

Assessment of the degree of involvement in family therapy for children with hearing impairment

Avaliação do grau de envolvimento familiar nos atendimentos de crianças com deficiência auditiva

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ABSTRACT

Purpose: The aim of the present study was to assess family participation in the therapeutic process of children with hearing impairment using hearing aids and/or cochlear implants enrolled at the Educational Audiology Clinic and Center for Interdisciplinary Studies on Hearing, Language and Education. **Methods:** This study was conducted with 25 families of children with hearing impairment between 0 and 14 years old enrolled in speech and hearing therapy for at least six months. Data was collected from the patient charts. The Family Involvement Rating Scale (Moeller) translated into Portuguese was administered to characterize the quality of family participation in the therapeutic process. **Results:** The mean degree of family involvement among the 25 families studied was 3.28. The therapists classified 40% of the families as presenting an average level of participation (score: 3); 20% were classified as presenting below-average participation and 8% were classified as presenting an ideal degree of participation. **Conclusion:** A large portion of the families analyzed exhibited an average level of participation in the therapeutic process of their children. No correlation was found between the different categories of family involvement and the degree of hearing impairment with or without hearing aids or cochlear implants. Additionally, no correlation was found between the duration of therapy and the degree of family involvement.

Keywords: Hearing Loss; Child; Family Relations; Rehabilitation; Professional-Family Relations

RESUMO

Objetivo: Caracterizar o perfil de crianças com deficiência auditiva que usam aparelho de amplificação sonora individual ou implante coclear, e avaliar a participação das famílias no processo terapêutico dessas crianças. **Métodos:** Participaram do estudo 25 famílias de crianças com deficiência auditiva, com idades entre 0 e 14 anos, atendidas nos ambulatórios pesquisados, que estavam em terapia fonoaudiológica por, no mínimo, seis meses. Foram levantados os registros das informações dos prontuários das crianças selecionadas e, posteriormente, foi aplicada a escala *Family Involvement Rating* (Moeller), traduzida para o português com o nome de Escala de Envolvimento Familiar. **Resultados:** A média do envolvimento familiar das 25 famílias estudadas foi 3,28, sendo que 40% das famílias foram classificadas com participação mediana, pelas terapeutas. Os testes utilizados não evidenciaram relação entre o envolvimento familiar e os limiares auditivos das crianças, nem entre o envolvimento familiar e o tempo em que as crianças estavam em terapia. **Conclusão:** A maioria das famílias apresentou participação mediana no processo terapêutico de seus filhos. Não houve diferença entre os diferentes graus de envolvimento familiar no processo terapêutico e os limiares auditivos das crianças com e sem dispositivos eletrônicos, nem diferença entre o tempo de terapia das crianças e o grau do envolvimento familiar.

Descritores: Perda Auditiva; Criança; Relações Familiares; Reabilitação; Relações Profissional-Família

Study conducted in the Speech, Language, Pathology and Audiology Course, Universidade Federal de São Paulo – UNIFESP – São Paulo (SP), Brazil.

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INTRODUCTION

The new possibilities for diagnosis of hearing loss have raised a new kind of patient: the child and his family, that provide context for transformative actions are established. His focus became the child's natural environment, where parents play an active role in language development⁽¹⁾.

Studies have shown that to improve hearing, language and social skills some care is necessary, such as the correct use of hearing aids (PSAD), appropriate therapeutic work family involvement⁽²⁾.

Professionals should actively involve parents, investigate their knowledge of their child's pathology in order to be able to absorb and meet the demands of families and patients that need special attention⁽³⁾. Because parents who become more involved in therapy communicate better with their children, contributing more to the progress of the child than parents who do not participate in the process^(4,5).

It is known that just working with the children without the family being committed to the therapeutic process is not enough. The family needs a participative posture toward the child for the success of the process⁽⁶⁾.

A longitudinal study⁽⁷⁾ conducted with three families of hearing impaired children, found that family involvement in the therapeutic process directly affects the child's development.

Another study with parents/guardians of 20 deaf children under 3 years of age, concluded that there is a need to involve the family in the child's therapeutic process, working with wants and needs and the child's expectations⁽⁸⁾.

