

# Impact of the therapeutic group setting on the needs of families of children with hearing loss

Impacto do enquadre terapêutico em grupo nas necessidades de famílias de crianças com deficiência auditiva

Impacto del encuadre terapéutico en grupo en las necesidades de familias de niños con deficiencia auditiva

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## **Abstract**

**Introduction:** Evidences from pediatric auditory (re)habilitation has indicated the potential transformative action of the family as a robust factor in the prognosis of treatment. It is also argued that interventions should be based on the assessment of the family needs. **Objective:** to evaluate the impact of the therapeutic group setting on reducing the needs of the families of hearing impaired children. **Method:** an intervention study performed at a government hearing service during a six-month period, in which a group of 10 families of children with hearing loss aged from 1 year and 4 months to 5 years and 3 months, hearing aids or cochlear implant users, responded to the Family Needs Inventory in the pre- and post-intervention moments, and the design of the intervention was made based on the needs evidenced by the instrument applied. The sessions included situations of group dynamics, simulations, skills training and conversation group. Descriptive and inductive statistical analysis was performed, in

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### **Authors' contributions:**

KJC: literature review, data collection and analysis, manuscript writing.

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addition to the qualitative evaluation, which included a focus group. **Results:** the most important topics for families were communication with the hearing impaired child, hearing loss and electronic devices issues, especially regarding cochlear implantation. The age and the educational status of parents, as well as the chronological and auditory age of the children were considered in the analysis of the reduction of the information needs by the families. **Conclusion:** there was a positive impact of the therapeutic group setting on the needs of the families of children with hearing impairment.

**Keywords:** Family; Needs Assessment; Self-Help Groups; Correction of Hearing Impairment.

### Resumo

**Introdução:** Evidências na área da (re)habilitação auditiva infantil têm indicado a potencial ação transformadora da família como um fator robusto no prognóstico do tratamento. Fundamenta-se ainda que as intervenções devam basear-se na avaliação das necessidades das famílias. **Objetivo:** avaliar o impacto do enquadre terapêutico de grupo na diminuição das necessidades de familiares de crianças com deficiência auditiva. **Método:** estudo de intervenção realizado em um serviço de saúde auditiva do SUS, durante o período de seis meses, em que um grupo de 10 famílias de crianças com deficiência auditiva na faixa etária de 1 ano e 4 meses a 5 anos e 3 meses, usuárias de AASI ou IC, responderam ao Inventário das Necessidades Familiares nos momentos pré e pós intervenção, tendo o delineamento da intervenção sido realizado a partir das necessidades evidenciadas pelo instrumento aplicado. As sessões contaram com situações de dinâmicas de grupo, simulações, treino de habilidades e rodas de conversa. Realizada a análise estatística descritiva e indutiva, além da avaliação qualitativa, que contou com um grupo focal. **Resultados:** destacaram-se como tópicos de maior necessidade das famílias a comunicação com a criança com deficiência auditiva, assuntos sobre a perda auditiva e dispositivos auxiliares à audição, em especial, quanto ao implante coclear. A idade dos responsáveis e a escolaridade, bem como a idade cronológica e auditiva das crianças foram consideradas na análise de diminuição das necessidades de informações pelas famílias. **Conclusão:** houve impacto positivo do enquadre terapêutico em grupo nas necessidades dos familiares de crianças com deficiência auditiva.

**Palavras-chave:** Família; Determinação de Necessidades de Cuidados de Saúde; Grupos de Autoajuda; Correção de Deficiência Auditiva.

### Resumen

**Introducción:** Evidencias en el área de la (re)habilitación auditiva infantil han indicado la potencial acción transformadora de la familia en el pronóstico del tratamiento. Se fundamenta también que las intervenciones deben basarse en la evaluación de las necesidades de las familias. **Objetivo:** evaluar el impacto del encuadre terapéutico de grupo en la disminución de las necesidades de familiares de niños con pérdida auditiva. **Método:** estudio de intervención realizado en un servicio de salud auditiva del gobierno, durante el período de seis meses, en que un grupo de familias de niños con deficiencia auditiva en el grupo de edad específico, usuarias de audífonos o implante coclear, respondieron al Inventario de las Necesidades Familiares en los momentos pre y post intervención, siendo la intervención realizado a partir de las necesidades evidenciadas por el instrumento aplicado. Las sesiones contaron con situaciones de dinámica de grupo, simulaciones, entrenamiento de habilidades y ruedas de conversación. Se realizó el análisis estadístico descriptivo e inductivo, además de la evaluación cualitativa, que contó con un grupo focal. **Resultados:** se destacaron como temas de mayor necesidad de las familias la comunicación, asuntos sobre la pérdida auditiva y dispositivos auxiliares a la audición. La edad y la escolaridad de los responsables, así como la edad cronológica y auditiva de los niños fueron considerados en el análisis de disminución de las necesidades de información por las familias. **Conclusión:** hubo un impacto positivo del encuadre terapéutico en grupo en las necesidades de los familiares de niños con deficiencia auditiva.

