Hearing rehabilitation in children: adhesion to treatment and use of hearing aids

Reabilitação auditiva na criança: adesão ao tratamento e ao uso do aparelho de amplificação sonora individual

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ABSTRACT

Purpose: Early diagnosis of hearing loss in children, as well as fast intervention, have been shown to be determining factors for hearing and language development, with important implications for the social inclusion process and communicative performance. The present study aims to analyze alternatives that guarantee adhesion to use of Hearing Aids and greater family participation in the initial steps of the intervention.

Methods: The study comprehended parents/caregivers of 16 hearing impaired children who attended the process of ADAPTI (Hearing Aid Fitting and Initial Therapy) during one year, who had formally applied for the Hearing Care Service. The parents were divided in three groups: Previously Determined (Families that attend both the speech therapy and the Family Adhesion Group (GrAF) from the first day set for the beginning of sessions, to the last day); Continuous Flow (Families that started attending the group from the moment they arrived for the ADAPTI); and Control (Families that only attended speech therapy, but not the GrAF).

Results: The study verified the effectiveness of parent adhesion to their children’s treatment with more than 66% of attendance in the proposed activities (therapeutic intervention and/or GrAF). The statistical analysis allowed the composition of three children groups regarding the datalog usage (hours a day), family participation and degree of hearing loss.

Conclusion: The systematic use of hearing aids was the only variable closely related to hearing and language skills. Degree of hearing loss and age at the beginning of amplification have not explained the development of the children in the study.

Keywords: Family; Rehabilitation; Hearing loss; Hearing aids; Language development

RESUMO

Objetivo: Discutir a adesão das famílias na fase inicial de intervenção quanto ao uso do Aparelho de Amplificação Sonora (AASI), a participação no processo, e sua relação com desempenho auditivo e de linguagem das crianças com deficiência auditiva. Métodos: Estudo realizado com pais e/ou responsáveis de 16 crianças deficientes auditivas em processo de ADAPTI (Adaptação de AASI e Terapia Inicial) no ano de 2009 e que estavam regularmente inscritos no Serviço de Saúde Auditiva Centro Audição na Criança – CeAC. Os pais foram divididos em três grupos: Pré-determinado - PD (famílias participantes da terapia fonoaudiológica e do Grupo de Adesão Familiar – GrAF, do primeiro ao último dia de atendimento estabelecido); Fluxo contínuo - FC (famílias que iniciavam a participação no GrAF a partir do momento em que chegavam ao serviço de saúde para a adaptação de AASI, sem início estabelecido) e Controle - C (famílias que participaram somente da terapia fonoaudiológica, mas não do GrAF). Resultados: Foi constatada a efetividade da adesão dos pais ao tratamento dos filhos, sendo registrado o comparecimento em mais de 66% dos atendimentos propostos (terapia fonoaudiológica e/ou GrAF). Na análise estatística dos agrupamentos de crianças, foi possível a formação de três diferentes grupos no que se refere ao uso do datalog (horas/dia), envolvimento familiar e grau de perda auditiva. Conclusão: O uso sistemático de AASI foi a única variável com forte relação com habilidades auditivas e de linguagem. O grau de perda auditiva e a idade de início de amplificação não explicaram o desenvolvimento das crianças do estudo.

Descritores: Família; Reabilitação; Perda auditiva; Auxiliares de audição; Desenvolvimento da Linguagem
INTRODUCTION

Early diagnosis of hearing impairment in children and early intervention are crucial for auditory and language development, with important implications for the social inclusion and the communicative performance.

Many authors report that for a better prognosis, diagnosis and intervention should occur before six months of life, thus ensuring the best use of the hearing potential of the child. Moreover, the effective use of hearing aid or cochlear implant, the family expectations, the degree of involvement with treatment and aspects related to socioeconomic and cultural conditions all affect this outcome(1-7).

The speech and language therapy aimed at the acquisition of oral language has been one of the main clinical proposals for children with hearing impairment. It implies considering the peculiarities in the constitution of social, emotional, psychological and cognitive development besides reordering interaction situations, thus favoring the mode of communication of these patients(8-10).

However, for this ideal to be achieved, it is necessary that parents of children with hearing loss understand what they aim at the Hearing Health Service in order to make their choices with clarity and insight, comprehend the potential of their children and set their expectations during this process.

