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# Mothers' adherence to a hearing and language development follow-up program

## Adesão de mães a um programa de monitoramento do desenvolvimento auditivo e de linguagem

## Adherencia de madres a un programa de monitoramiento del desarrollo auditivo y de linguagem

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### Abstract

**Introduction:** To analyze the use of strategies for adherence of mothers of infants with risk indicators for hearing loss of late onset to a hearing and language development program; to know the profile of mothers, the difficulties and the reasons for their adherence to the Program. **Methods:** Transversal study using quantitative and qualitative analysis. The data have been collected throughout the records of the infants and semi structuralized interviews. The strategies used were a folder about hearing and language development and phone calls. **Results:** We studied data from 464 files whose infants came to the assessment in 2009, 2010 and 2011 and 53 mothers decided to participate in the research. The majority of mothers was housewives, completed high school, had no job, lived with a partner; in the city of the study. Fifteen mothers (32,5%) had difficulties to come to the institution due to the distance between their home and the institution, the schedule of the evaluation, dismissal of the work, the need of taking care of other children. The main reasons for adherence were: concern about the infant hearing, presence of risk indicator and scheduled return. **Conclusion:** It is possible to increase adherence of mothers using some strategies to make them to remember the day of the assessment and the importance to evaluate the child. The answers of the mothers showed their interest in participating and following the orientations. It is necessary that professionals help families, clarifying, creating and motivating them to actively participate in the follow up process.

**Keywords:** Language development; Hearing loss; Loss of sequence; Health promotion.

### Resumo

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**Authors' contributions:** MFT collection, analysis and discussion of the data. MFCF analysis and discussion of the data. MCMP analysis and discussion of the data.

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**Objetivo:** Analisar a utilização de estratégias para adesão de mães de crianças com indicadores de risco para perda auditiva de início tardio a um programa de monitoramento do desenvolvimento, conhecer o perfil das mães, as dificuldades encontradas e as razões para a adesão. **Método:** Pesquisa transversal, com análise quantitativa e qualitativa. Foram coletados dados do livro de registros de comparecimento dos lactentes e entrevista semiestruturada. As estratégias para adesão foram entrega de um panfleto sobre desenvolvimento da audição e linguagem e ligação telefônica. **Resultados:** Foram levantados dados de prontuários de 464 lactentes nos anos de 2009, 2010 e 2011 e 53 mães se dispuseram a participar da pesquisa. A maioria possuía ensino médio completo, união estável, residia na cidade da pesquisa, sem vínculo empregatício. A adesão das mães aumentou de forma significativa com as estratégias de ligação telefônica e de entregar folheto explicativo. Quinze mães (32,5%) disseram ter dificuldades de comparecimento, tais como: deslocamento da casa até a Instituição; recursos financeiros; horário das avaliações; dispensa no trabalho; falta de transporte, e necessidade de cuidado de outros filhos. Principais razões de adesão: preocupação quanto à audição, presença de indicador de risco e retorno agendado. **Conclusão:** Pode-se aumentar a adesão de mães com estratégias que as façam se lembrar do dia agendado e sobre a importância de se avaliar a criança. As respostas das mães revelaram interesse em participar do programa e seguir as orientações. Os profissionais da saúde devem atuar junto à família, esclarecendo e motivando a participação ativa no processo.

