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Communication between deaf people who had early diagnosis and late diagnosis and their pairs

A comunicação entre sujeitos surdos com diagnóstico precoce e com diagnóstico tardio e seus pares

Lá comunicación entre sujetos sordos con diagnóstico precoz y con diagnóstico tardío y sus pares

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Abstract

Hearing loss diagnosis must occur in the first six months in a child's life. As soon as the child's hearing is evaluated, in case of a hearing disability, medical and educational interventions can be initiated. Late diagnosis can promote late language development and, in many times, misunderstandings between hearing parents and the deaf child. The goal of this study was to observe two groups of deaf children and teenagers who started rehabilitation earlier and later, with regard to the use of oral and sign language and to verify how the communication with their relatives has been occurring. It is a qualitative study. The collection of data occurred through semi-structured interviews with the mothers of the deaf children and teenagers and observations of the interactions between mothers and children. We observed that some factors hinder the deafness diagnosis and the beginning of auditory rehabilitation, such as fast access to adequate resources and professional posture, because the parents have better diagnosis assimilation when the professional shelters them and uses accessible language. It was also found that children who started rehabilitation earlier demonstrated a more effective communication with their mothers, but it is difficult for mothers to acquire LIBRAS, because learning a new language requires time, practice and

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NCR, MCMPL and IRS: Involved in all stages of the study, which includes data collection; tabulation of the results; analysis and writing of the text.

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dedication. Multiple factors determine the language development of the deaf. We concluded that it is important to diagnose hearing loss early, as this diagnosis will guide the processes of habilitation and rehabilitation of the deaf child.

Keywords: Early Diagnosis; Delayed Diagnosis; Deafness; Sign Language

Resumo

O diagnóstico de surdez deve ocorrer nos primeiros seis meses de vida de uma criança. Quanto mais cedo é avaliada a audição, nos casos de algum grau de comprometimento auditivo, mais cedo poderão ser iniciadas as intervenções médicas e educacionais. O diagnóstico tardio pode acarretar em atraso no desenvolvimento da linguagem oral e, muitas vezes, falta de entendimento entre pais ouvintes e filho surdo. Os objetivos do presente estudo foram observar dois grupos de crianças e adolescentes surdos que iniciaram a reabilitação precocemente e tardiamente, no que diz respeito ao uso da linguagem oral e língua de sinais e verificar como vem ocorrendo a comunicação dos sujeitos com seus familiares. Trata-se de um estudo qualitativo. Foram realizadas entrevistas semiestruturadas com as mães dos surdos e observações da interação das díades mãe ouvinte e criança ou adolescente surdo. Verificou-se que alguns fatores dificultaram o processo do diagnóstico de surdez e o início da reabilitação auditiva, tais como acesso rápido aos recursos adequados e postura profissional, pois os pais têm uma melhor assimilação do diagnóstico quando o profissional os acolhe e utiliza linguagem acessível. Observou-se também que as crianças que iniciaram a reabilitação precocemente demonstraram comunicação mais efetiva com suas mães, mas há dificuldade por parte das mães em adquirirem a LIBRAS, tendo em vista que o aprendizado de uma nova língua demanda tempo, prática e dedicação. Conclui-se sobre a importância em diagnosticar a perda auditiva precocemente, pois este diagnóstico norteará os processos de habilitação e reabilitação da criança surda.

Palavras-chave: Diagnóstico precoce; Diagnóstico tardio; Surdez; Linguagem; Linguagem de Sinais.

Resumen

El diagnóstico de la sordera debe ocurrir en los primeros seis meses de vida del niño. Cuanto más temprano es evaluada la audición, caso esta venga a presentar algún grado de comprometimiento auditivo, más temprano podrán ser iniciadas las intervenciones médicas y educacionales. El diagnóstico tardío puede llevar a retraso en el desarrollo del lenguaje oral y muchas veces a falta de comprensión entre padres oyentes e hijo sordo. Los objetivos de este estudio fueron observar dos grupos de niños y adolescentes sordos que han comenzado rehabilitación muy temprano y tardíamente, con relación al uso del lenguaje oral y lengua de señas y verificar como está la comunicación de los sujetos con sus familiares. Se trata de un estudio cualitativo. La recopilación de los datos se dio por entrevistas semiestructuradas con las madres de los sordos y observaciones de la interacción de los pares madres oyentes y niño o adolescente sordos. Se verificó que algunos factores dificultaron el proceso de diagnóstico de la sordera y el inicio de la rehabilitación auditiva, tales como acceso rápido a los recursos adecuados y postura profesional, dado que los padres tienen una mejor asimilación del diagnóstico cuando el profesional los acoge y usa lenguaje accesible. Se observo también que los niños que iniciaron la rehabilitación precozmente mostraron comunicación más efectiva con sus madres, pero hay dificultad por parte de las madres en adquirir la LIBRAS, teniendo en vista que el aprendizaje de una nueva lengua demanda tiempo, práctica y dedicación. Se concluye sobre la importancia en diagnosticar la pérdida auditiva precozmente, pues este diagnóstico orientará los procesos de habilitación y rehabilitación del niño sordo.