**Palabras clave:** Familia; Evaluación de Necesidades; Grupos de Autoayuda; Corrección de Deficiencia Auditiva.



## Introduction

Evidence obtained from studies on hard of hearing children has proven the impact of the family as a robust factor in the clinical prognosis of their children's development. This fact has fueled research related to interventions directed at these family members<sup>1, 2, 3, 4, 5, 6, 7</sup>.

Thus, it is considered that subsequent to the diagnosis process, the needs of families should be met for better adherence to the auditory habilitation process, by relying on the advice and guidance that may be offered in individual or collective settings, or in both<sup>8, 9</sup>.

In order to analyze the needs of families, Yucel, Derim & Celik (2008) proposed the Family Needs Survey<sup>10</sup> instrument, which was translated and adapted to suit the Portuguese speaking population and renamed as the Family Needs Inventory (FNI)<sup>11</sup>. It assessed the needs of parents of hard of hearing children by covering the following seven topics: general information; hearing and hearing loss information; communication; educational services and resources; family and social support; community services and care; and financial issues.

To boost hearing and language development beyond the clinical setting, the key role of specific interventions that address information and support needs of families should be emphasized, especially at the time of joining the auditory habilitation programs, which should ideally start early<sup>12</sup>.

Hence, in addition to the audiological data related to the prediction of the child's developmental outcomes, the audiologist should also consider the facilitators and barriers that could be associated with the characteristics and needs of the families, as well as how these family members will be able to absorb and apply the guidelines given to them by the specialists to boost their routine<sup>10</sup>.

Literature has pointed to the age at which the intervention with hearing devices was initiated, as well as how long these devices were used daily as key points for achieving linguistic performance compatible with typical development<sup>14, 15, 16</sup>. In addition, the family-child interaction has been pointed out as a determining indicator for the healthy development of oral language in children with hearing loss<sup>4, 17</sup>.

A qualitative study that analyzed the report of a thousand families of hard of hearing children found that in supportive parent care these families

frequently inquired about topics related to hearing loss, early intervention, disabilities associated with hearing loss. The authors also noted multiple differences between the needs of English and Spanish-speaking families receiving such support<sup>18</sup>.

Communication features prominently among the needs of families, who are not always able to satisfactorily apply the communicative strategies that professionals use during speech therapy. Working with this theme in different settings is justified since it facilitates understanding in families, who can consequently incorporate in daily interactions with their children<sup>3, 4, 19, 20, 21, 22, 23</sup>.

Hence the realization that, when at the time of therapy, attention was not devoted to imparting knowledge based on each family's needs, the families might not absorb the guidelines, resulting in a negative impact on the child's development<sup>1, 24</sup>.

Therefore, when parents of hard of hearing children are enrolled in auditory habilitation programs in which the orientations and strategies are worked out in a specific manner, in group situations or through personalized sessions with varied resources, these families tend to act more effectively to enrich their children's auditory and language experience, with positive expectations for child development, family dynamics, and the inclusion of children<sup>25, 26, 27</sup>.

As the audiologist might not always be able to dedicate a weekly session, for addressing the needs of families, the parent group strategy becomes viable and is recommended because it has scope for saving time and supporting families by providing them with a unique and meaningful experience<sup>19, 24</sup>.

Given the above, an analysis of the group therapeutic framework for families of hard of hearing children is of great importance because such interventions that focus on parents and caregivers will be more effective in successfully promoting any therapeutic or educational process with the child<sup>1, 2, 8, 26, 27</sup>.

Based on the understanding that the family should be the foci of the therapy in the child's auditory habilitation program, the general objective was to evaluate the impact of the group therapeutic framework in reducing the information needs of family members of hard of hearing children.



## Methods

This was an intervention study, with a pre and post-test group; and quali-quantitative approach, whose implementation was administered by the Committee for Ethics in Research (CEP) of the institution responsible, under technical advice number 1.144.295.