**Palavras-chave:** Desenvolvimento da linguagem; Perda auditiva; Perda de seguimento; Promoção da saúde.

### Resumen

**Introducción:** Analizar el uso de estrategias para la adherencia de madres de niños con indicadores del riesgo para la pérdida auditiva de inicio tardío a un programa del seguimiento del desarrollo, conocer el perfil de las madres, las dificultades encontradas y las razones la adherencia. **Métodos:** Investigación transversal con análisis cuantitativo y cualitativo. Los datos fueran recogidos por medio del libro de registros de asistencia de los lactantes y entrevista semi estructurada. Las estrategias para adherencia fueron la entrega de un folleto sobre el desarrollo de la audición y llamada telefónica. **Resultados:** Fueron levantados datos de registro clínico de 464 lactantes en los años de 2009, 2010 y 2011 y 53 madres se mostraron dispuestas a participar de la investigación. La mayoría poseía educación media completa, unión estable, habitada en la ciudad de la investigación, sin enlace de empleo. La adherencia de las madres aumentó de forma significativa con las estrategias de llamada telefónica y entrega del folleto explicativo. Quince madres (32.5%) dijeron tener dificultades de asistencia tales como: dislocación de la casa a la Institución; recursos financieros; horario de las evaluaciones; despido en el trabajo; carencia de transporte, necesidad de cuidar de otros hilos. Principales razones de la adherencia: preocupación con la audición, presencia del indicador de riesgo y retorno programado. **Conclusión:** Es posible aumentar la adherencia de madres con estrategias para recordarles el día de las citas y la importancia de evaluar el niño. Las respuestas de las madres revelaron interés en participar del programa y seguir las orientaciones. Los profesionales de la salud deben actúan junto a la familia, clarificando y motivando la participación activa en el proceso.

**Palabras clave:** Desarrollo del lenguaje; Pérdida auditiva; Pérdida de seguimiento; Promoción de la salud.

## Introduction

Monitoring the development of an infant is highly relevant considering the process of early detection and health promotion and education. The audiological diagnosis conducted during the first year of life enables medical, speech-language and audiological intervention still in this critical period of maturation and functional plasticity of the central nervous system, preventing future alterations and providing a more favorable prognostic regarding the global development of the child<sup>1</sup>.

In Brazil, it was enacted the Law 12.303<sup>2</sup>, which provides for the obligation of conducting Evoked Otoacoustic Emissions (EOAE) in all public hospitals and maternity hospitals. The Neonatal Auditory Screening (NAS) must include, in addition to the screening procedures, the research of risk indicators and the follow up of infants who present such indicators, since their presence may lead to the late onset of hearing loss. Isolated NAS programs are doomed to failure if they are not part of a broader program of auditory health that links the several levels of health care, creating a network of identification, guidance and support to the families, diagnosis, and intervention<sup>3</sup>. Therefore, monitoring constitutes a way of screening and following up the development of hearing and language acquisition in children with one or more risk indicators for late onset hearing loss.

Family participation is required during the process of hearing screening in order to take the child to be tested and, in case hearing loss is detected, so they can be guided and integrated to enabling programs<sup>4,5</sup>. When parents are well informed and in favorable emotional conditions to understand the reasons for monitoring, they can realize the importance of having their child followed up and adhere to these programs<sup>6</sup>.

The adherence to medical or rehabilitation treatments is a great challenge in health care. The non-adherence implies high costs to public health and results in waste of resources and frustration to both professionals and patients<sup>7</sup>.

The benefits of adherence to treatment extend to patients, families, health system and the countries' economy. A broader and more embracing definition from the Ministry of Health (2008)<sup>8</sup> points that adherence is a dynamic and multifactorial process that includes physical, psychological, social, cultural and behavioral aspects, and requires

shared and co-accountable decisions with the individual, the team and the social network.

The aim of the present study was to analyze the use of strategies for the adherence of mothers of children with risk indicators for late-onset hearing loss to a Follow-up Program of Hearing and Language Development, as well as to get to know the profile of mothers, the difficulties and the reasons for their adherence to the Program.

## Methods

The research was cross-sectional, with quantitative and qualitative analysis of data. Considering the complexity and importance of the investigated topic, we opted for a hybrid approach, with potential to identify the factors that interfere, in different aspects, with the adherence to the treatment. The project was approved by the Research Ethics Committee under protocol number 253/2011. The subjects were enrolled in the Follow-up Program of Hearing and Language Development at the outpatient training clinic from an Undergraduate Program in Speech-Language Pathology and Audiology in the State of São Paulo. All parents signed the Free and Informed Consent.