Palabras claves: Diagnóstico Precoz; Diagnóstico Tardío; Sordera; Lenguaje; Lenguaje de Signos.

Introduction

It is from the access to the hearing experience that an individual gets in touch with the structures of language learning[1]. According to Vygotsky (1993)[2], language provides the forms and concepts of the reality organization, which mediate between subject and object. Language constitutes the subject and the whole communication process will be affected if there is anything that makes the subject unable to understand the language, such as the deafness.

Studies show that until the beginning of 2000, the diagnosis of deafness was often late due to the time lost between the suspicion of the family and the diagnosis, whether due to the fear of the family regarding the confirmation of the hearing loss, or due to the difficulty of access to healthcare services[3]. However, in the same decade, the Joint Committee on Infant Hearing [JCIH][4] recommended the detection of congenital hearing loss up to three months of age and the beginning of rehabilitation up to six months of age, as this age represents a period conducive to the development of language skills, thus evidencing when a significant progress is achieved[5]. Thus, many Neonatal Hearing Screening programs were implemented aiming to diagnose the child up to 3 months of age and to initiate rehabilitation up to 6 months of age.

In case of a diagnosis of hearing loss, the family must be oriented to seek rehabilitation services and informed on the existing educational resources in the community in which they live. In the history of deaf education, there are different approaches that can be followed in order to establish the communication. According to the literature[6,7], three approaches were widespread: the oralism, total communication and bilingualism. Bilingualism has as a principle that deaf individuals use sign language as a first language, and their native language as second language. In this approach, the vocalization is not mandatory, but an option[7]. Currently, bilingualism is the most accepted educational approach, although all three coexist[6].

In addition to the importance of the early diagnosis of deafness, and regardless of the approach chosen, it is critical that the family has the necessary support of the professionals involved, be oriented about the development of language, and on the developments and limitations that the child may reach[8]. When bilingual approach is chosen, the family members should clearly understand the times when it is necessary to interpret the world through sign language and the times in which the oral language should be used, in order to encourage their child to have a second language. The speech-language therapy in bilingual approach should be based on the early diagnosis and also on the indication and fitting of hearing aids. In this way, it enables a greater access of deaf people to auditory and visual meanings, as well as to gestures, facial expressions and perception of phonemes. However, these interpretations are achieved by the Brazilian Sign language (BSL), which uses the vocalization as a second language[9].

The BSL must be inserted into the life of the deaf as soon as possible. Although it differs from oral language, as in any other language, it presents a high degree of complexity. The deaf child should be in contact with deaf signers in order to spontaneously learn the sign language, thus becoming able to express their ideas and feelings[10,11].

Therefore, from these statements, it may be understood that the sooner the subject receives the diagnosis of deafness, the sooner their parents will be able to search for a professional help in order to receive guidance, including on the importance of the cognitive and social development of the deaf child in a bilingual approach. Thus, this study aimed to observe two groups of deaf children and adolescents, who started early and later rehabilitation, with regard to the use of sign language and oral language, and to analyze their communication with their families.

Method

This is a qualitative, observational and cross-sectional study. It was approved by the Research Ethics Committee (CEP) at the Universidade de Campinas, under no. 83872/2012. The qualitative research reflects the relations and phenomena that permeate the research, in addition to work with motivations, values and attitudes of the participant.[12] In a cross-sectional study, the researcher collects data in a single moment, conducting a momentary clipping of the phenomenon under investigation.[13]

All deaf subjects of a program called Education and Deafness were invited to participate in the study. In addition to the participation in the program, which is provided in a rehabilitation center connected to the Speech-Language Pathology

and Audiology Course of a public university in São Paulo state, participants should comply with the following inclusion criteria: Participation in the Education and Deafness program, age range between 11-15 years old, have a moderate to serious hearing loss, parents or caregivers should be with their child in the care and should have signed the Free and Informed Consent Form (FICF). Participants aged below 11 years, with mild hearing loss and those who had other issues, such as low vision or neurological changes, were excluded from the study.