The contact of the family with the speech and language pathologist and audiologist in the process of adaptation of individual hearing aids (HA) also serves as clarification of treatment goals and clinical and educational options available in the community. Within the hearing health, it is essential to also clarify the function of the use of amplification for auditory and oral language development.

The intervention involves several professionals with the ability to carefully absorb and meet the demand of patients who need special attention. Thus, it is important that the health professional is able to perceive the changes that may occur within the family, the anguish on the problem and possible denials so one can contribute to the process of reorganization of the family on the diagnosis, monitoring the development of the child(11).

The Child Hearing Center (Centro Audição na Criança - CeAC) of the Division of Education and Rehabilitation of Communication Disorders (Divisão de Educação e Reabilitação dos Distúrbios da Comunicação - DERDIC) and part of the structure of the Pontifícia Universidade Católica de São Paulo (PUC-SP), is a service of high complexity accredited by the Brazilian Public Health System (Sistema Único de Saúde – SUS), which provides care to children with suspected or diagnosed hearing loss under 3 years of age. The following services are offered: diagnosis, selection and fitting of hearing aids, speech and language therapy, monitoring and guidance to families. The CeAC also offers therapy for part of the demand that is created by its own diagnostic service. The other part is referred to municipal services or other service locations near the residences of families. This implies the need to perform procedures for systematic evaluation of hearing, language and family involvement in order to ensure the quality of care for all children, inside and outside of the center, which is responsible for tracking the cases.

When the diagnosis is completed and the hearing impairment is confirmed, the hearing aid fitting process is carried out in parallel to the selection of hearing aids, involving the initial stages of the therapeutic process, with the purposes of adaptation, and speech and language therapy with an emphasis on family participation besides the reception and initial guidance to parents. This step process is named ADAPTI.

As part of the initial therapeutic process, the Group of Family Involvement (GrAF) occurs weekly. The goal of the GrAF is to provide different modes of action with all the parents of children. The GrAF includes beginner parents to discuss the auditory potential of the child, the possible intervention methods and the referral to appropriate programs of intervention. This period lasts four months on average, depending on the availability of family and counter-reference process to centers closer to home.

Given the importance of the family in all stages of intervention for the child to achieve the best prognosis, GrAF aims to contribute to approximate parents to the hearing rehabilitation of their children in order to develop a set of actions that involve different modalities in the initial phase of treatment. Such actions are part of the therapeutic process. This step of the process is accomplished by focusing on parents or guardians.

Historically, it has been observed that some families quickly engage in the process, achieve consistent use of hearing aids and position themselves in relation to treatment. Other families seem content to be receiving the service, but do not know what to expect from the device use and often, though regularly attending therapies, children do not use the device at home.

Given this situation, the present study aimed to examine alternatives that can ensure adherence to the use of hearing aids and greater family involvement in the initial stages of the intervention.

In fact, the proposed actions are necessary under the intervention in Hearing Health Services that ensure adherence to treatment, both in regard to family involvement - willingness to participate - as the systematic and consistent use of hearing aids. Moreover, relations between auditory and language performance and monitoring of family involvement can contribute to a better understanding of the therapeutic process and, consequently, better results in Hearing Health.

The purpose of this study was to discuss the involvement of the families of children with hearing impairment on the initial intervention phase regarding the use of hearing aids, participation in the rehabilitation process and their relation to auditory and language performance.
METHODS

This consisted on a qualitative descriptive study with parents (or guardians) and speech language pathologists and audiologists of 16 children with hearing impairment who had initiated treatment at ADAPTI (hearing aid fitting and initial therapy) and who were regularly enrolled at CeAC. All participants signed a consent form, obeying ethical principles. This study was approved by the Ethics Committee of Pontificia Universidade Católica de São Paulo (PUC) under protocol number 292/2008.