Analyzing alternatives that ensure compliance with the use of individual hearing aids (HA) and greater involvement of families in the early stages of the intervention, a study of parents/guardians of 16 deaf children found that actions are needed, under the assistance in Hearing Health Services, to ensure adherence to treatment. The same author pointed out that measures of auditory performance and language usage monitoring amplification and family involvement, analyzed together, further our understanding of family's commitment to the treatment⁽⁹⁾.

Based on these theoretical assumptions, the objective of this research was to characterize the profile of children with hearing loss who use individual hearing aids or cochlear implants, and evaluate the participation of families in the therapeutic process of these children.

METHODS

This study, conducted in the research line Monitoring and Diagnosis of Hearing Disorders, Universidade Federal de São Paulo (UNIFESP), was approved by the Research Ethics UNIFESP (CEP 0530/11). All parents or guardians signed the consent form, as well as the therapist responsible for the care of children and the supervisors of clinics involved.

All children included in the study were previously evaluated in the outpatient evaluation of language at UNIFESP, proving the acquisition disorder and language development. We selected children aged between 0 and 14 years, of both genders, who had no syndromes and/or obvious cognitive impairment, with some degree of hearing impairment, who were users of individual hearing aids and/or cochlear implant (CI) and who were in speech therapy through the aural approach for at least six months.

For this study, information records were collected from medical records of selected individuals (name, date of birth, education, degree of hearing loss, date of diagnosis, etiology, hearing thresholds with and without hearing aids, type of electronic device, unilateral or binaural adaptation, time use of hearing aids individual and/or cochlear implant and length of therapy).

The Family Involvement Rating Scale has also been applied, translated into Portuguese⁽¹⁰⁾, which aims to characterize the quality of participation and family involvement in the intervention process. Each family received a comprehensive evaluation on a numerical scale from 1 to 5, reflecting their participation in the intervention. For this evaluation, we considered aspects such as family adaptation, participation in sessions, family attitudes and behaviors and effective communication with the child.

The scores were given according to the following criteria:

- 1 (Limited participation): the family has limited understanding of deafness and its consequences for the child. Participation can be sporadic and ineffective. Parent child communication is restricted to the most basic needs.
- 2 (Below average participation): the family suffers and struggles to accept the child's diagnosis and may be inconsistent in frequency to calls and to place and maintain hearing aids in children, at home and at school. There may be some significant stresses in their lives that interfere with this inconsistency. Communicative interactions with the child are basic and lack fluency.
- 3 (Median participation): Family struggles to understand and accept the diagnosis of children and family members participate in most sessions. Hectic schedules and family tensions may limit opportunities to apply at home what has been learned. The family participates in the planning, but in general, undergoes mainly the professionals' opinion. Specific family members (eg. the mother) can get the most of the responsibility for developing the communication needs of the child. The family develops at least the basic skills to deal with the communication mode of the child. Family members plan to use expansion techniques of language, but they need support and direction frequently.
- 4 (Good participation): family members regularly attend the meetings and parent meetings, serve as good language models for children and strive to bring the techniques back home. Parents play an active role (perhaps not the main role) in the planning of clinical and educational goals for

the child. Some family members have a reasonable ability to work with the communication of the child and/or techniques for language stimulation.

- 5 (Optimal participation): family members actively participate in the sessions and regular meetings and seek information independently. Children are effective advocates for their inclusion in health services and education. Become firmly active as partners in conversation with children and serve as language models consistently. Become fluent and active users of the child’s communication mode, as well as being able to apply techniques to expand the language.

In this study the scale was applied by three professionals who had direct contact with the child and family, after 12 weeks of observation: the therapist responsible for the care of the children and two supervisors of the clinic. To arrive at the final ranking that best describes the degree of family involvement in each family, we calculated the average of the scores given by the three judges.

The collected data was stored in spreadsheets and then analyzed by statistical tests such as ANOVA test for comparison of means using the variances; Testing Equality of Two Proportions to compare the proportion of responses to two specific variables and/or levels is significant, the Pearson correlation, to measure variables related to each other and the confidence interval for the average. The level of significance was $p \leq 0.05$.

RESULTS

The average age of participating mothers was 34 years and 8 months and of the fathers, 36-years and 2 months. These data allowed the conclusion that the sample of participating parents was homogeneous and composed of young adults. It was found that the most common level of education among mothers was completed High School (36%) and between the fathers, the two most frequent levels were completed Elementary and Junior High School (24% each).

Of the 25 participating children, 17 (68%) were users of individual bilateral hearing aids and eight (32%) used unilateral cochlear implants.