According to the above criteria, six participants were selected for the research, of which: 3 children under 11 years old and 3 adolescents ranging between 13-15 years (classified as such according to the Brazilian Child and Adolescent Statute)[14] and their respective mothers. The birth years of the participants ranged between 1997 and 2001, but it is worth noting that there was no Neonatal Auditory Screening program at the time, which was established by Federal Law no. 12,303, in 2010.

Subjects were divided into two groups: Group 1 for those with early diagnosis of deafness and that started their treatment with up to 2 years old; and 2 Group for those who had a late diagnosis of deafness, that is, after 2 years old and started their treatment after 5 years old.

The information about the participants (deaf individuals and their mothers) provided by this research were obtained through the survey of medical records. Some information has been supplemented with the interviews conducted with the mothers. The names of the children and adolescents and their mothers are all fictitious.

The study aimed to learn more about the language acquisition process in deaf children with early and late diagnosis, from semi-directed interviews with their respective parents and observations of interaction with the mothers, as listeners, and their deaf children or adolescents.

The semi-direct interview included topics such as: age at which the child received the diagnosis of deafness and started a rehabilitation Program; how is the communication of children and adolescents at home and with other family members; and if there was a vocational guidance for the choice of the approach. The interviews were recorded on audio file and were later transcribed.

Then, the interviews were analyzed according to criteria of repetition and relevance. The criterion of repetition emphasizes the aspects in common that appear in the reports of the subjects, whereas the criterion of relevance aims to emphasize any aspect, without necessarily repeating. The application of the criterion of relevance "consists of a speech that is rich in content to confirm or refute the initial hypothesis of the research".[15]

Data were described in results, with especial attention to the age at which the child received the diagnosis of deafness and started the Rehabilitation Program, as well as the forms of communication used in the family context.

The observations of the mother/child and mother/adolescent dyads were performed in order to investigate how the communication is established between them and which language resources they used in the interaction. The records included video records and real-time observations, on which relevant data were noted, which allowed a greater deepening in data collection[16]. The recording was used to capture sounds and images that contributed to reduce factors that may interfere with the reliability of the data collection.

In the observations of the mother/child and mother/adolescent dyads, some playful activities were proposed, such as "The Game of Life" and magazine reading, and sometimes the two options were presented and the dyad could choose the activity, while others had only one option due to the age range of the child. Prior to the observation, some criteria were established to guide the researcher, such as: interaction between the mother and the child; type of communication used between them; effectiveness in communication; mother's response to the child's expectations in the child's conversation and response to the mother's expectations.

Some transcription conventions were used in this study for a better understanding of text excerpts in the results item, as described below:

- BSL (in the translation to Portuguese): **lowercase letters in bold**.
- BSL simultaneous to Portuguese (with or without sound): ***lowercase letters in bold and italics.***
- D-A-C-T-Y-L-O-L-O-G-Y: uppercase letters separated by hyphen.
- Portuguese: *lowercase letters in italics.*
- (Explanatory comments made by authors): lowercase letters in parentheses.

Results

Table 1 details the characterization of children and adolescents of this research.

[Insert Chart #1]

With respect to the characterization of these mothers, they had an average of 38 years old,

Chart 1. Characteristics of deaf children or adolescents.

NÚMERO	Fictitious name / Age	Child's age at diagnosis	Deaf sibling(s)	Degree of hearing loss and affected side	Child's age at the start of the rehabilitation	Main communication mode of the child	Education level
1	Viviane 11 years old	At birth	No	Deep Bilateral HI	4 months old	BSL	5th grade
2	Marcelo 11 years old	1 year and 7 months old	No	Severe Bilateral HI	9 years old	BSL	5th grade
3	Kátia 15 years old	1 year and 8 months old	No	HI Deep Bilateral	2 years old	BSL	1st Year in HS
4	Juliano 11 years old	2 days old	Yes – Júlia	HI Deep Bilateral	2 years and 1 month old	BSL	5th grade
5	Graziela 13 years old	5 years old	Yes - Rebeca	HI Moderated Bilateral	6 years old	Oral Portuguese and BSL	5th grade
6	Rebeca 13 years old	5 years old	Yes - Graziela	Severe HI in RE and Deep HI in LE	6 years old	BSL	5th grade

Legend: HI: Hearing Impairment; BSL - Brazilian Sign Language; HS - High School; RE - Right Ear; LE - Left Ear

most had completed primary school. Regarding their occupation, they were "housewives" or had an informal job. Some mothers, such as Juliano's mother and Graziela and Rebeca's mother had three more children, while the mothers of Marcelo, Kátia and Viviane had another child, in addition to the deaf child or adolescent. Three participants of the research had deaf siblings: Juliano, Rebeca and Graziela.