Study participants were divided into three types of modalities according to the participation on the Family Adhesion Group (GrAF) and type of fit:
- Pre-determined (PD): composed of six families of children enrolled in ADAPTI. These families attended both speech and language therapy and GrAF in the first semester of 2009 – from the first to the last established day of attendance – with twelve meetings scheduled. In this group there were no entries of family members after the beginning of service or outputs before the time established and agreed upon all participants.
- Continuous flow (CF): composed of six families who participated in the GrAF in the second half of 2009, from the moment they arrived at CeAC and started the ADAPTI. The immediate participation in GrAF was allowed underway. Fifteen meetings were scheduled.
- Control (C): composed of four families of ADAPTI who participated in speech and language therapy, but not GrAF. All 16 planned sessions were carried out and included care and guidance to parents.

The inclusion of subjects was conducted according to the following criteria: members of families with children with hearing loss who regularly followed their speech and language therapy performed at CeAC; the child should be using hearing aids for a maximum of six months, with the appointments scheduled at ADAPTI; availability of parent or guardian to attend the activities proposed by the established schedules and agreement on participation in the study.

With the aim of evaluating family involvement in the therapeutic process of the hearing impaired child, the following instruments were used:
- Interview Guide (12): questions that lead parents to identify the attitudes of the child’s communication, the participation of these parents in the intervention program, the guidance received to deal with the child and expectations regarding the development of the hearing impaired child;
- Family Involvement Rating (13): rating scale consisting of five items: 1 - limited participation; 2 - participation below average; 3 – median participation; 4 - good participation; 5 - ideal participation. The families were classified by therapists who had extensive contact with the parents and the child;
- MUSS (13): scale in the form of a questionnaire that aims to assist in evaluating oral language/speech production skills of children in situations of daily life;
- IT MAIS (14): it aims to evaluate auditory behaviors of children in situations of daily life, reflecting on changes in vocalization, integrated to the use of the electronic device, attention to the various environmental sounds and assigning meaning to sounds;
- Activities of cultural awareness (12): activities used as the triggering at GrAF, aiming to let the parents more comfortable to talk about their own individual issues and bring issues relating to their children. The activities themselves were not evaluated and described after GrAF because their only goal was to trigger conversations and discussions on issues related to hearing and language skills of the children attended;
- Evaluation of the effective use of hearing aids: note of average daily hours of use.

From the data obtained in the different procedures and instruments used in this study, the analysis was conducted considering the following:

1. Characterization of family according to the PD, FC and C groups in terms of gender, age and education level; evaluation of attendance of families in the sessions (therapy and GrAF); description of the audiological characteristics of children studied with respect to the following aspects: age of onset of hearing aid selection (months); degree of hearing loss; electronic device and therapeutic purposes after the end of the group. The frequency of daily use of hearing aids was determined at the time of periodic monitoring through the Datalog registry in children in which the device was available.

2. Establishment of groups of children according to IT MAIS, MUSS, Datalog hours/day, Family Involvement and Degree of Hearing Loss, through the preparation of tables with descriptive statistics of these variables according to groups. Tables with frequencies and percentages of the categories of those who participated in the GrAF were also created. The condition set was that the groups were internally homogeneous and heterogeneous among themselves according to the variables IT MAIS and MUSS. The technique used was the average of the distances. The distance between the subjects was measured by Euclidean distance by applying the technique of cluster analysis (15).

3. Families C1 and PD3 were excluded from the statistical analysis because the child from C1 had performed cochlear implant surgery at the time of filling the IT MAIS and MUSS, and the child from PD3 was being reinstated to the service after a long period of absences. Therefore, data from both families were used only to evaluate their participation in GrAF and not in the statistical analysis together with other research subjects. This is justified because their data would cause a large discrepancy for reliable analysis of the sample.
The values of descriptive statistics for Degree of Hearing Loss, Family Involvement and Datalog (hours/day) are presented in Tables 1, 2 and 3 respectively. The individual and mean values of these variables for each group are shown in Figures 3, 4 and 5.

It is observed in Table 1 and Figure 3 that individuals in the group 3 had, on average, a smaller degree of hearing loss than those of groups 1 and 2.

The degree of hearing loss was not a variable that justified the formation of clusters.

Children from families PD2, PD5, C2 presented hearing losses of 110 dBHL (mean 500 to 2 kHz) being represented respectively in groups 1 and 2. Those with the same degree of hearing loss were allocated to different groups regarding responses in IT MAIS and MUSS due to expectations and possibilities of hearing and language presented by each.

