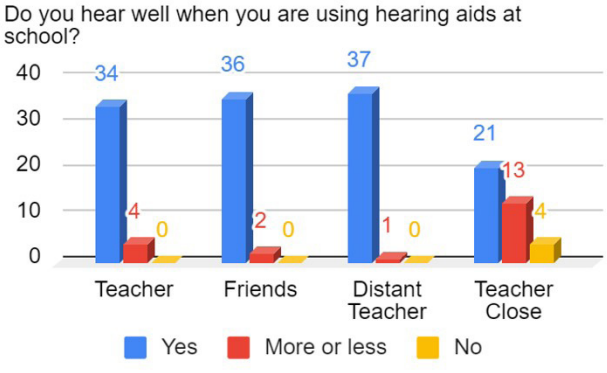

Figure 4. Part B: "at school", the children/adolescents were asked if they could hear well while they were at school using only the hearing aids. Source: Author

that involve a lot of hearing, such as listening to music, watching television (TV) and talking. Only 2 participants answered that games such as playing ball and with dolls were the ones that child most liked to perform using the device.

On the other hand, for the question "What activities does the child not like to do when using the device?", 10 answered that motor activities were limitations for children, such as playing ball, practicing physical activities, running, among others; 20 guardians reported that there was no activity in which children did not use the hearing aid; 4 mentioned that their children did not like to use the hearing aid in noisy environments, with loud sounds, or in activities such as watching TV; one reported that, in the school environment, his/her child did not like to use it and 3 answered that the child/adolescent did not like to use the hearing aid in daily activities, such as washing dishes.

When asked about the possible difficulties and challenges that children and adolescents faced due to the use of the devices, 18 families reported that their children did not present difficulties or barriers to the use of hearing aids; 16 of them mentioned great difficulty in understanding speech sounds and using FM at school; 2 mentioned the existence of insecurity about handling the device and 2 said that social issues, involving self-advocacy[16], which is the ability to speak or act for oneself, affected their children.

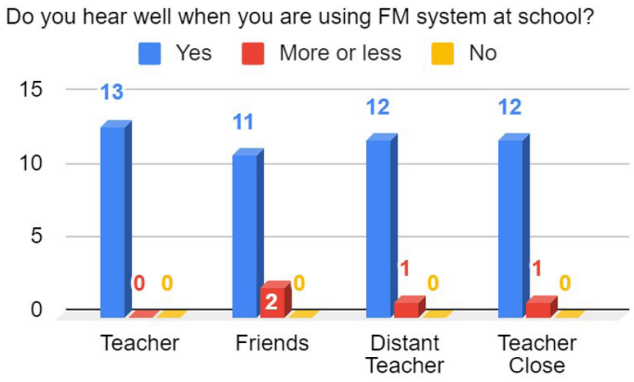

Figure 5. Answered by 13 children/adolescents who use the FM System at school, when asked if they hear well using this device. Source: Author

As to the question "What would make your child use the device more?", we found that 22 families considered that nothing would add to the longer time of use; 14 of them believed that better awareness of the importance of use by children and adolescents would be the differential, and 2 said that if the child's device was well adapted, there would be greater benefit and use.

Chart 1 shows the qualitative analysis of the families' perception of their children's daily lives with hearing aids, based on the categories arising from the questions.

DISCUSSION

The analysis of self-perception of children and adolescents with hearing loss about the use and benefit of their hearing devices is an important tool in their monitoring in hearing rehabilitation programs[1,3-5,18].

The perception reported by participating families induces the speech-language therapist to consider important information in the therapy sessions, especially the moments of personal and informative adjustment counseling[3,12-14].

In this study, the perception measures used helped to understand important points, such as:

a) even if the average value of hours of use/day was effective in the evaluated sample, it can still be improved, considering the negligible agreement between data logging measures and reports from children and adolescents and the slight agreement between objective measures and the families' report on the number of hours/day of device use. For the patients, the possibility of failure to understand the question should be considered, indicating the need to adjust the tool with clearer instructions to support their answers. Families also overestimated the use of devices, which may reflect the fear of reporting a use below that recommended by speech-language therapists or even the age group of the sample, less time spent with their children, leading to less realistic estimates than that of parents of young children[12,13]. There are still children with few hours of use, which puts them at significant risk to their development, especially considering that they are school-age children, most of whom have moderate or severe hearing loss[2,4,6,8].

Chart 1. Qualitative analysis of daily life with hearing devices, according to families' perception

Activities that the child likes to do wearing hearing aids	Activities that the child does not like to do with the hearing aids	Challenges faced by parents	Parents´ doubts	What would make your child consistently wear hearing aids?
Watch TV	Physical Activity (playing soccer, running, playground, physical class, at school)	Child/adolescent comprehension	Handling FM system	Child awareness of the benefit of hearing aids
Listening to music on the phone	Cell Phone	School tasks	Handling hearing aids	
Sing	School	Handling hearing aids	About new device	Improvement in child's autonomy
All activities	Noisy environment	Speaking on the phone		Teacher awareness about FM System
	Bus	Noisy situations		Awareness of other family members about the importance using hearing aids
	Tour (go to the mall)	Use of FM Systems		

Source: Author

b) thirty-seven of the children and adolescents in the sample reported enjoying using hearing aids, probably because of the perceived and reported benefits of these devices. However, not all of them reported the same benefit with their FM systems. This is a very alarming fact and requires further investigation, since it would be expected that, by helping patients in more hostile listening environments, they would indicate benefit and satisfaction with its use. Issues such as the objective verification of the FM/Remote Microphone Systems, the replacement of these devices, as well as the process of adapting such resources, and family-speech-language therapist-school partnership should be observed in the continuity of research with this population[15,17].

We can highlight that children's perception of the benefit of the devices when playing was positive and that, for the families, the same perception did not always occur. We could question whether, for example, parents were concerned about the possibility of damaging the hearing aids in some types of games or sports, which would make them anticipate removing the devices from children.

c) even if supported by a rehabilitation service, the respondent families perceived the need for more guidance regarding the handling and use of hearing aids, especially as to FM/Remote Microphone System. This points to the importance of a personalized intervention for the empowerment of these family members in this issue, as well as to the therapeutic protocols traditionally used, with the involvement of the school team and support network. They were, identified by families as essential for the effective use of hearing devices by children and adolescents with hearing loss. This is in line with recent literature regarding the implementation of specific programs on the effective use of electronic hearing aids, both for families[5,14] and patients[16].

The limitations of this study were sample size and the questionnaires which are not instruments validated in Portuguese, only adapted to the research situation.

Thus, this research will continue with the proposal to increase its methodological robustness, with the validation of questionnaires on the perception of children, adolescents, and families and an increase in the number of participants, with the prospect of including other centers in the sample.

Based on the observations of this study, we developed an intervention program centered on children and adolescents to be conducted in a group situation, called "Super Hearing". It was initially validated with the team of the service in which this study was performed. We expect that the program is implemented soon.

CONCLUSION

Respondent users showed a positive perception of their hearing devices, indicating a benefit on the use of these resources in situations at home, at school, and in social environments, even though the use of the FM System was observed only in a portion of the sample.

Children, adolescents, and families overestimated, respectively, by an average of 5.3 and 2.5 hours a day the time of use, compared to the data logging measure, and there was a mild agreement between the family members' response and the data logging.

Considering the benefits and difficulties mentioned, especially by families, it is important to continue studies that use personal and informative adjustment counseling tools, both for families and for children and adolescents with hearing loss, given the relevance of the effective use of hearing aids for their development, educational inclusion and quality of life.

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