The Neonatal Auditory Screening carried out at the outpatient training clinic uses either the Transient Otoacoustic Emissions (TOAE) or the Brainstem Auditory Evoked Potential (BAEP). Infants who pass the screening (test or retest), but present risk indicators for hearing loss are referred to the Follow-up Program of Hearing and Language Development, and an evaluation is scheduled to be conducted between 4 and 5 months of age. If the child's response is according to the expected for the age group, she is evaluated again with 8 and 12 months of age, and is discharged after being reassessed at 24 months. The mother receives information on how to stimulate hearing and oral language. If after the age two the child still presents a delay in language development, she is referred to the Speech-Language Pathology service at the same clinic or in other possible referral resource in the community.

The participants of the research were mothers of infants born in good health conditions and that had at least one risk indicator for deafness, who stayed in shared hospital rooms and were brought for the first assessment in the Follow-up Program of Hearing and Language Development at 4 months

of age. The following conditions were considered risk indicators for hearing loss in a healthy population<sup>9</sup>: history of permanent deafness cases with onset during childhood in the family, which was considered as hereditary risk; family inbreeding, exposure to ototoxic drugs such as aminoglycoside antibiotics and/or loop diuretics; neonatal Apgar score of 0 to 4 at 1 minute or 0 to 6 at 5 minutes; congenital infections (toxoplasmosis, rubella, cytomegalovirus, herpes, syphilis); presence of the Syndrome of Human Immunodeficiency Virus (HIV), craniofacial anomalies involving ear and temporal bone, genetic syndromes that usually express hearing loss, and mother's use of alcohol or drugs during pregnancy.

Infants who presented the result of FAIL results in the OAEs or in the BAEP in the first assessment or reassessment, and infants who did not come to the first assessment at 4 months of age were excluded from the research.

Data related to the number of attendances at the Follow-up Program and the strategies used for mothers' adherence in the years 2009 and 2010 were used to compare with data from 2011. The total number of cases was 464.

In 2009, the appointments to participate in the Follow-up Program of Hearing and Language Development were made when the infant was 4 months chronological age, and the mother received a note with the date and time of the assessment. In 2010, it was used the strategy to make a phone call to the mother two days before the appointment to remind her of it. In 2011, two different strategies were used: the phone call and a brochure explaining the importance of hearing and the consequences of late onset hearing loss. In the cases where the contact by phone was not possible due to non-existent numbers, change of phone number or missed calls, after three attempts in different times of day, the date and time of the call were registered in the follow-up notebook with the signature of the researcher, and the infants were excluded from the study.

From the 195 mothers who brought their infants to the follow-up, 53 were interviewed. Data collection was interrupted considering the data saturation process, that is, when the information started to be repeated. Moreover, we interviewed the mothers who had time and schedule available to participate.

The semi structured interview was conducted according to a script composed of two open

questions (which provide richer data for an assessment) and closed questions regarding identification, family situation, family composition, and economic situation<sup>10</sup>. The open questions were: 1 – Was it difficult for you to return here? Why?; 2 – Which reasons made you come to the follow-up?. The interview was conducted in a room of the institution, recorded with an MP3 player and fully transcribed. After that, readings were performed to group the contents and identify the meaning cores. Then, data were described and analyzed.

The aim of the interview was to explore the difficulties of mothers to attend the Program and their conceptions about the consequences of hearing loss in a child.

Data regarding the number of mothers who attended the Program and the presence of risk indicators were entered into the software EPIINFO 6.4 and analyzed using the Chi-square Test and the Cochran-Armitage Trend Test, with the aim to evaluate the presence of an association between a variable with two categories. The significance level adopted was 5% ( $p < 0.05$ ).

## Results

Regarding the presence of infants in the Follow-up Program of Hearing and Language Development, it was noticed a significant increase in the adherence of mothers returning with the infant at 4 months, comparing the year 2011 with previous years ( $p = 0.0435$ ) (Table 1).