The child of family PD2 was unable to undergo surgery of the IC since he had inner ear malformation and ossified cochleas bilaterally. The children of the families C2 and PD5 were being
evaluated for cochlear implant surgery. Thus, even with similar hearing loss, each child, due to whether or not they received a cochlear implant, could also differ in the questionnaires.

The child of family PD4, from group 3, had hearing loss of 55 dB HL (mean 500 to 2 kHz), which shows that the smaller the degree of the hearing loss, the better the responses of scores found in IT MAIS and MUSS. Probably due to the degree of hearing loss and therapy attendance over 70% (72.7%) there was a good assessment of family involvement (score 4) and also in relation to the use of hearing aids for six hours per day. The hearing aid fitting initiated when the child was 10 months.

Family involvement (Table 2 and Figure 4) was similar in the three groups. Two extremes were found in the evaluations of the degree of family involvement performed by speech

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**Table 1. Descriptive statistics for hearing loss degree according to group**

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Mean</th>
<th>Standar deviation</th>
<th>Minimum</th>
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<th>Maximum</th>
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<td>17.5</td>
<td>55</td>
<td>90</td>
<td>110</td>
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**Table 2. Descriptive statistics for family involvement according to group**

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**Table 3. Descriptive statistics for Datalog hours/day according to group**

<table>
<thead>
<tr>
<th>Group</th>
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<th>Standar deviation</th>
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<th>Median</th>
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<td>8</td>
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therapists who met the children in ADAPTI (Figure 4).

The FC3 family presented a score 2 on the scale of family involvement, possibly by having attended few therapeutic sessions (54.5%), suggesting little involvement of the family in the hearing rehabilitation process of the child.

In contrast, despite the family FC6 score 2, they attended all scheduled visits (100%), both in therapeutic interventions and in Graf. Therefore, the rationale for the evaluation from the therapist would not be attending the service, as in the previous case. So probably this note reflects the fact that the child has started late in hearing aid fitting.

Children from families FC3 and FC6 received diagnosis and speech and language therapy after two years of age, with 35 and 34 months respectively.

The other end shown in Figure 4 refers to the family PD5, which was received a score of five on the family involvement scale. This score is justified because as soon as the child had her hearing aids fitted (at two months), she simultaneously began ADAPTI and evaluation process for cochlear implant surgery. Parents attended 72.7% of scheduled therapeutic sessions, being involved in all the treatment proposed by the Hearing Health Service.

It is observed that individuals in group 3 tended to use the device for more hours than those in the other groups (Table 3 and Figure 5).

The scarce daily use of hearing aids (two hours) by the child of family FC6, even attending all therapies and Graf, can be related to the fact that the Brazilian Sign Language (LIBRAS) was the choice of the family from the beginning. In this case, considering low audibility of speech sounds, the use of the device cannot be perceived as a factor that contributes to the communication, considering that LIBRAS became the main communication mode of the child.

Children of families FC2 and C3 from Group 3 use the hearing aid eight and two hours per day, respectively.

The group that demonstrated greater involvement was the one of children who, in most cases, had an average hearing loss of 55dBHL (PD4), 65 dBHL (C3) and 70dBHL (FC1), representing 75% (Figure 4). In this group, there was a child with average hearing loss of 90 dBHL (FC2), but with the longest use of hearing aids (eight hours/day). It is noteworthy that this was one of the oldest children in the group, with 80% attendance in therapeutic care, whose family, although with a score 3 in family involvement, was present in Graf, worried about future issues of the child regarding hearing, language and education. Good answers in the questionnaires occurred because it is an older child (she started the hearing aid fitting at 37 months) and, therefore, quickly acquired the skills questioned at the instruments IT MAIS and MUSS, with high percentage in scores in both instruments.

Another exception in this group is that the child from C3 presented only two hours of use of hearing aids monitored in Datalog. According to the mother, the child was not wearing hearing aids as before (more often) because the twin brother was very ill, burdening the family and leading the mother to put the device less often in the child. In this case, although it is considered a mother who is actively participant, the use of hearing aids does not seem to be appreciated by the family.

It was observed that most mothers of the three groups participated in the Graf. The percentage of parents who did not participate is greater than or equal to 50% in the three groups, with the lowest percentage of participation observed in group 2. There was no difference as to whether or not parents have participated in the Graf PD or FC given the similarity in frequencies (Table 4).