Interviews were conducted with mothers because they were accompanying their children in the care and they participate in some activities, such as the BSL course offered by the Program. In addition, in most cases, the mothers had a greater involvement in the deaf child rehabilitation process.

The mothers were asked about the time when they received the diagnosis of deafness of their children and the need to start the rehabilitation process. Here are some answers:

Interview with Rebeca and Graziela's mother

Interviewer (I): When were they diagnosed with deafness?

Mother (M): [...] I started to realize when [...] They were 3 years old.

I: And who told you that they were deaf?

M: Well, they were small and they didn't speak yet, they didn't. Back there, I lived in Minas Gerais, but we don't have this treatment there. Then I went to UNICAMP and we went to the pediatrician who referred me to the otolaryngologist, so the otolaryngologist did conducted the test that confirmed the diagnosis of deafness. [...]

I: How old were they when they moved to here? 3? [...]

M: Yes... [At this time the mother reflects for a moment and replies, but not so sure] with four years old they started, it took a while.

I: Ok, so this was the first place where they were treated?
M: Yes, it was the first place.

In the text excerpt above, it was possible to check the process of discovery of the deafness, due mostly to the lack of resources available in the city of origin of deaf children and also due to the little access of the family to information about deafness. The mother of Rebeca and Graziela stated to the researcher that her children started to treat their condition when they were four years old. However, according to the medical records of the institution, they started in the program only when they were six years old.

Interview with Marcelo's mother

Interviewer (I): When he was diagnosed with deafness?
Mother (M): He was 1 year and 7 months old.
[...]
M: He was treated for 3 to 4 years with Speech--Language Pathology [from another institution] and they just kept asking him to talk, to talk anyway... But he couldn't! He wasn't showing any development in the school, he wasn't feeling upheld by society, so I decided to try to bring him here. [...], then, it's been two years since we are here [when he was 9 years old].

According to data provided above, the family did not present any issue with respect to receiving the diagnosis of deafness, the child was diagnosed before he was two years old. However, the family had doubts in choosing the therapeutic approach and concerning the start in a rehabilitation program, which should favor the language, social and educational development. In this case, the mother reported that her son was better adapted to the bilingualism approach. And it occurred when he was nine years old.

Interview with Viviane's mother

I: When she was diagnosed with deafness?
M: As soon as she was born.
I: So she was really tiny when she came here for the first time [in the Rehabilitation Program]...
M: Yes, my daughter was 12 days old when we arrived here.

The deafness of Viviane was diagnosed at birth, so the mother was advised to seek the rehabilitation program immediately. In this case, the time from diagnosis to intervention was not a factor hampering the development of the child; on the contrary, it was facilitated.

The attitude of the professionals involved is another important aspect that facilitates the diagnosis and the start of early hearing rehabilitation. She was asked about this at the time of diagnosis. The following is an answer of the mother:

Interview with Juliano's mother

Mother (M): [...] I remember well that the physician was very affectionate, she was not rude [...] she spoke slowly so I was able to understand what she was talking about, It was not like "Hey, your son is deaf and that's it [...]".
Interviewer (E): However, at that moment [...] the physician [...] told you that he was deaf and everything else, ok, but has she provided any guidance?
M: No.
I: So you just went home without any guidance?
M: Any guidance at all.

In the excerpt presented, it was possible to notice that the mother felt welcomed by the doctor responsible for the diagnosis. Despite not being provided with important guidance at this point, the words and the care used by the professional to inform that Juliano was deaf called her attention. In addition, the mother reports that she understood well the language used by the physician, and it probably facilitated the understanding of the diagnosis by the family.

Information was also obtained from the interviews on how communication was at home and with other family members. All the interviews showed that few people in the family know the BSL. In some cases, only the mother knows it, while in others only the siblings, but just in a few cases the father knew the BSL. Most of the time, the mother acted as interpreter between the child and the family.

Interview with Viviane's mother

M: It always been using the BSL, but now she is trying to talk, so I talk to. [...] People of my family also talk with her. Sometimes she gets it, and sometimes she asks me "what?" and "why?".