**Table 1.** Number of infants who attended the auditory screening and the Follow-up Program of Hearing and Language Development in the years 2009, 2010 and 2011

Year	Infants who attended auditory screening	Infants with RI referred to the Program/frequency	Infants who attended the assessment at 4 months/frequency
2009	1694	246 (14.52%)	121 (49.19 %)
2010	1890	295 (15.61%)	148 (50.17%)
2011	1742	334 (19.17%)	195 (58.38%)

RI – Risk Indicators                      Chi-square Test p=0.0435

Applying the Cochran-Armitage Trend Test, the value of  $Z$  was 0.0219, showing a linear trend of adherence increase between the years 2009, 2010 and the year 2011. In the Chi-square Test, the p-values showed significant differences between the years analyzed, that is, the change of strategy with mothers caused an increase in the adherence to the Follow-up

Program.

In 2011, 195 mothers returned to the Follow-up Program of Hearing and Language Development when their children were 4 months old. From these mothers, 53 were interviewed and accepted to participate in the study. Data for the mothers' profile are in Table 2.

**Table 2.** Sociodemographic profile of interviewed mothers (age, level of education, marital status, profession, and family income) and infant's birth order

Profile of mothers	Absolute frequency (N)	Relative frequency (%)
<b>Age in years</b>		
14-19	13	24.52%
20-30	26	49.05%
31-37	12	22.64%
+ 38	02	3.77%
<b>Level of education</b>		
ES - IHS	23	43.39%
CHS or more	30	56.60%
<b>Marital status</b>		
Single	32	60.37%
Living with partner	02	3.77%
Separated		
<b>Birth order</b>		
	25	47.17%
1st child	18	33.96%
2nd child	10	18.86%
3rd or more child		
<b>Profession</b>		
Housewife	28	52.83%
Secretary	06	11.32%
Commerce	11	20.75%
Maid	05	9.43%
Student	03	5.66%
<b>Family income</b>		
	49	92.45%
≤ 2 minimum wages	04	7.54%
> 2 minimum wages		

ES - Elementary School; IHS - Incomplete High School; CHS - Complete High School

Table 3 shows the relation between the studied risk indicators in the years 2009, 2010 and 2011. Data showed a linear trend of increase for risk indicators in

general between the years, mainly regarding family history for hearing impairment, Apgar < 4 at 1 minute, and presence of HIV ( $/Z/=0.002$ ).

**Table 3.** Presence of risk indicators in each year analyzed

Risk indicator	2009		2010		2011	
	N	%	N	%	N	%
Family history	89	36.17	104	35.25	87	26.04
Congenital infection	39	15.85	46	15.59	54	16.16
Craniofacial anomalies	06	2.44	01	0.34	08	2.39
Ototoxic drugs	13	5.28	22	7.46	25	7.48
APGAR	39	15.85	55	18.64	64	19.16*
<4 at 1 minute and <6 at 2 minutes						
Genetic syndromes	--	---	05	1.69	02	0.59
Use of alcohol or drugs	11	4.47	21	7.11	27	8.08
HIV+	16	6.50	17	5.76	39	11.67*
Family inbreeding	33	13.41	25	8.47	28	8.38
Total	246	100.00	295	100.00	334	100.00

Note: RI – Risk indicators, APGAR- APGAR score, HIV- Human Immunodeficiency Virus, N- absolute number of infants with risk indicators

\* Cochran-Armitage Trend Test  $z=0.002$

The qualitative results of the study will be presented next, based on the answers of mothers about the adherence to the Follow-up Program of Hearing and Language Development.

From the 53 mothers interviewed, 15 (32.07%) had difficulties coming to the Follow-up Program. The difficulties reported by them are presented next. The economic factor seems to be a strong component to non-adherence:

*"Sometimes there is no money to come."* (Mother 3).

Transportation is also a difficulty, especially for mothers who depend on courtesy transportation provided by the city.

*"I came with the city bus and had to bring the stroller; it almost didn't fit; what would I do without the stroller?"* (Mother 14).