The research was conducted in a philanthropic high complexity hearing health service of the Unified Health System. While twenty-four families were selected, only ten families of hard of hearing children were enrolled based on the criteria: family members of children with hearing loss of any type or grade and hearing aid or cochlear implant (CI) users who had effectively participated in the support group. The age group of children ranged from 1.4 years to 5.3 years.

Some participants in the study were lost due to non-attendance of families to the group sessions.

As part of the procedure, all subjects signed the informed consent document and all doubts regarding the study were clarified. The sessions were conducted by the institution's audiologist, a researcher and a service psychologist, supported by a speech pathology student.

Regarding the FNI instrument, from among 38 items, divided into seven themes, the families had the following answer options, considering the adaptation to Brazilian Portuguese: YES, in case they felt totally uninformed about the particular subject and wanted information; Doubtful, in case they had questions relating to the item and needed

more information about it; and a NO option, in case the parents did not find it necessary to obtain information about the particular item.

The families responded to the inventory pre and post intervention and at the end of six months. The group work was carried out by a focused group that addressed a qualitative analysis based on perception of the families, the impact on the parent group, their satisfaction with the support on their information needs regarding their child's (re) habilitation process.

In the collection and analysis of this study's data, the following were considered:

- the eight-session treatment plans carried out during the 6 months by the above-mentioned team based on responses to goals, strategies, and outcomes that were used in the qualitative analysis;
- pre and post intervention assessment instrument - Family Needs Inventory - INF<sup>10</sup>
- an analysis of the focus group session using a qualitative research technique<sup>28</sup> that helped in examining questions relating to the clarifications and doubts of the families that were addressed during investigation for therapeutic group work;
- some of the demographics and children's data (reported in Tables 1 and 2) contributed to a more comprehensive analysis of outcomes relating to the needs of the families.

The characterization of the participants and their children will be presented in Tables 1 and 2 below.



**Table 1.** Families Description

Family (Mother)	Age of the family member	Education	Occupation	Economic rating	Government Aid
F1	31	HS	Housewife	E	BF
F2	35	IHS	Hairdresser	E	BF
F3	32	IES	Manicure	E	B
F4	43	HS	Saleswoman	E	BPC
F5	31	UD	Pedagogue	E	B
F6	18	IES	Housewife	E	B
F7	20	IES	Housewife	E	B
F8	31	ES	Housewife	C	N
F9	32	HS	Housewife	E	B
F10	26	HS	Cashier	E	N

Abbreviations: Education Level: IUD – Incomplete Undergraduate Degree; UD - Undergraduate Degree; ES – Elementary School; IES – Incomplete Elementary School; HS – High School; IHS – Incomplete High School. Economic rating: E - Up to 2 minimum wages; C - From 4 to 10 minimum wages. Governmental Aid: BF - Bolsa Família; B - Benefício; BPC – Benefício Prestação Continuada; N – None.

**Table 2.** Children Description

Child	Chronological age	Auditory age	Type of hearing loss	Level of hearing loss	Devices
C1	1 y 11 m	3 m	SL	Profound bilateral	Bilateral CI
C2	2 y 3 m	4 m	SL	Profound bilateral	Bilateral CI
C3	1 y 4 m	1 m	SL	Profound bilateral	Bilateral CI
C4	2 y 6 m	1 y 9 m	SL	Severe Bilateral	Bilateral Hearing Aids
C5	2 y 3 m	4 m	SL	Profound bilateral	Bilateral CI
C6	5 y 3 m	11 m	SL	Profound bilateral	Bilateral CI
C7	4 y 5 m	3 y	SL	Profound bilateral	Bilateral CI
C8	3 y 5 m	2 y 2 m	SL	Profound bilateral	CI LE
C9	1 y 10 m	1 y 2 m	CHS RE SL LE	RE/ Mild LE/auditory conduct atresia	Hearing Aids LE
C10	3 y 11 m	1 y	SL	Deep bilateral	Bilateral CI

Abbreviations: Chronological /Auditory age: y – years; m – months. Side of hearing loss: RE - Right Ear; LE - Left Ear. Devices: CI - Cochlear implant. Type of hearing loss: SL - Sensorineural loss; CHS - Conductive hearing loss.

The children's chronological ages were obtained from their medical records. The auditory age was determined by considering the recorded data relating to the period in which the hearing aids were activated for each child.

