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Therapeutic itinerary of a deaf child in the Network of Health Care

Itinerário terapêutico da criança surda na rede de atenção à saúde

Itinerario terapéutico de ninõs sordos en la red de atención a la salud

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Abstract

Introduction: In children, hearing impairment is more serious than in adults or elders, because it interferes in the language acquisition and development. For this reason, there must be a healthcare network aimed at offering diagnoses and medical intervention quickly. **Objective**: to analyze child hearing care as from the therapeutic itinerary (TI) of a deaf child using the services of a *Centro de Reabilitação Auditiva* (Hearing Rehabilitation Centre). **Methods**: this research is a case study of qualitative nature. Our starting point was the health services of a city in the urban area of Campinas/SP, and also some regional references. We conducted an in-depth interview with the child's mother for the reconstruction of the TI and 10 semi-structured interviews with managers and professionals in order to obtain information about the type of hearing care. **Results**: the maternity unit was important for the early detection of hearing impairment, but there were flaws in the screening protocol it employed. The Rehabilitation Centre fulfilled its role, but there was an unmet need of rehabilitation services in the home city of the users. There were also flaws in the healthcare coordination of the *Unidade Básica de Saúde* (Primary Health Unit) for deaf children. **Conclusion**: The reconstruction of the TI was an important tool to analyze the completeness of attention to health services, allowing us to understand the user's real story in the search for health care and the way the healthcare network operates.

Keywords: Hearing Impairment; Deafness; Rehabilitation; Health System

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Resumo

Introdução: Na criança, a existência da deficiência auditiva é ainda mais preocupante que no adulto ou idoso, devido à interferência no processo de aquisição e desenvolvimento da linguagem. Por esse motivo, é preciso que haja uma rede de atenção à saúde organizada de modo a oferecer diagnóstico e intervenção rapidamente. **Objetivo:** Analisar a atenção à saúde auditiva infantil a partir do itinerário terapêutico (IT) de uma criança surda usuária de um Centro de Reabilitação Auditiva. **Método:** A pesquisa, de natureza qualitativa e do tipo estudo de caso, foi realizada tomando-se como ponto de partida um município da região de Campinas/SP, os serviços da rede municipal de saúde e referências regionais. Foi feita entrevista em profundidade com a mãe da criança para reconstituição do IT e 10 entrevistas semiestruturadas com gestores e profissionais para obter informações sobre a linha de cuidado à saúde auditiva. **Resultados:** A maternidade foi um importante ponto de atenção para detecção precoce da deficiência auditiva, porém há falhas no protocolo de triagem utilizado por ela. O C*entro de Reabilitação* cumpria com seu papel, mas foi apontada a necessidade de serviços de reabilitação nas cidades de origem dos usuários. Houve problemas na coordenação do cuidado da Unidade Básica de Saúde de referência para a criança surda. **Conclus**ão**:** A reconstituição do IT foi uma importante ferramenta para analisar a integralidade na atenção à saúde, permitindo compreender a trajetória real do usuário na busca por cuidado, permitindo que se conheça e como funciona a rede real de atenção à saúde.

Palavras-chave: Deficiência Auditiva; Surdez; Reabilitação; Sistema de Saúde.

