Deafness: from suspicion to referral for intervention

Surdez: da suspeita ao encaminhamento

Sordera: de la sospecha al encaminamiento

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ABSTRACT

RESUMO

Objective: To investigate the experiences of mothers concerning the suspicion of deafness, the diagnosis and the referral to rehabilitation, as well as their perception about how the diagnosis was presented and explained.

Methods: Qualitative study with ten hearing mothers of deaf children who attended specialized treatment at São Paulo State, Brazil, for at least two years. A semi-structured interview with the mothers was performed and data were analyzed by examining of participants speeches, seeking to understand the meaning that mothers attributed to their own words.

Results: Although the diagnosis of six children was done before 12 months of age and considering mothers' multiple feelings on facing the deafness of their children, earlier diagnosis would have been possible if maternal observations have been given adequate value. Health professionals showed some difficulties in "listening" mothers' doubts, complaints and inquiries. In some cases, even when the diagnosis of deafness was appropriate by newborn hearing screening or clinical tools, children's treatment was delayed because referrals for specialized centers were inadequate. At the moment of communicating the problem, social, cultural and emotional needs of the mothers were not considered.

Conclusions: The qualification and attention of health professionals is important to enable the early diagnosis of deafness, allowing appropriate support for the family and patients' referral and follow-up.

Objetivo: Investigar a vivência das mães entre a suspeita, o diagnóstico de surdez e o encaminhamento para habilitação, bem como a percepção delas a respeito da forma como foi dado e explicado o diagnóstico.

Métodos: Estudo qualitativo com dez mães ouvintes com filhos surdos que frequentavam atendimento especializado em Centro de Estudos e Pesquisas em Reabilitação, no Estado de São Paulo, há pelo menos dois anos. Realizou-se entrevista semiestruturada com as mães e foi feita análise da fala das participantes, buscando compreender o sentido que as mães deram à sua comunicação.

Resultados: Apesar do diagnóstico de seis crianças ter sido feito antes de um ano de idade e, considerando-se os múltiplos sentimentos das mães frente à surdez de seus filhos, observou-se que, em alguns casos, o diagnóstico poderia ter ocorrido antes se a fala das mães fosse valorizada. Percebeu-se dificuldade de "escuta" dos profissionais da saúde em relação às dúvidas, queixas e questionamentos das mães. Constatou-se que, em alguns casos, mesmo quando ocorreu a triagem auditiva neonatal ou o diagnóstico oportuno, retardou-se o atendimento à criança porque não foram feitos encaminhamentos adequados para locais que trabalham na área da surdez. No momento do diagnóstico, a forma como foi comunicada a surdez à família necessitaria levar em consideração as condições sociais, culturais e emocionais das mães.

Conclusões: Ressalta-se a importância da qualificação e atenção dos profissionais de saúde, para possibilitar o diagnóstico precoce, o apoio aos pais e o encaminhamento e seguimento adequados para os casos de surdez.

Key-words: deafness; diagnosis; mothers; pediatrics. Palavras-chave: surdez; diagnóstico; mães; pediatria.

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RESUMEN

Objetivo: Investigar la vivencia de las madres entre la sospecha, el diagnóstico de sordera y el encaminamiento para habilitación, así como la percepción de ellas respecto a la forma como se dio y explicó el diagnóstico.

Métodos: Estudio cualitativo con diez madres oyentes con hijos sordos que frecuentaban atención especializada en Centro de Estudios e Investigaciones en Rehabilitación, en la provincia de São Paulo, hace como mínimo dos años. Se realizó entrevista semiestructurada con las madres y se hizo análisis del habla de las participantes, buscando comprender el sentido que las madres dieron a su comunicación.

Resultados: A pesar del diagnóstico de seis niños haber sido realizado antes de un año de edad y teniendo en cuenta los múltiples sentimientos de las madres frente a la sordera de los hijos, se observó que en algunos casos el diagnóstico podría haber ocurrido antes si el habla de las madres fuera valorada. Se percibió la dificultad de «escucha» de los profesionales de la salud respecto a las dudas, quejas y cuestionamientos de las madres. Se constató que, en algunos casos, aun cuando tuvo lugar la selección auditiva neonatal o el diagnóstico oportuno, se retardó la atención al niño porque no se hicieron encaminamientos adecuados para locales que trabajan en el área de la sordera. En el momento del diagnóstico, la forma como se comunicó la sordera a la familia necesitaría tener en cuenta las condiciones sociales, culturales y emocionales de las madres.