All the sessions that had occurred through dynamics and simulations were recorded through daily reports for qualitative analysis.

A descriptive statistical analysis of the results of the INF was given by the total scores in the pre and post intervention periods by calculating the means of each inventory category and permitting visualization of a midpoint of the applications for each topic.

The inferential analysis of the data employed the JT statistical method, which compares the re-

sults obtained before and after the intervention, for the purpose of identifying whether the changes that had occurred were reliable and clinically relevant, even though it was not possible to apply this treatment to a large number of subjects<sup>29</sup>.

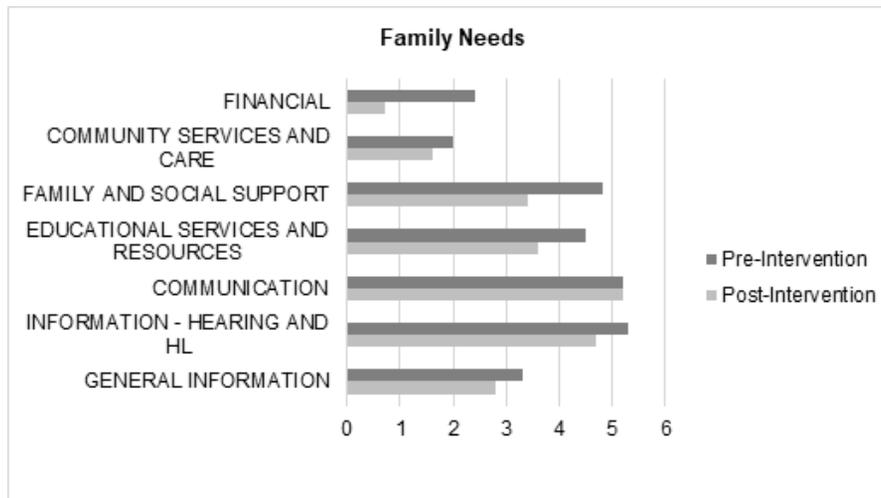
Although the limited amount of data allows us to perform the analysis only for the specific sample collected, descriptive statistics was used through box plot graphs, and simple linear correlations were applied to correlate demographic data of families and the chronological and auditory ages of the children in relation to the decrease in the needs of the families involved in the group therapy setting.

The verbal material obtained through the focus group technique was transcribed and inserted into

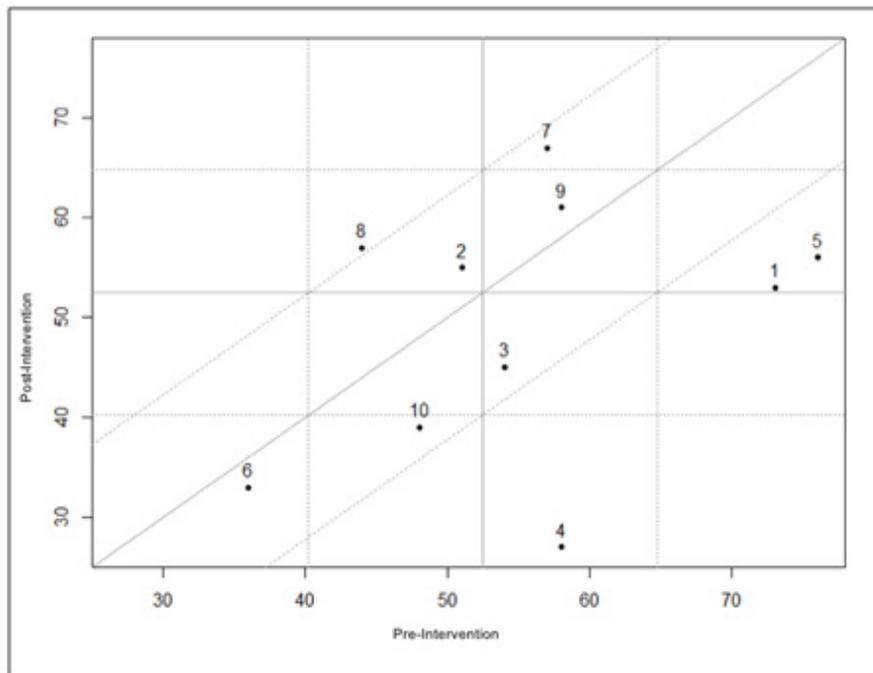
the *Iramuteq* software, which allows quantifying and employing statistical calculations on qualitative variables<sup>30</sup>, and makes it possible to analyze the word frequency that was presented in word cloud graphs, organized from the focus group's two key questions.