Interview with Juliano's mother

M: You know, we communicate using BSL, so everything he (Juliano) wants to know, I use the BSL, he uses it as well. [...] no [not everyone in the

family knows BSL], the one who understands the most is Julia [deaf sister, older], she understands it more than I do. I understand a little, his brother [listener] understands even less than I do and his father understands even less than his brother, but that does not prevent them from communicating, they communicate with each other all the time. [...] He uses the expression quite a lot, so I think he realizes that they understand better with the expression, sometimes the sign is not everything.

In this specific case, in which both siblings are deaf, the family felt less need to learn the Sign Language, since the deaf child who is able to vocalize is the interpreter of the one who isn't, as was shown by Juliano's mother in the above excerpt.

We can notice another family setting in the excerpt below. The father of the child (Marcelo's father) does not know the BSL. Actually, he knows some signs, although he is not fluent.

Interview with Marcelo's mother

I: So, [you said that] he uses a little of everything in language, right? A little bit of speech, a little bit of signs. He usually understands more when using the sign language?

M*:* The thing is that, generally, it is "know signal", so my husband asks him to get water or coffee, or my husband asks him to shut down the computer. [...] He understands these signs that my husband knows.

In other cases, the father began to use the BSL after the mother, as he initially was against other approaches than the vocalization. In the text excerpt below, Kátia's mother illustrates this situation:

Interview with Kátia's mother

M: At first, my husband was against the sign language, as he thought she was going to talk anyway [...] Just because he had seen a deaf speaking normally on TV [...] So, at first, he was against it, then he realized that he was wrong, the BSL is a help tool. Then currently, he uses the BSL.. I mean, he still talks more [...] but he uses it too.

In the cases of the above families, there is a linguistic variety (father using expressions, BSL, but no fluency) vocalized deaf child, deaf child and mother using sign languages. According to some authors, it is possible to notice the existence of a multilingualism[17,18] in these situations, with the presence not only of formal languages (oral and sign languages), but also a presence of a variation of both, which are efficient in these contexts, or allow communication between two people.

Chart 2. Type of communication used by the mother-child dyads during observations.

Child and mother	BSL	Oral language	Act of pointing
Viviane and her mother	X (Mother and daughter)	X (mother)	X (Mother and daughter)
Marcelo and his mother	X (mother)	X (mother)	X (Mother and son)
Kátia and her mother	X (Mother and daughter)	X (Mother and daughter)	X (Mother and daughter)
Juliano and his mother	X (Mother and son)	X (mother)	X (Mother and son)
Graziela and her mother	X (mother)	X (mother and daughter)	X (Mother and daughter)
Rebeca and her mother	X (daughter)	--	X (Mother and daughter)

Legend: X - presence of communication between the dyad. BSL - Brazilian Sign Language.

Results related to the observation of dyads:

With respect to the observations of the mother listener/deaf child or mother/adolescent dyads, the table below shows the types of communication used by them.

[Insert Chart #2]

Regarding the type of communication, all dyads used BSL, oral language and the act of pointing; however, in a more detailed analysis, it was possible to observe that there were significant differences between them, which will be described below. The following is each dyad with its established type of communication and the effectiveness of the communication:

Kátia and her mother

During the observation, both used sign language and vocalized as a form of communication. Kátia and her mother understood each other, they even used fingerspelling, that is, the manual alphabet, when they didn't know any sign, thus demonstrating an effective communication. The following excerpt illustrates the observation of dyad playing "The Game of Life":

> Kátia (reading to her mother): ***If you want life insurance, you should pay 10 thousand.***
> Mother nods and daughter gives money to her.
> Mother: ***Again.***
> Kátia spins the roulette and says: **10**.
> Then, she looks at her mother, her mother makes a facial expression and nods.
> Mother: **Now, read what is written on it.**
> Kátia: **Business**. B-U-S-I-N-E-S-S. **Needs** *advertising.* **A-D-V-E-R-T-IS-I-N-G**.
> Mother: Advertising.
> Kátia: **That's right. Pay 60 thousand**
> Mother: **60 thousand... To you.**
> Then, the mother gives the money to K.

It can be noticed in the communication of the mother with her deaf daughter how many resources are used in addition to the BSL and the speech (Oral Portuguese), for a better understanding of each other. During the game, mother and daughter construct a dialogue in which the rules can be understood and followed, so that the game can be effectively played. Communication is carefully constructed by both of them, and it even includes other communicative resources for better mutual understanding, such as dactylology, speech, lip reading, pointing and mimicking.