*"We depend on the city transportation, but sometimes it doesn't come to our house."* (Mother 2)

*The lack of social support and restricted schedule of service were indicated by mothers as obstacles to access the service:*

*"No, only the schedule. Sometimes there's no one to bring the child."* (Mother 5)

*"I do work, and had to be absent from work."* (Mother 9)

*"I had to leave work, but I need to go back,"* (Mother 11)

*Having other children also made it difficult to adhere, when the mother had no one to take care of the children:*

*"I left my other kid at home, it's hard to come".* (Mother 7)

Regarding the reasons that made them return to the Program, some mothers said they were concerned:

*"Because I wanted to check if everything was fine with him."* (Mother 2)

*"To check her hearing. I had toxoplasmosis, and was worried."* (Mother 13)

*"I was worried, but she (the speech-language pathologist) said it is normal. It is just to check it out."* (Mother 23)

Other mothers have reported that only came back because it was scheduled, showing that they did not have a clear understanding of the reasons to come.

*"But the return was scheduled; the doctor (the speech-language pathologist) said there was no problem, but we had to follow-up."* (Mother 34).

There were also reports that point to reasons to participate in the Follow-up Program. One mother referred the need for early intervention, in case the suspicion of deafness is confirmed:

*"The main thing is care. Sometimes there is a problem that we don't know, so the sooner the better." (Mother 32).*

Other mothers mentioned feeling guilty for the child's deafness – in case it was confirmed – due to the use of tobacco or drugs, and some justified themselves:

*"Because I smoked a lot during pregnancy. He already hears well, sees well, laughs... Pretty smart." (Mother 30).*

*"I don't measure efforts. I didn't know I was pregnant and used to do drugs. I'm terrified to know that something might happen to her." (Mother 19).*

## Discussion

This research is part of a project focused on the auditory health of infants who go through neonatal auditory screening and present one or more risk indicators for late onset or progressive hearing loss. This study is a first mapping of a relatively new type of program which, therefore, still has few studies, including the use of different performance strategies in Speech-Language Pathology.

Regarding the presence of infants in the Follow-up Program of Hearing and Language Development, it was noticed a significant increase of mothers' adherence by returning with the child at 4 months, when data from 2011 was compared to the previous years.

One of the reasons for our study to have increased the number of mothers in the Program might be the use of two strategies (phone call + explanative brochure). The brochure was a way of helping mothers to understand the importance to follow up the infants' development due to risk indicators for hearing loss. Researchers<sup>11</sup> have stated that improving the quality of the adherence measurement in both clinical and research contexts are important for several reasons. In the clinical context, the follow-up of adherence is essential to early identify patients under risk of non-adherence,

or the ones who are already presenting difficulties, in order to plan interventions for treatment support, according to each case. Regarding the research context, improving adherence measurement may provide more accurate information on the prevalence of non-adherence, on low adherence predictors, and on the identification of more vulnerable populations to be prioritized in the development of public policies.

According to Reiners (2008), the factors for non-adherence might be related to the health services – location of the service unit, whether it is too far from home – or to the patient – cultural factors, financial difficulties, forgetfulness of the appointment's date, little knowledge about the disease, psychological difficulties on dealing with the situation; geographic data; group age (too young); low education level; single<sup>12</sup>. Forgetfulness of the appointment's date was a frequent factor in this study, since there is a 4-month period between the schedule and the date of the appointment. The phonecalls were made to avoid such factor, helping the mothers to remember the date, since many of them reported having forgotten the return date and actually thanked the researcher for having called.

A research with mothers who were supposed to return for a retest in an auditory screening program<sup>5</sup> emphasized, among the factors that seemed to negatively influence the adherence of dyads: mother's low level of education, mother with only one child, and absence of risk indicators for hearing loss. The factors that might have been omitted from mothers' discourses must also be considered. They frequently believe it is not necessary to complete the hearing evaluation, since the assessment will not present alterations. Hearing loss, for a significant portion of mothers, does not represent a problem that would need concern or investigation by specialized professionals.

In another study, it was noticed that among the reasons for not showing to the recommended returns are: parents' lack of information regarding the causes, symptoms and impact of hearing loss in the child's global development; the common idea among mothers that their children present no risk for hearing loss; and the anxiety of mothers for having their children tested<sup>13</sup>.