## Results

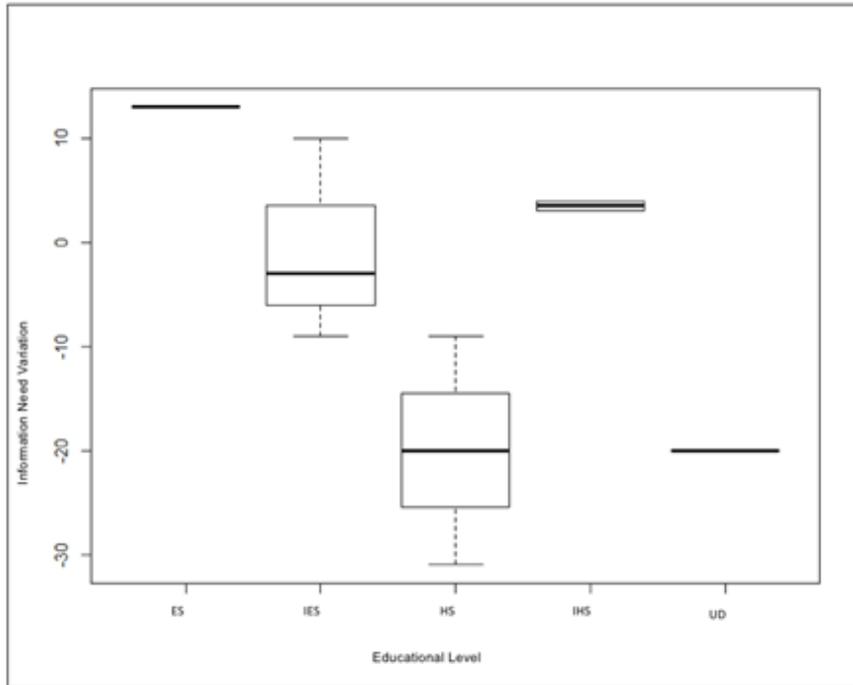
The following are the results obtained from the calculation of the median total scores of each family in the Family Needs Inventory (INF) in the pre and post intervention periods.



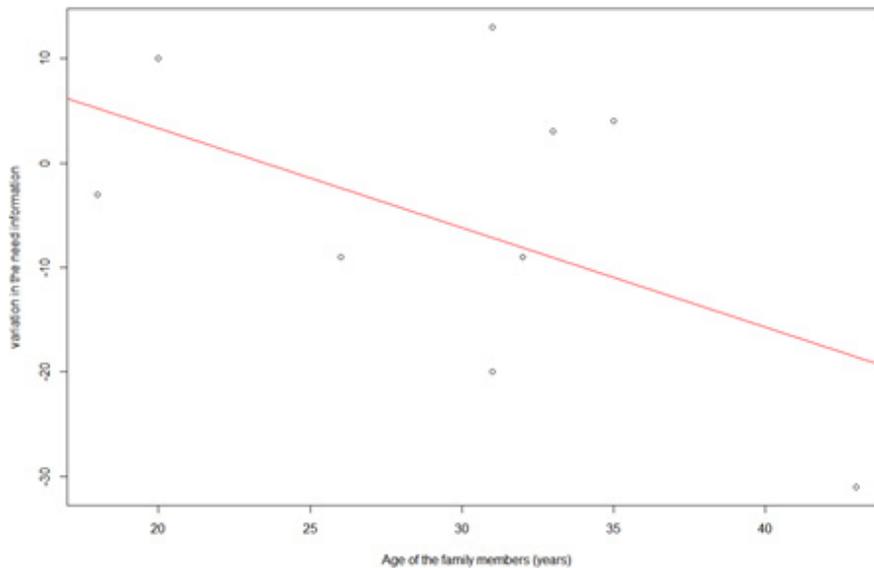
**Figure 1.** Results regarding family needs in the pre and post-intervention period.