Conclusiones: Se subraya la importancia de la cualificación y atención de los profesionales de salud, para hacer posible el diagnóstico temprano, el apoyo a los padres y el encaminamiento y seguimiento adecuados para los casos de sordera.

Palabras clave: sordera; diagnóstico; madres; pediatría

Introduction

Of all communication disorders, hearing loss is special because the consequences to the global development of human beings are very serious if language is not acquired. According to Vygotsky⁽¹⁾, language provides the concepts and forms of organizing the world that constitute the mediation between an individual and the object of knowledge. It is language that constitutes the subject, and it has two basic functions: social interchanges and generalizing thought. Considering that most deaf children are born into hearing families, it is fundamental that an early diagnosis of hearing loss should be made so that parents can receive guidance, as they generally communicate using oral language, inaccessible to deaf people. The difficulty in accessing oral language results in difficulty in acquiring a language, which leads to problems in the child's cognitive, social and emotional development^(1,2).

After the diagnosis of hearing loss, parents are strongly affected by the information received. The way that they perceive deafness and the functions of the hearing system, as well as the attitude of the professional that has dealt with them, as well as the quality of their counseling, interfere in parental decisions about the communicative resources⁽³⁾ that will be used in their interaction with their deaf children.

Parents often find it difficult to identify hearing loss because deaf people usually have some residual hearing capacity, and they may respond to vibrations, visual stimuli, or the pressure of the air due to the movement of noisy objects; therefore, they may give pseudoresponses⁽⁴⁾. This may also occur during pediatric consultations, the suspicion may be difficult to establish, and the referral to the otolaryngologist may be delayed⁽⁵⁾.

When parents realize that the child does not hear, they suffer the loss of the fantasy of a perfect child⁽⁴⁾. According to Marchesi⁽⁶⁾, a diagnosis of hearing loss is extremely painful for hearing parents. Receiving the diagnosis of deafness is a stressing experience⁽⁷⁾ and the source, for parents, of feelings of not only sadness, but also anxiety and insecurity in face of the unknown and the future consequences of hearing loss⁽⁸⁾. Studies^(4,7-11) indicate that finding out that a child is deaf may trigger different reactions in the family. However, when feelings of denial, anger, grief, pain, guilt and, depression, for example, are shared, it is more likely that parents may be able to face reality and seek strategies that facilitate and minimize the consequences of hearing loss.

Currently, neonatal hearing screening is routine in several maternity wards. Initial procedures can detect hearing impairment at an early stage, and newborns can be referred, in indicative cases, to other tests to confirm the diagnosis⁽¹²⁾.

The moment the diagnosis is made is crucial for parents, because that is the time when they receive information that is, most times, unexpected. Parents are often in shock because they do not understand or are unfamiliar with the terms and procedures, which may trigger panic^(4,7). The importance of this moment for families is clear. Therefore, this study evaluated the experiences of mothers from deafness suspicion to diagnosis and referral to early intervention, as well as the perception they had of the way the diagnosis was made and communicated.

Method

This study is part of a larger qualitative research project called *Psychosocial aspects of deafness: the social representations of hearing*

Chart 1	- Characteristic:	Chart 1 - Characteristics of mothers and their deaf children	^r deaf children					
Mother	Mother's age (years)	Mother's education (years)	Mother's occupation	Monthly per capita income (MW)	Age of deaf child	Degree of hearing loss	Etiology of child's hearing loss	Child's age at diagnosis
-	37	ω	Homemaker	-	6 years and 1 month	Profound bilateral	Unknown	2 years
7	33	4 to 8	Homemaker	2	5 years and 7 months	Severe bilateral	Probably genetic	8 months
з	37	11	Housekeeper	ž	7 years and 8 months	Moderate to profound bilateral	Usher syndrome	4 years
4	30	8	Homemaker	٢	8 years and 1 month	Profound bilateral	Waardenburg syndrome	5 months
5	29	9 to 10	Homemaker	ž	4 years and 3 months	Severe bilateral	Prematurity sequelae and neonatal complications	2 years
9	26	8	Homemaker	1 to 2	8 years	Moderate to profound bilateral	Waardenburg syndrome	5 months
7	39	ω	Manicure	ž	4 years and 10 months	Profound bilateral	Prematurity, anoxia and neonatal complications	4 months
ø	38	11	Nursing assistant	3 to 4	10 years and 5 months	Profound bilateral	Prematurity and excessive use of antibiotics	1 years and 6 months
თ	36	11	Accounting assistant	2	4 years and 11 months	Profound bilateral	Congenital rubella	8 months
10	34	11	Homemaker	1 to 2	9 years	Profound bilateral	Congenital rubella	5 months
MW: mini	MW: minimum wage							

mothers⁽¹³⁾. Qualitative approaches investigate processes, that is, how phenomena naturally occur and how the relations between these phenomena are established⁽¹⁴⁾. Therefore, this study investigated the process of experiencing events and the meanings assigned by mothers from suspicion that something was "wrong" with their infant to the attitudes after diagnosis. This study was approved by the Committee on Ethics and Research of the School of Medical Sciences of Unicamp, Brazil.