No electronic devices, 48% of the participating children had hearing thresholds above 90 dB, consistent with profound hearing loss and 24% had thresholds between 71 and 90 dB, consistent with severe hearing loss. Applying statistical test, there was no difference between the thresholds ($p=0.077$). Now with electronic devices, 64% of patients had hearing thresholds between 41 and 55 dB (Table 1).

Among those who had severe hearing loss (six children) and profound (12 children), only 44.4% were using cochlear implants. The others used individual hearing aids.

Among all patients in the study, 40% were in speech therapy for over 48 months, and three children had been in therapy for 108 months.

Table 1. Distribution of thresholds

Thresholds	No electronic devices		With electronic devices	
	n	%	n	%
25-40 dB	0	0	6	24
41-55 dB	2	8	16	64 *
56-70 dB	5	20	3	12
71-90 dB	6	24	0	0
> 90dB	12	48	0	0

* Significant values ($p \leq 0.05$) - Equality test of two proportions

As for the evaluation of family involvement, the average degree awarded to all families was 3, indicating median involvement. In this study, five families (20%) were classified as below average participation, ten families (40%) with a median participation, nine families (32%) and good participation and two families (8%) as the ideal proportion.

After analysis of family involvement, the evaluator was asked to assign a level of trust to their own judgment, may be good, reasonable or otherwise objectionable, according to security that the judge felt while evaluating the family. It was observed that there was a tendency of evaluators/supervisors to rely more on their judgments as to the involvement of every family in the therapeutic process, since more than half of their judgments were classified as good.

In order to verify the relationship between the hearing thresholds of each patient and the degree of family involvement attributed to his family, were grouped grades 2 and 3 (participation below the average and median share) and grades 4 and 5 (good attendance and participation ideal) and there was no difference between the categories of family involvement and hearing threshold with and without electronic devices. So it was not observed in this study, the relationship between family involvement in the therapeutic process and the hearing thresholds of their children (Figure 1).

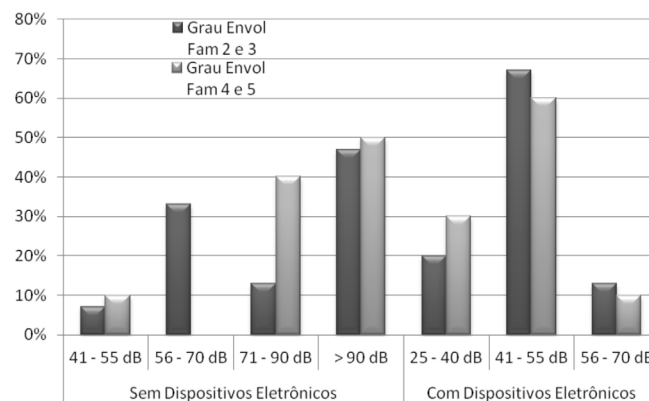


Figure 1. Correlation of family involvement and hearing thresholds

The Pearson correlation test showed no difference between the time of therapy of children and the degree of involvement

of his family in the therapeutic process, because the correlation was 15.4%, $p=0.464$ (Figure 2).

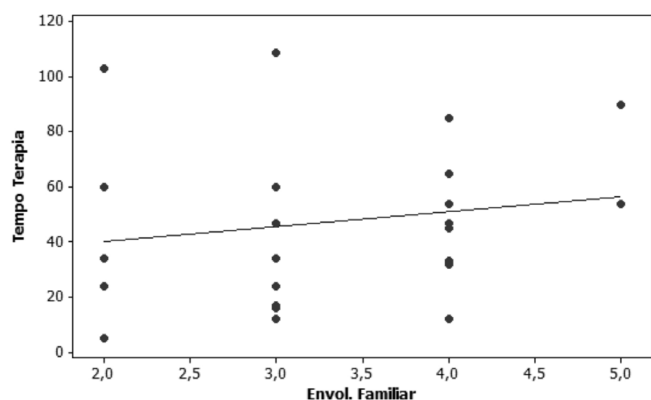


Figure 2. Correlation of the degree of family involvement in therapy time

DISCUSSION

The results for the educational level of the parents participating in the study – complete High School (36%) for mothers and complete Elementary and Junior High School (24% each) for fathers - are similar to those found by other authors^(8,9).