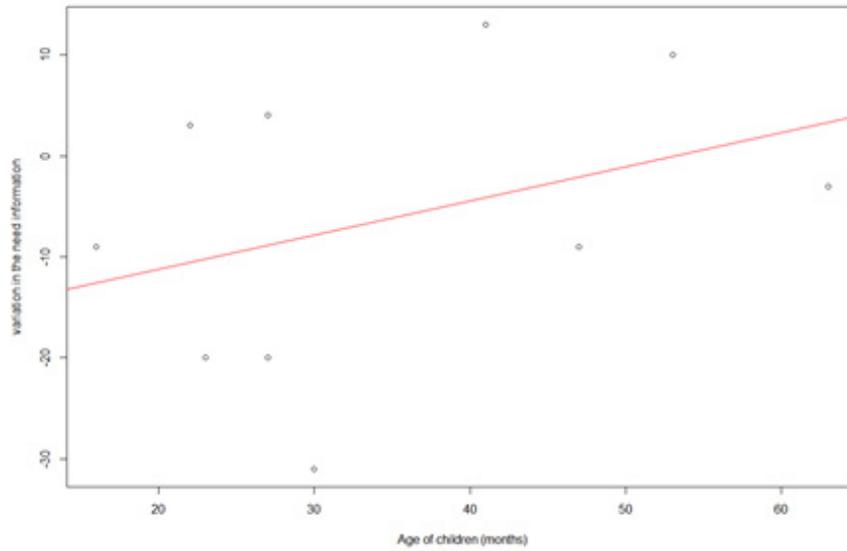
**Figure 2.** Reliable change clinical analysis of information needs for families of hard of hearing children participating in group intervention.



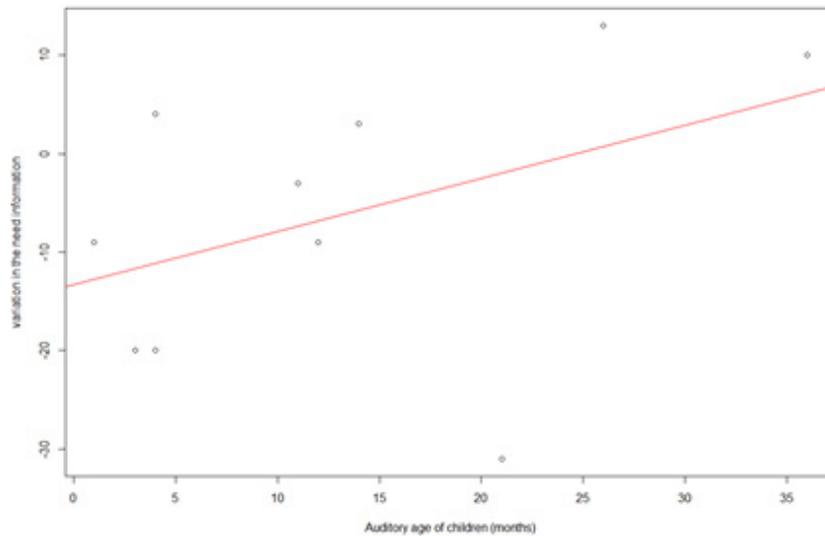
**Figure 3.** Comparative analysis of the variation in the information needs regarding the educational level of the family members participating in the study.



**Figure 4.** Comparative analysis of the variation in the need information regarding the age of the family members participating in the study.



**Figure 5.** Comparative analysis of the variation in the need information of families regarding the chronological age of children.



**Figure 6.** Comparative analysis of the variation in the need for information of families regarding the auditory age of children.

For the qualitative analysis of the focus group, some of the family members' statements on the positive impact of the group therapy framework were highlighted and Figures 7 and 8 will present statistical analysis with the content frequency through word cloud graphs.

According to the families, the group plays an important role after the discovery of hearing loss, as it gives an opportunity to clarify doubts about hearing loss, via mediators and other participants, through the exchange of experiences, besides promoting a welcoming environment. As can be seen in the following statements:

(F1): "... I think it's very important, because here I ask a lot of questions, plenty of them" [...] "We learn more from each other's experiences, right? Each one has a different experience and we learn from their experience so that we can deal with the child later [...] so we are already preparing for that moment."

(F2): "I feel very welcomed here, I love being here in this group, I see every example of a mother that makes me stand up. So, I had a little depression at first, right? But with her account of everything that happened, it made me think differently, today I am someone else, after I met you."

The families also reported that their main reason for participating in the group was to enhance their understanding on hearing loss and to promote the improvement and development of their children.

As for the questions answered during the semester, most parents reported during the focus group that they no longer had doubts about mold cleaning; devices and their handling; CI surgery; and how to promote their child's development during routine activities. Some thoughts of the families are reproduced below:

(F1): "I was afraid of the implant. I was afraid of not knowing how to take care of this device. How to take care, how to keep it, because it could break, and I could not buy another. My desperation was just that. I have calmed down, because now I can take care, I can clean, I can put it in the ears of others, I can do everything."