This study included ten hearing mothers and their deaf children who attended a specialized service in a Center for Studies and Research on Early Interventions in a city in the state of São Paulo, Brazil, for at least two years. As a qualitative study, the number of participants was not defined in advance and sampling was limited by theme saturation. Chart 1 shows the characteristics of mothers (age, education, occupation), their deaf children (age, degree of hearing loss, etiology, age at diagnosis) and family income.

Mothers received explanations about the study and signed an informed term to participate in the study. After that, they answered a semistructured interview, which was recorded using an audiocassette recorder and later transcribed. The guiding topics for this study were the diagnosis of hearing loss and referrals, and the following points were analyzed: when, how and who suspected that the child did not hear; when and how the diagnosis of hearing loss was made; and how was the referral to early intervention.

Results and discussion

Interview data showed that, before the confirmation of the diagnosis of hearing impairment, most mothers went through a time of suspicion that something was not right with their child, because the child was either not startled and did not react to sounds and noises, or did not speak. Some mothers tried to share their suspicions with the child's pediatrician, but, according to their reports, their questions were not always investigated.

The analysis of diagnoses revealed that six mothers in the study received confirmation of their child's deafness before the infant was one year old. For the Brazilian reality, these diagnoses were made at an early stage. Two of them, as there were other deaf people in their families, were already being followed up by a geneticist to investigate the probable cause of hearing loss (Waardenburg syndrome). Three of the other children received a diagnosis of hearing impairment between one and two years of age, and the other, who had a diagnosis of Usher syndrome, in which case deafness may be progressive, at four.

The early diagnosis of the children in the group was frequently a result of their mother's observation and their search for a

professional that would be open to their suspicions, as reported by Mother #2: "I realized, because of the radio clock; I was changing her diapers when the alarm went off, a noise like that, and she was not startled [...] she was six months old, I realized [...] and started making a lot of noise, making noise behind her ear and nothing, she did not respond; then, I went to the doctor, we took her for a consultation and he said, no, it is just your feeling, and that I should wait a little longer; then I returned at eight months and he referred her to BERA (brainstem evoked response audiometry) and she took that test at 11 months."

A similar case was experienced by Mother #10, who had rubella during pregnancy. She reported: "I had rubella during pregnancy, then, when she was born, I was paying attention, especially when I was alone. I made noises and I realized, like, she did not follow them. And when she was near me in the baby carriage, I started banging things. Nothing startled her, nothing. She slept a lot, I turned on the music and she did not wake up." When referring to her search for a diagnosis, she reported that: "For me, it was, like, a little complicated, because I talked to the pediatricians, like, what I thought was happening, but some of them said, 'Well, mother, she is still so small, let's wait a little longer'. And then I would go and see another pediatrician (laughter). I went to four pediatricians, just the same [...]. Then I went to one and I said, B. was about three months, and I said, 'Look, I am almost sure that she cannot hear', and then he said, 'Mother, do you want her to have the test?' And I said: Yes."

Mother #9 also had rubella during pregnancy, but her journey to have the test made was different, as she reported: "[...] a boy in the street fired a firecracker and he did not react, and then I was scared and he continued sleeping, and then I said to my husband: this boy does not hear, he is deaf [...]. We took him to the pediatrician, and he said, the pediatrician made some movements there and he reacted, he turned around, and he said: no, it's because he is very hyperactive [...] he hears, he reacts to the sounds'. He turned his head [...] then he stopped, he said he had nothing, everything was fine, this went on like this, when he was around 6 months, he could not keep his head up, his head was soft [...] I mentioned that to the pediatrician and then he told us to go into the neuropediatrician's office." The mother said that the neuropediatrician referred the child to a physical therapist, who suspected hearing loss and referred the child to an otolaryngologist. The diagnosis was made when the child was eight months old, but interventions for hearing impairment started only at 1 year and 8 months of age.