Juliano and his mother

The analysis of the episodes allowed noticing that Juliano and his mother used oral language, Sign Language and the act of pointing. The boy used the BSL, pointed and vocalized (unintelligible emissions). While the mother used the BSL, pointed and vocalized almost all the time. Although Juliano had started just a few discursive topics, he responded to the mother's expectations in the speech, such as in the following excerpt in which the mother asked what the sign to "fix" was and Juliano replied:

At Juliano's turn to play, the mother reads what is written in the little house and explains to her son.

> Mother (looking at Juliano): ***The pipe...the water pipe just... puufff,*** **we need to call that man who can fix it**... *Fix? Fix?* [Then the mother asks the sign of "fix" to her son].
> Juliano: **Fix.**
> Mother: ***Fix***. ***Is that correct?***
> Juliano nods.

An important detail for the above dialogue is that listening parents often learn the BSL to dialogue with their deaf children; however, generally, they are not fluent and they learn signals from (and with) their own children.

Viviane and her mother

The communication was present throughout the observation, whether through the BSL or through looking and oral language. It was possible to notice how both established an effective communication, that is, when one did not understand the other, the other struggled to be understood, by changing the way they explained, pointing, or using another sign. This proved to be effective in the communication. In the following example, Viviane and her mother were reading riddles "Can you guess what is...?" So that the other would guess:

> Mother: **Can you guess what is... blue... dot... grass**?
> Viviane: **Water**?
> Mother: ***No***.
> Mother: ***It's a little ant. It's a little ant wearing jeans***.
> [silence]

The mother replied, but she seemed unsatisfied, as if she realized that the daughter did not understand. Then the mother gets up from her chair and shows her jeans, complementing with the signs for "Pants" and "blue dot". The daughter looks astonished, and asks: **On the grass**?

> Mother: **That's right, did you understand**?
> Viviane: **Yes. Now it's my turn to ask**.

It is not sure if the understanding was effective in the above case, since the child didn't find it funny. However, the mother struggled to explain the blue dot on the grass. It should be taken into account that the absence of humor in a joke told by a listener can be associated to the shortcomings and limitations in the signaling, that is, it represents the difficulty and the lack of fluency in the sign languages by the listeners.[19]

Rebeca and her mother

Rebeca barely communicated with her mother, when she wanted to say something, she made some sign or just pointed at it. Graziela, Rebeca's twin sister, took the role as interpreter during the observation. When the mother communicated with Rebeca, most of the time she vocalized, but her daughter did not understand. They looked at each other, and used facial expressions and random signs. The communication established between Rosimeire (mother) and Rebeca (deaf daughter who is not vocalized) was not very effective during the observation. Along with the observation of the communication between Graziela and her mother, there are some examples below of Rebeca's interaction with her mother and with her twin sister.

Graziela and her mother

Graziela and her mother communicated to each other mainly through oral language. Graziela explained how to play the game. The mother listened to her daughter and even questioned her, so Graziela replied. This proved to be effective in communication, as the daughter met her mother's expectations during the speech and the mother met her daughter's expectations.

In the following excerpt, as proposed by the observer, Rosimeire and the twin daughters were looking at a magazine and there is a data related to the little interaction of the mother with the daughters and to the evident role of interpreter that Graziela takes before the mother and the sister Rebeca.

The mother flips through at all the pages and doesn't say a word, so she hands the magazine to her daughters and says in a low voice: *Do you want to see it?*

Rebeca looks at the images of the magazine, then she points to a laptop and says: **I like it, I want one of these.** (Looks at her mother and smiles) **But you don't like it, do you?!** (Rebeca smiles, while her mother expresses no reaction).

Rebeca continues to flip through the magazine and another figure draws her attention, so she points to a picture of a girl balancing on a wire, as if she was walking to a distant place. Rebeca tells to her sister: **She walks on a wire.**

> Graziela: **She can go to her boyfriend's house by walking the wire**.

Still flipping through the magazine, Rebeca looks at a page with pictures of vegetables. At this point, Rebeca points to her mother and tells to her sister: **She prepares it for us to eat.**

The mother only notes, apparently not understanding what the daughters are saying, so Graziela laughs and says to the mother: *You make food, right*?