(F2): "My panic was about the surgery. And here, I got all my doubts cleared with their testimonials."

(F3): "I think GIP helped me from the very first moment, to understand her disability, how to help her. Because I had no idea what to do. It helped me to keep the device as good as possible because I didn't know anything."

(F4): "I think it helped me to accept it. Because previously I didn't accept that she had a hearing loss."

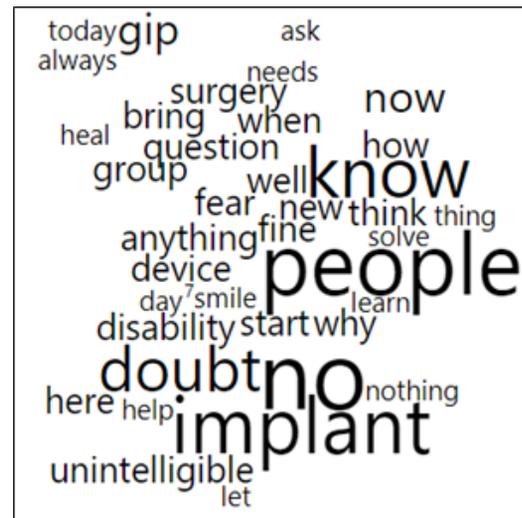
(F5): "That one of mold cleaning, of handling, was also very important for me".

Still, according to the reports of families, the intervention also allowed parents to transfer what was learned to the child's routine, by bringing their

doubts to the group situation, a result exemplified by the mother's speech:

(F1): "I already leave home thinking about my doubts, I will ask this, and I will ask that..."

Figures 7 and 8 show the statistical analysis of word frequencies regarding the perception of families about the needs worked during the parents' group.



**Figure 7.** Word's frequency graph about the families' perceptions of their needs worked in the group.



**Figure 8.** Word's frequency graph about the families' perceptions of their needs that still exist, after 6 months in the group.

## Discussion

Literature has shown how families of hard of hearing children play an important role in the therapeutic prognosis of their children<sup>1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 16, 18, 19, 21, 22, 23.</sup>

The present study identified that the therapeutic group approach, planned on the basis of the families' needs, had a positive impact on clarifying the doubts of the families and the knowledge acquired by them during the sessions. Therefore, it highlights the importance of interventions that focus on the needs of families based on their realities and the common experiences among members of therapeutic groups<sup>1, 11, 12, 13, 14, 15, 17, 23.</sup>

Based on the literature, it was possible to know the topics on which family members needed the most information, namely: communication, hearing, and hearing loss<sup>10, 11, 13, 19, 20;</sup> followed by: family and educational support; and educational services and resources. Information on financial issues were sought less frequently, possibly due to the inclusion of families in a Services for the UnderServed (SUS), corresponding to their socioeconomic reality, noting that eight families received government benefits and nine fell under a low economic rating.

Even after the months of intervention, the families still required information on subjects relating to hearing and hearing loss, communication, family and social support, educational services and resources, and general information.

It is important to emphasize the fact that families still wanting information on certain topics does not necessarily indicate that they have not acquired or used information received during the group sessions. Family needs are dynamic and the selection of one topic in a given intervention situation can generate other questions from the families. In addition, the moment of life itself and the parents' experiences related to some of the topics, or the phase of feelings experienced by them may trigger information needs, a fact that should be considered by professionals for an analysis of therapeutic scenarios<sup>11, 23, 24, 27.</sup>

The topics listed from the FNI application and those agreed upon by the families for being addressed by the group include: the understanding and acceptance of hearing loss, the aspects about the use, handling and care of electronic devices, especially the CI<sup>12, 19.</sup>

The CI was a common point of interest since eight family members were parents of children using this device, which was highlighted by the doubts about the CI revealed in the word cloud graph presented in Figure 7, in the pre intervention test. In the qualitative analysis of the sessions, it was also evident that the emphasis on CI and how to play and talk with hard of hearing children were the topics addressed in the strategies of several sessions, with visible reduction of doubts, especially about CIs, as can be seen in the word cloud shown in Figure 8.

It is also noted that the word *doubt*, which is quite frequent in the pre-intervention period, changes to the word *know* in the word cloud graph, similar to the word *group* that frequently appears in the post-intervention phase, in family members' statements, expressing the importance of the support group approach in their children's therapeutic process.