A different path was followed by Child #7, who was premature, had anoxia and neonatal complications. At the time, the maternity ward where the child was born conducted neonatal hearing screening of infants at risk. The test of otoacoustic emissions was attempted more than once, and the infant was referred to the BERA test, after which hearing impairment was diagnosed at four months of age. The otolaryngologist referred the child to an ophthalmologist and justified it by the fact that the drugs that the infant had been administered might have affected his sight. As there were no ophthalmologic impairments, the infant was referred to the neurologist, who referred the child to the institution that provides early intervention programs for hearing impairment at one year and three months of age. Although suspicion was raised at an early age, the complications in the case of this child delayed referral to early intervention and, as well as in the other cases (#2, 9 and 10), the lack of concurrent or more accurate referrals contributed to the delay.

An early diagnosis is important because it may minimize the effects of the anxiety that the parents experience when they do not know what is happening with their child, a situation that may affect the affective and emotional relationship between infants and their parents at a fundamental time for their development^(15,16). It may also prevent difficulties that the child may face in linguistic, communicative, cognitive, social and emotional aspects⁽¹⁵⁾.

According to Vieira, Macedo and Gonçalves⁽¹⁷⁾, the diagnosis of hearing loss, including the degree and type of loss, is based on history and focused on the investigation of gestational, periand postnatal risks, history of infectious and respiratory diseases, otolaryngological assessment and hearing tests. Therefore, the pediatrician that follows up the infant may identify these risks and conduct the first hearing tests and, in case of any suspicion, make the referral to an otolaryngologist.

Studies⁽¹⁸⁻²⁰⁾ about the way pediatricians face deafness draw attention to the fact that, in general, they do not routinely examine hearing and have little information about the causes of hearing loss, its classification and assessment methods, which makes it difficult to detect it and delays treatment.

Colozza and Anastasio⁽²⁰⁾ included physicians working in neonatology in their study, in addition to pediatricians, and found that most (83%) adopt specific procedures for hearing loss when treating high risk infants, but do not investigate hearing in their routine examinations. The authors found that, despite that, all interviewees agreed that the doctor should be responsible for caring for the infant's communications capacity.

Studies conducted in Brazil show that the diagnosis of hearing impairment in our country is delayed and made at about three or four years of age, and the time from suspicion of hearing impairment to its confirmation is 11 to 48 months⁽²¹⁾.

Our study found that, in some cases, mothers (#1, 5 and 8) received a diagnosis for their children at one and a half to two years, although they had suspected hearing impairments earlier. Child #5, for example, had no severe impairment and responded

to sounds, but did not speak at one year and nine months. The mother suspected that something might be wrong, but the diagnosis was delayed because there was a history of "speaking late" in the family, as she reported: "He was already one year and nine months and did not speak, but responded to any sound, and I made no idea. Then, at two years, I said: I'm going to see the doctor, because up to that time, the pediatrician, nobody had said anything, they saw it and said it was normal, and as there was a case in my family, my brother and my husband's sister spoke only when five years old, we thought: OK, let's wait, let's see, if he turns two and has not started developing any speech, I'll take him, yes I will, to someone that can check it."

It should be noted that the family, when faced with a suspicion, tries to find an explanation for the fact that their child is taking too long to speak. This mechanism may make the family delay the decision to take the child to the doctor for an examination. In contrast, when the families tell pediatricians about their suspicions, some reassure them, as reported by Mother #5: "When I told the pediatrician that my boy was taking too long to talk, that he only mumbled "mamma", "papa" and could not say mother, father, he could not say that, the doctor made those noises and he turned to see where the sound was coming from and she thought that... 'oh, he is just a little lazy, leave it alone, he is developing', but she didn't she never had any suspicion."

Something similar happed to Mother #8, who had a premature baby who received antibiotics intensively after a surgery to correct duodenal atresia on the third day of life. The mother reported that: "I took her to the pediatrician all the time: and, well, she is still too young, you have to wait at least some six months, because sometimes her development is really slower because she was premature, was kind of malnourished at birth and that went on like this."

Deafness, as it is not apparent, is often overlooked in routine clinical examinations⁽²²⁾. Many healthcare professionals lack familiarity with hearing problems and the use of visual cues by the baby may confuse the evaluation of responses to sounds⁽²²⁾. In the case of Child #1, the pediatrician saw that she was not startled when there was a noise in the room and referred her to an otolaryngologist. The mother said: "Coincidently, a ruler fell on the floor, one of those rulers to measure babies, it fell and I was startled, the doctor was startled, but the baby did not even flinch."