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**DISCUSSION**

As observed in the present study, the increased participation of mothers in ADAPTI indicates that they spend most of their time with their children and are responsible for following them in appointments and therapy sessions. Because of the fact they exercise professional activities, fathers are less present at these commitments. It is for the speech language pathologist and...
audiologist to recognize the importance of fathers in children’s lives and aim to increasingly insert them in the process of auditory (re)habilitation\textsuperscript{16-18}.

The intervention soon after diagnosis of hearing impaired children is of utmost importance for development of auditory skills, speech and language to occur. Therefore, the use of hearing aids and/or other devices such as cochlear implants is essential\textsuperscript{11,18-21}.

The fact that the answers are not yet consistent at early stages of hearing aid fitting - depending on the degree of hearing loss - decreases the motivation of parents to insist on the use of the devices. As the answers appear, child and family miss the hearing aids\textsuperscript{43}.

In this study, adherence to the use of the electronic device was not related to statistical significance to any specific factor given the small number of subjects in the sample. However, there was a trend for better answers on the scale of assessment of family involvement, use of hearing aids and frequency of attendance in therapies of children who had early diagnosis and intervention process. Treatment adherence is a multifactorial process that is comprised of a partnership. It regards to frequency, constancy and perseverance in the pursuit of health\textsuperscript{22}.

The involvement of some families in the group and participation on the proposed activities suggest that this may be a strategy with repercussions on the access to the process of auditory rehabilitation. In fact, to engage, embrace, and build partnerships and linkages with the family during the speech and language therapy are essential to achieve a favorable outcome and satisfactory results regarding the use of hearing aids by children\textsuperscript{5,23}.

The diversity in the characteristics of the families in this study on the groups organized according to auditory and language skills suggests that special attention is needed at the initial processes of intervention, with procedures of hosting families so that the partnership between the professional and the family can be established in order to promote a more consistent use of hearing aids in everyday situations\textsuperscript{23}. The more the child has access to information transmitted through the social contacts established, the better the development of oral language will be. Therefore, if the use of hearing aids is not effective and consistent, the child loses auditory information, which leads to communication difficulties\textsuperscript{24-27}.

The professionals involved need to guide and advise parents by providing clear information on diagnosis, hearing aid use, its benefits and limitations, handling, maintenance and care for the safe use of the device as well as on the progress that the child can achieve with the device and the intervention program. Accordingly, ensuring the adaptation and the daily use of hearing aids allows children to have experiences with their hearing at practically every hour of the day.

The speech language pathologist and audiologist should guide parents or guardians on the controls of the device, ear molds, battery and care in relation to handling and maintenance\textsuperscript{27,28}. It is important to fit the hearing aids in children as early as possible and also to follow up in a specialized service\textsuperscript{11,19}. However, our experience with the groups suggests that family comprehension on the importance of hearing rehabilitation depends on motivation strategies and adjustment of expectations, besides the information on the importance of the electronic device.

Importantly, many times a positive attitude to the processes of scheduled appointments may be confused with what the scale of family involvement seeks to determine. Hence the discrepancy found in different families evaluated in this study.

CONCLUSION

The systematic use of hearing aids was the only variable with a strong relationship to auditory and language skills. Degree of hearing loss, age of onset of amplification and therapeutic process with or without participation in the Group of Adhesion did not explain the development of children studied. Low adherence to the systematic use of hearing aids by parents who participated in GrAF suggests that specific and short-term goals must be included in the goals to be achieved by the groups.

Manifestations of family involvement mirrored in the willingness to participate not always ensured systematic and consistent use of hearing aids. In this sense, hearing health intervention actions that ensure adherence to treatment are necessary so that result measures may reflect the investment in residual hearing. This suggests that, even in families apparently committed to intervention, it is essential to verify the number of hours of hearing aid use per day through objective measures such as the Datalog.

In the case of profound hearing loss, the sooner the tests to referral to cochlear implant surgery are carried out, the more accurate the positioning of professionals about the prognosis for oral language and hence adaptations to the expectations of the family.

Further studies that involve monitoring results of auditory and language development and characteristics of adhesion to the intervention program in the Hearing Health Services are necessary.

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