From the analysis of reliable clinical change, it was observed that families 1, 4, and 5 presented reliable negative change, i.e., there was a statistically significant decrease in their information needs after the intervention. Six families' information needs have not shown any significant change, although the needs of families 3, 6, and 10 decreased, though not at a statistically acceptable level. Family 8 presented the need for more information after the intervention, which may be explained by the fact that more emphasis was given during the intervention sessions to the themes CI and How to play and talk with a hard of hearing child, and not addressing other topics in which these parents presented information needs. These data corroborate the previous study that analyzed the effectiveness of a therapeutic group of 20 sessions with families of hard of hearing children<sup>23.</sup>

Regarding the analysis of the demographic variables of the families, those that correlated with the decreased information needs were the educational level and ages of the family members, according to Figures 3 and 4.

It is noticeable that the need for information had significantly decreased in families that had completed higher education (CHE) and high school (HS) and this fact has also been observed in other studies involving better performance of parents with higher education in a course for parents<sup>7;</sup> as well as the families' needs decreasing with higher education, in a research with the Family Needs Sur-



vey. This is a very important point for researchers and professionals in the area to reflect upon: how to plan and execute interventions that reach the least educated families? What resources should be used to enhance this work? While these issues have been addressed to some extent in several studies, they still require further analysis in different contexts and cultures to produce robust evidence, especially in the national scenario <sup>7, 19</sup>.

During the planning of the sessions, with the realization of dynamic activities, such as the use of simulations, group conversation, group dynamics, skills training, there was a concern about how to make the informative content as accessible as possible to the families. However, the statistical analysis described above, alerts researchers on the need to study the most appropriate number of sessions to meet the needs of families with lower education, the use of other session tools, or informational materials that may be “consumed” by families at other times during the week, the combination of group and personalized approaches for better information retention, the analysis of the tutoring system between parents, because of the greater identification between them, among other strategies. It may also involve the use of technologies, such as the use of video feedback, among many other possibilities for technological innovations <sup>16, 21, 24, 25, 26, 27</sup>.

Regarding the age of family members, the decreasing graph indicates that the older the family member, the greater the need for information, indicating that older parents tended to absorb more information treated in group sessions. The analysis of the age factor was not found in studies on interventions with families of children with hearing loss, and this factor should be better investigated in a more representative sample.

Concerning the variables related to some of the characteristics of the children, chronological and auditory ages had a correlation with the families’ information needs.

Relating to age of the children, it was observed that information needs of older children’s parent had diminished less, indicating that their families’ needs were greater, possibly due to the complexity of the demands that had occurred during their development, such as child socialization, school entry, use of devices like the FM system, the need for specialized educational support, among their other needs, for which the family would require

information on how to deal better with these issues <sup>1, 11, 21</sup>.

Regarding auditory age, the analysis was analogous to that performed for chronological age, i.e., family members of children with higher auditory age had a greater need for information. In a counterpoint, the graph indicates the need to start, as soon as possible, specific and systematic interventions with guidance based on the needs of families, in accordance with literature on the need for early intervention in a family-centered approach.

It was also evidenced, from the qualitative analysis, that besides playing an informative role, the group also provided counseling and emotional support to the participating families, by sharing their anxieties and achievements during the sessions, which was identical in the situations reported. Literature widely reinforces the statement about the importance of support among family members, in addition to speech therapy <sup>1, 2, 17</sup>.

## Conclusion

The positive impact of the proposed group therapy approach on the needs of the families of hard of hearing children was established.

The use of dynamic strategies and the encouragement of a support network between parents strengthened the involvement of the ten families that participated in the study.

The limitations comprise: the small sample that does not allow inferences about the applicability of the framework investigated to other realities; logistic issues related to the loss of the sample, since of 24 family members only 10 were present during auditory habilitation service of group intervention; the lack of a control group also represented a restriction on determining the efficacy of the group’s therapeutic setting for this population. The increase in the number of subjects and the more robust methodological design will be pursued in the continuation of this work.

The potential of this study highlights the possibility of analyzing the clinical significance of group intervention, even in a limited sample, using the JT method, with the possibility of strengthening future research involving a larger number of subjects.

Investigations into the most effective group frameworks for meeting the needs of families of hard of hearing children present a promising future



with the use of resources and technological innovations that could enable or enhance these children's developmental outcomes through the empowerment of their families, as true transformers of their children's reality.

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