> Mother: *Yes, I do and I like it.*

Marcelo and his mother

The main means of communication has been the BSL, before it the mother used to vocalize and also used home signs. During the observation, the boy did not say anything; sometimes he looked towards his mother and pointed. The mother vocalized almost all the time, sometimes she used the BSL and at other times she simply read what should be done and even did it for her son, without saying anything, without even explaining it. This leads to poor communication effectiveness. As mentioned by an author[20], the deaf person's interaction with listeners occurs through several resources such as speech, lip reading, natural gestures, some signs of the BSL, and even pantomime and dramatization. Both the BSL and the oral language form a product of social interactions that in this specific case, not even the use of home signs is enough to set an effective communication, as shown in the following

excerpt in which Marcelo and his mother were playing " The Game of Life":

> Mother (reads what is on the board): ***You found the old treasure*** *on the backyard*. **24 thousand**.
> Then the mother looks at the bank of the game, and gets the 24 thousand that she needed. Marcelo watches it, but he doesn't say anything, so it is not possible to know if he understood what his mother just did.
> Mother: *Ok, go* (and points to the roulette to indicate to Marcelo that it is his turn to play).
> Marcelo spins the roulette.
> Mother: **four**.
> Marcelo moves forward four spaces, then her mother takes the pawn of his hand, checks the four spaces and reads.
> Mother (reading): **Business**. *Needs* (then the mother looks at the observer and asks for the sign of "advertising". The observer does not provide the answer, and the mother does not explain what is written to the child) **Pay 40 thousand**.
> The mother points out the correct bills for Marcelo to take, without explaining the reason, then she spins the roulette and laughs, while Marcelo does not show reactions, as he just observes his mother. [...]
> Marcelo spins the roulette and gets a six.
> Mother: **Six**.
> Marcelo moves forward six spaces and looks for his mother, waiting for some help.
> Mother: ***You bought an apartment, now pay 40 thousand***.

Marcelo pays attention to the signs, then looks at the fake money, but he waits until the mother points out which bills he should pick up.

Discussion

This study aimed to monitor two groups of deaf children and adolescents, who started early and later rehabilitation, with regard to the use of sign language and oral language, and to analyze their communication with their families. The limitations of the study are the reduced number of participants and the fact that the data were based on the mothers' perception of the development of their children, without a specific evaluation of this process, from diagnosis to rehabilitation.

Three participants in the study had an early diagnosis and start of the intervention, while the three others had a late diagnosis and start of the intervention. The posture of the professional is a key aspect for early initiation of rehabilitation after diagnosis of deafness. When asked about the guidance and follow-up provided at the time of diagnosis, the mothers reported significant emotional aspects, as it can be noticed in Juliano's mother's report that although the health professional did not provide any effective guidance, the attention provided by the professional enabled the mother to assimilate the deafness and to seek the services required for rehabilitation. In the report of the Graziela and Rebeca's mother, it is possible to notice the professional and resource shortage and the journey of the mother to get the diagnosis of deafness and the appropriate follow-up. She had already noticed that the daughters couldn't listen and as so, she sought help in another city, as there were no means to diagnose deafness where they lived. There are citations in the literature mentioning that the healthcare professionals involved can provide significant contribution to parents if, at the time of diagnosis and in the form of communicating about the deafness, they take into account their social, cultural and emotional conditions[21,22]. At this time, the attention of healthcare professionals is important to enable early diagnosis and support for parents as well as the appropriate referral and follow-up for deaf patients. A study focused on this topic associated the posture of the professional, based on information, support, guidance and understanding to the emotional adjustment of the mothers at the time of diagnosis. The mothers to whom the intervention of the team was provided presented better elaboration of the situation and also less negative feelings[23].

There is little research on the father's perception on his own involvement, feelings, and importance in the development of the child. Most of the time, studies are carried out based on reports provided by the mothers[24,25]. However, a survey with fathers of deaf children pointed to a variety of feelings and reactions experienced by them, such as shock, guilt, nonconformity, which are often accompanied by a lack of knowledge about deafness. Immobility, impotence, fragility and sadness also were reported by parents, as well as the lack of internal resources to deal with the requirements of the new situation. Time and coexistence proved to be important in the re-signification of deafness and acceptance of the child[24]. This study verified the remarkable presence of the mothers in the life of the deaf child. Most of the time, they stayed at

home to take care of their children, and they also took them to the doctor and to the school Therefore, these mothers were who took their deaf children to the Deafness and Education Program. While they waited for the therapies of their deaf child, they had a BSL course, and that's why the mothers learned the sign language in a faster and wider way than the fathers. According to data of this study, it was possible to notice that the father of Marcelo knew only some specific signs of the BSL, and his communication with his son was restricted to these signals, therefore, resulting in little communicative effectiveness; While for Kátia, her father began to learn the BSL after a few years, as initially he did not accept the bilingual approach and her mother was the main interpreter of the dialogue between father and daughter. Then, the father later realized the importance of the Sign Language and started to communicate with Kátia.