One of the frequent reasons for delays in suspecting that the child does not hear, both for the family and the healthcare professionals, is the fact that the child does not have a severe hearing impairment. The greater the hearing residue, the harder it is to realize that the child does not hear, as the response to stronger and deeper sounds ends up masking the child's inability to understand the sounds of oral language. When the parents receive confirmation of the diagnosis, the shock and emotional reactions depend on how much they suspected that something was wrong with their child's hearing. At this moment, the attention and willingness to hear of the professionals that break the news are fundamental, and it is their role to make sure that the parents understand despite the emotional shock. They should also take into consideration the sociocultural conditions of those parents.

The family builds a set of ideas about the "disease" that are strongly affected by subjective issues, such as personality and culture⁽²³⁾. Even when suspecting that their children have hearing losses, the emotional shock may hinder their parents' comprehension, and there might by discrepancies between what the healthcare professional tries to explain to parents, the form it is explained and the way the contents are approached, and what parents understand or are able to comprehend^(24,25).

Mother #5 clearly explained her difficulty in understanding medical terms, as she reported: "The first otolaryngologist, to be honest, I didn't understand a thing, I had already read the test result because it was sent to my home, and I can't control my curiosity, I opened and saw, and I saw that there was severe bilateral loss, but I had no idea what that meant; then, I got there, she sat down, read it and said: well, your son has severe bilateral loss. And I said: what does that mean in my language? Because I have no idea what you are talking about. She said: Your son is deaf. Then, there, I did not believe it, I was stunned [...] I made an appointment with a speech therapist covered by my medical insurance plan and she was the one and she explained, she gave me the number of C (Institution), gave me the things, but the otolaryngologist herself only left me feeling stunned because she did not give me any explanations."

Gilbey⁽²⁵⁾ evaluated parents' experiences when they receive the information about their children's hearing loss, and concluded that 50% were unhappy about the diagnostic process, and one of the frequent complaints was the fact that information was given directly and thoughtlessly. In contrast, Fallowfield and Junkins⁽²⁶⁾ found that healthcare professionals report having difficulties in giving bad or sad news to patients and their families because there is a stressing interaction at such moments and physicians, when they lack effective training, may do it inappropriately, which may affect acceptance, understanding and adaptation to the problem.

Mother #7 reported not being unhappy about the diagnosis maybe because it mitigated the limitations set by hearing loss due to the confusion she made from the explanation that the doctor gave her about the hearing test that had been performed, that is, when she was told about a hearing loss at 80 decibels (db), the mother understood that her daughter had 80% hearing capacity and, therefore, had a good hearing. To measure the loss and residual hearing in percentage seems to be important for parents to have a clearer idea of how much their child can hear.

In the case of Children #4, 6 and 10, who had an early diagnosis and whose doctor was able to make the necessary referral rapidly, parents had support at a time when they needed it the most, and this made a difference in their experience. For example, Mother #10 said: "I prayed to God to show me the best way to go, because I really knew nothing, nothing, nothing. I did not know what to do, then I looked forward to the day to come here and talk to somebody [...] I got my feet back on the ground fast." The mother said that she started using sign language with her daughter at home, but saw no return, which generated considerable anxiety, but eventually, after four months, she realized that she was on the right path: "Four months, and that was what I did, but, my God, is this right? It was always like that, doing it, but, was it right? Is the sign correct? [...] Then B started responding and understanding, I saw that she understood, God, the best thing I ever did and I'd do it all over again." The mother, at first, had feelings of anxiety and insecurity about the guidelines on how to use the signs, but, as she felt assisted and supported, she trusted the professionals and rapidly became confident that she was treading the right path.

Although all children had a diagnosis before one year of age, and considering the multiple feelings of mothers in face of their children's hearing loss, we found that, in some cases, diagnostic suspicion might have been raised before if the mother's words had received more attention earlier. That is, our findings showed that it was difficult for healthcare professionals to "hear" the mother's questions, complaints and inquiries, even when there was a history of risk factors, such as congenital rubella. In some cases, even when neonatal hearing screening was performed and there was a timely diagnosis, care was delayed because referrals to services that provide early interventions in cases of hearing loss were not adequate or not concurrent. Moreover, at the time of diagnosis, the way that the information was communicated to the family should take into consideration the mother's social, cultural and emotional conditions.

The qualification and attention of healthcare professionals should ensure an early diagnosis and support to parents, as well as adequate referrals and follow-up of confirmed cases of hearing loss.

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