Regarding the profile of mothers who returned to the Follow-up Program, it was noticed that they presented quite variable ages, from 14 to 39 years. However, there was a total of 13 mothers (24.52%) between 14 and 19 years old. This data is relevant because studies have indicated low level of education and young age of the mother as relevant factors for non-adherence to healthcare measures. However, this data contrasts with another study<sup>14</sup> that observed that 42.6% of the mothers with less than 26 years of age, and 40.0% of those with 26 years or more, did not come to the return. In the present study, the number of young mothers (total of 13) may be related to the concern regarding the hearing of their first child, and also to the children's grandmothers role, since we registered the presence of 32 grandmothers who accompanied their daughters and grandchildren and reported to be helping and encouraging them to continue the treatment, thus actively participating in the process.

Regarding education, 30 mothers (56.60%) had completed High School or College. This data corroborates two other studies<sup>5,6</sup> that suggested that the no show was more common among mothers with lower level of education, compared to the ones with higher level of education. This evidenced that the lower the number of years of mother's education, the lower the probability of her participation on the return.

As for marital status, 32 mothers (60.37%) were living with a partner. Family participation on the child's treatment is relevant, not only to the psychomotor, cognitive and linguistic development, but also to favor socialization, affective bonding, and prevention of secondary disabilities<sup>15</sup>. Mothers demonstrate to be more secure in the daily care of their children and in complying with orientations to be developed at home when the father or the grandmother of the child is present. In this study, the familiar caregiver emphasized the involvement of partners, siblings and extended family members (uncles, grandparents) in the speech-language intervention process, recognizing them as an essential support so the primary caregiver could take the child to the follow-up appointments. The greatest responsibility, though, lies on one member of the family, almost always the mother.

Regarding the number of children, 25 mothers (47.17%) had no other children; therefore, almost half of the infants who participated were the first child. This may be because the mothers were very

young, which might indicate that primiparous mothers adhere more to the follow-up. The non-adherence of mothers with more children may be related to the difficulty of managing more kids. This data contrasts with another study, which noticed that mothers with only one child presented greater proportion of no show (50.0%) when compared to the mothers who had more children (31.3%)<sup>13</sup>.

Mothers from our study who had no job outside the home were 28 (52.83%). These mothers, many times, have no one to watch the kids and end up not working, performing housework. In a study carried out in the state of São Paulo<sup>16</sup>, Brazil, it was noticed that 34% of mothers who attended a return in a follow-up program had a job, 34% were housewives, and 92.45% of the families had incomes lower than or equal to two minimum wages. The high dropout rate in this study was mainly from the low-income population, for not having economic resources to go to the appointments. However, it was noticed that, even when the variable financial situation was controlled, there was a high number of absences in the proposed schedule, demonstrating that this would not be the main factor to interfere in treatment adherence. The adherence to the treatment by the family and the patient depends on several social, economic, educational, cognitive and interactional aspects<sup>17</sup>.

Regarding the item related to the presence of risk indicators, a research carried out in a maternity hospital from São Paulo<sup>18</sup>, Brazil, found that, from a sample of 589 protocols obtained, 152 (25.8%) presented risk indicators compatible with those defined by the Multiprofessional Committee on Auditory Health (COMUSA)<sup>9</sup>, and that the most prevalent risk indicators observed in the sample were: family history of hearing loss, Apgar score of 0 to 4 in the first minute, use of ototoxic drugs. In 98 protocols (65%), only one risk indicator was found.

This study corroborates the findings of the above authors, showing that the risk indicator with higher prevalence was family history of hearing loss. Other indicators with high incidence were: intrauterine infections (13.55%) and use of ototoxic drugs (13.55%). A research with 798 newborns found that, from the population in shared hospital rooms, 25.6% presented risk factors for hearing loss, and the one most frequently found was the presence of family history for hearing loss (25%)<sup>19</sup>.