There was one particular case, regarding Marcelo, in which the child began the rehabilitation in the oralism approach, and then the parents chose for the bilingualism approach. And two other cases, regarding Kátia and Juliano, who had been on bilingual therapy since their diagnosis, but their parents refused to learn the BSL, because they believed that the child could vocalize. The bilingual approach, which indicates the BSL as the first language of the deaf person, allows a development of language and constitution of the subject; however, the bilingualism also determines that the Portuguese language should be taught to the deaf person as a second language, as the acquisition of a first language does not prevent the acquisition of a second one[9]. This study does not disregard the importance of the two forms of communication (BSL and oral language), as both should be exposed to the child, showing their differences and particularities, without one form canceling the other; however, the importance of parental access to this information is highlighted.

During the research, the use of "home signs" among deaf children and their mothers was observed as an important way to establish the family communication. There are some studies on this subject that refer to the use of home signs as a valid communicative alternative that does not need to be discarded and that it occurs mainly between hearing parents and deaf children due to their communication needs[26]. In this study, it was possible to notice that some mothers, especially with children who had a late diagnosis of deafness, reported the use of home signs to communicate with deaf children at home. In these situations, families make use of various resources, such as speech, lip reading, idiosyncratic gestures, gestures of pointing, mimicry and even the standard language signs that they already know. According to the observations of the dyads on this study, the home signs were often used and they allowed communicating; however, in some situations in the observation of children who obtained a late diagnosis, the great difficulty of the mothers to teach their children, to explain rules and to make them understand abstract concepts was evidenced. On the other hand, the mothers of the subjects who received an early diagnosis and were instructed to use BSL early on, showed less difficulties to communicate with the child, to explain the rules, to tell them something that they read in a magazine and even to explain concepts.

As noted, subjects who had an early diagnosis of deafness (in the first year of life) and who start early their rehabilitation program, that is, up to two years of age (Kátia, Viviane and Juliano) showed better development in communication, presenting spontaneous and natural use of Sign Language, communicating more effectively with their hearing relatives, responding to the mother's expectations during speech. On the other hand, subjects who had a late diagnosis of deafness (Rebeca and Graziela), or who had an early diagnosis, but late start (after 5 years) of rehabilitation program, presented greater difficulty in communicating with their mother during the observations, such as Marcelo who did not present a discursive initiative with his mother, and not even an effective communication. It should be considered that there is difficulty on the part of the mothers in learning the BSL, since the learning of a new language requires time, practice and dedication. The continuity of the studies is essential for the language fluency and, as so, the earlier the deafness of the child is detected and the therapeutic approach is chosen, the sooner the mother and other relatives can start to learn the Sign Language[27,28]. A study of two twin siblings, one being a listener and the other being deaf, showed that there are many variables related to the communication development in the family environment, such as the exchange of glances, facial expressions and the exchange of attention, and all of these aspects impact the potential of the deaf child to learn a language. When the family makes use of such communicative resources, they

are favoring the communication between adult listeners and deaf children[29].

Therefore, the importance of the early diagnosis of a hearing loss can be noticed, as this diagnosis will guide the habilitation and rehabilitation processes of the deaf child. If hearing loss is identified early, in addition to enabling a further development of the language potential, the behaviors to be adopted will be more efficient.

Conclusion

The results of this research allow us to conclude that the subjects who received an early diagnosis of deafness and started early rehabilitation demonstrated a greater effectiveness in the communication, presenting spontaneous use of the Sign Language. The mothers of individuals who received a late diagnosis and who started late rehabilitation reported greater difficulties in educating and teaching young children, often using home signs that are effective within the family context. However, the use of home signs brings out the limited communication of these children only within their families.

It can also be concluded that at the time of diagnosis, professional support and guidance are of the utmost importance in order to direct parents to seek rehabilitation and family counseling programs as soon as possible.

In the family contexts of this study, the mothers were the family member who learned the BSL and communicated more with their deaf children, but they faced difficulties, as it is a second language. Thus, it was possible to notice the mothers using various communication resources at several moments.

Finally, it is worth noting that there are many factors that trigger a good language development in deaf subjects, but the early diagnosis of hearing loss can be regarded as essential and as a starting point for a great advance.

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