Regarding thresholds of children without electronic devices - 48% thresholds characteristic of profound hearing loss and 24% thresholds characteristic of severe loss - it was found that similar data has also been raised by other studies in the literature^(8,9).

It is known that in the severe or profound hearing loss, the child can not perceive any sound of speech in normal conversation, which prevents the development of spontaneous speech and language, creating serious problems for speech as well as difficulty in group communication or in the presence of noise. These skills can be developed through extensive training and amplification, depending on the age at which the intervention is initiated⁽²⁾.

Several studies in the literature have shown the benefit that the use of an electronic device, either a hearing aid or cochlear implant provide for the child in terms of audibility and conditions for the acquisition and development of communication skills^(2,11). In this study, the thresholds found in patients with devices were between 41 and 55 dB in most children, confirming the efficiency of the hearing aids in relation to the gain in audibility.

The literature points out that not only are users of electronic devices who are benefited, but also all those who suffer limitations and participation restrictions, due to the existence of a deaf person involved in the actions of their daily lives, or their families. One study found that adults who have greater familiarity and contact with children tend to have a broader view of their behaviors, being more attentive to their reactions and preferences. Therefore have greater vision of how electronic devices influence the skills and behaviors of children⁽¹¹⁾.

Data for analysis of the time in which child participants were in therapy - 40% for over 48 months and three having already exceeded 100 months - reaffirm that the therapeutic process for the hearing impaired is a long process and singular, in which the elements should be articulated in an integrated manner for the well being of the child and family.

From the concept of the electronic devices providing greater audibility for hearing impaired children and considering that the better audibility, the greater the chance of development of listening skills, communication and social, through extensive training with the support and involvement of parents, created the expectation that there was a relationship between the benefits of electronic devices that improve the auditory thresholds of children and the degree of family involvement in their families. However, this relationship has not been proven by statistical tests, ie. there was no difference between the various degrees of family involvement in the therapeutic process and the hearing thresholds of children with electronic devices.

In this study, the majority of households were classified by therapists as having a median participation, receiving a level 3. This result indicates that there is a tendency for families to participate in the sessions, daily transferring to the child what has been learned, helping in planning sessions, bringing the difficulties and needs of the child to be worked and seeking the development of the child's basic communication skills. However, it is important to emphasize that this involvement has not yet reached the optimal level for a great auditory and language development of the child, which would be level 5, in which family members seek information independently, they become highly effective as conversation partners with children and serve as language models consistently.

These results were similar to those found by other authors who used the same instrument in their studies. Based on the findings and analysis of their studies, they concluded that high levels of family involvement can mitigate the effects of late diagnosis and intervention, since children who showed a pattern of greater recovery in their study were those with families involved^(8,9).

Other authors have stressed the importance of participation and family involvement in the therapeutic process of hearing impaired children to better prognosis, not just hearing, but in terms of overall development^(2,7-9,12-15).

The comparison made in this study between the degree of family involvement and time assigned by the therapists speech therapy children, showed that families can be very involved, participating actively in the therapeutic process of their children even after many years of therapy, as well as other families who initiated the therapeutic process in lesser time and were not as involved.

Thus, using the scale of family involvement enabled the professionals involved in the care of these children to reflect on the involvement of families in the therapeutic process, in order to lift the strengths and weaknesses of each family, and

consider the influence of this involvement in the development and evolution of children and invest in guidance and family counseling to improve family involvement in therapy.

The fact of hearing thresholds having been used in the validation of AASI adapted in children may be considered a limitation of this study because it is known that with the compression systems used in current technologies, a check should be performed, preferably, with objective measurements, such as measurements in situ, enabling us to gauge the performance of the amplification being provided to children and to achieve the target of amplification, targeting better perception of speech sounds.

Although the results have demonstrated important findings, further studies are needed in order to more adequately understand the factors that influence family involvement and adherence to the therapeutic process of hearing impaired children.

Also needed are studies that seek to correlate the family involvement and perception of speech sounds of individuals, considering the different technologies currently present in electronic devices because it is known that the thresholds are not only quantitative measures and evaluate the benefits provided by the use amplification in relation to speech perception, a very important factor, especially in the auditory development of children.

CONCLUSION

Most families had median participation in the therapeutic process of their children. There was no difference between the different degrees of family involvement in the therapeutic process and the hearing thresholds of children with and without electronic devices. There was no difference between the time of therapy of children and the degree of family involvement.

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