In our study, there was a linear trend of increase of risk indicators in general along the



years, especially regarding the Apgar score  $<4$  at 1 minute and the presence of HIV. We do not have an explanation for the increase of Apgar scores  $<4$  at 5 minutes, since this score has been used for a long time as a method to evaluate the newborn's responses after the maneuvers performed with him at birth. We hypothesized that the maternity hospital in which these infants were born serves the population from a certain area in the city of Campinas that attend cases of low-risk pregnancy, but is also a secondary reference maternity hospital for a microregion and a tertiary reference for more complex cases in a population of 5.000.000 people from a macroregion around Campinas, with all its counties. Thus, there are more occurrences of high-risk births and, therefore, a higher chance of complications for both mother and newborn.

Regarding the presence of mothers with HIV+, it is mentioned in the literature that there has been an increase of AIDS cases (condition in which the disease has already expressed) since the beginning of the epidemic, in 1980<sup>20</sup>. Currently, there are still more cases of the disease among men than among women, but this difference has been decreasing throughout the years. This proportional increase in the number of AIDS cases among women can be noticed by the sex ratio (number of cases in men divided by the number of cases in women). In 1989, the sex ratio was about six cases in men to one case in women. In 2011 – last data available –, it was up to 1.7 cases in men to each case in women. The age group where AIDS is more incident, for both genders, is from 25 to 49 years of age. Regarding young people, data indicate that, although they present high knowledge about the prevention of AIDS and other sexually transmitted diseases, there is a trend for HIV increase. The sexual form of transmission is the most prevalent among people with more than 13 years of age. In women, 86.8% of the cases registered in 2012 came from heterosexual relationships with people infected by HIV<sup>20</sup>.

Regarding the mothers' report about the adherence to the Program, it was noticed that the logistics of transportation with the baby to come to the service, the lack of economic resources, the assessments' schedule, the need to be absent from work, and the presence of other children are reported reasons that hinder the systematic participation in the Follow-up Program. A previous study on the adherence to a follow-up program<sup>21</sup> demonstrated that, initially, the reasons for the follow-up are not

clear to parents, and the first assessment is expected with concern because they fear the possibility of negative results. In the development of follow-up programs it is expected that parents are clarified, welcomed and followed during the entire process, since they tend to experience anxieties and concerns. The study mentioned above recommends that information about the assessments must be clear and detailed, which may help to minimize the concerns. Besides, a provision of funds must be forecasted to families of poor segments of the society, in order to ensure the presence in the assessments. Another aspect observed in the study is that the work must be developed by a multidisciplinary team, creating opportunities to value the attitudes of parents regarding the child's health and so the parents can realize that their involvement makes the difference in the child's developmental process.

On the other hand, some mothers from our study showed to be aware of the importance of their role in the treatment and the consequent evolution of the child. Others demonstrated doubts or did not show awareness of the meaning of their participation. Mothers who adhered to the Follow-up Program of Hearing and Language Development said it was important to follow up the child. It was also noticed that information and clarifications of the mother about the disease have influenced the process of adherence. The role of mothers is essential to the child's evolution regarding hearing and language, and to bring the children to the service<sup>22</sup>. Mothers' reports also guide the work in orientation and evolution. Finally, there is a constant exchange between mothers/families and professionals involved in the process of care, noticed in the study.

## Conclusion

This study showed that adherence to the Follow-up Program of Hearing and Language Development increased with the strategies used, that is, phone calls two days before the return date and delivery of explanatory brochures.

The mothers who returned to the Program and were willing to participate on the interviews were those who lived with a partner, were young, residents of the city where the study was carried out, completed High School, had no job outside the house, and income of up to two minimum wages.

The answers from the mothers revealed their interest in participating on the program, following

the orientations provided by the professionals. The expectations of mothers concerning the possible diagnosis of hearing loss have influenced the adherence to the Follow-up Program. The difficulties in participating, on the other hand, were related to social conditions: lack of economic resources, schedule of assessments, difficulties with being absent from work, and the care with other children.

In addition to the strategies used, the listening and welcoming of the mothers by the speech-language pathologists and audiologists possibly contributed to the process of adherence to the follow-up. Thus, other studies should be developed to investigate such aspects. It is necessary that health professionals work together with the family, supporting, clarifying, creating a space for listening, and motivating them to actively participate on the process.

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