Résumen

Introducción: La existencia de discapacidad auditiva es más preocupante en el niño que en el adulto o el anciano debido a la interferencia en el proceso de adquisición y desarrollo del lenguaje, siendo necesario que haya una red de salud organizada que ofrezca un diagnóstico e intervención oportunas. **Objetivo:** Analizar la atención a la salud auditiva infantil partiendo del itinerario terapéutico (IT) de un niño sordo usuario de un Centro de Rehabilitación Auditiva. **Método:** La investigación cualitativa, de tipo estudio de caso, consideró: servicios de la red municipal de salud de una ciudad de la región de Campinas/SP y referencias regionales. Fue realizada una entrevista en profundidad con la madre del niño para la reconstitución del IT y 10 entrevistas semiestructuradas con gestores y profesionales para obtener información sobre la línea de cuidado a la salud auditiva. **Resultados:** La *maternidad* fue un importante punto de atención para la detección temprana de la discapacidad auditiva, aunque con fallas en su protocolo de cribado. El C*entro de Rehabilitación* cumplía con su papel, pero fue señalada la necesidad de estos servicios en las ciudades de origen de los usuarios. Hubo problemas en la coordinación del cuidado de la *Unidad Primaria de Salud* de referencia para el niño sordo. **Conclusión:** La reconstitución del IT fue una herramienta importante para analizar la integralidad a la salud, permitiendo tanto comprender la trayectoria real del usuario en la búsqueda por atención, como que se conozca la red real de atención a la salud y su funcionamiento.

Palabras clave: Discapacidad Auditiva; Sordera; Rehabilitación; Sistema de Salud.

Introduction

Present in several countries, the strategy of organizing the health system in networks became a guideline for Brazilian health policy at the beginning of this decade. Five Thematic Networks were defined as priorities to be implemented in the health regions of Brazil, including the *Care Network for People with Disabilities*[1]. Established during discussions of the Ministry of Health on the Health Care Network as a strategy to health care comprehensiveness, this Network was a development of the *National Plan for the Rights of Persons with Disabilities - Living Without Limits*, which was instituted by Decree No. 7,612 / 2011.

Through this plan, the Brazilian Government defined a public policy in defense of the rights of people with disabilities as a priority, in which the health area took an important role[2].

Health is a right of each and every Brazilian citizen, as guaranteed by the Constitution. However, the presence of a disability may undermine the exercise of this right; considering a disability not only by functional impairment, but by the interaction of these impairments with the various barriers that these individuals face and that can hinder the full and effective participation in the society on equal terms[3].

With regard to hearing impairment, which is the third most prevalent disability and affects 5.1% of the Brazilian population, the consequences may result in social isolation and even linguistic and cognitive impairment, in the event of hearing loss in children in development.

As for the population of newborns, epidemiological studies indicate that the prevalence ranges from one to six newborns for every thousand live births, and from one to four for every hundred newborns who needed care in the Neonatal Intensive Care Unit[4].

In children, hearing impairment is even more serious than in adults or elders, due to its impacts in language acquisition and development. Thus, international and national expert committees, such as the Joint Committee Infant Hearing[5] and the Multiprofessional Committee on Auditory Health[6], recommend that Neonatal Hearing Screening should be performed on all newborns so that all measures in favor of the child's development are provided in a timely manner when hearing loss is suspected.

The *Care Network for People with Disabilities* is responsible for the care of children's hearing health, including three components: *Primary Care, Specialized Care in Hearing, Physical, Intellectual, Visual, Ostomy and Multiple Disabilities Rehabilitation and Hospital, Urgent and Emergency Care*[1]. In this way, in an articulated and regulated manner with the other components, specialized care is responsible for the care of children's hearing health with suspected or confirmed hearing loss.

The assistance in specialized care may be provided in services that offer only hearing rehabilitation or that also work with the rehabilitation of other disabilities, in addition to hearing impairment. The institutions that provide assistance exclusively for one disability are considered qualified health establishments and that existed before the creation of the *Care Network for People with Disabilities*[1], namely, the *Hearing Rehabilitation Centers* of medium or high complexity. This qualification possibility was created with the publication of the *Brazilian National Hearing Health Care Policy*[7], which, although revoked, still governs the operation of the services enabled by it, providing important health care institutions in the *Care Network for People with Disabilities*.

On the other hand, the institutions that can provide rehabilitation for more than one type of disability are called Specialized Rehabilitation Centers (CER), which are considered the major innovation of this policy, since they include three different ways to be configured, depending on the amount and types of rehabilitation provided. Therefore, they could be constituted as CER II, CER III or CER IV, respectively; providing two, three, four or more rehabilitation modes, which can be auditory, intellectual, physical and visual[1;8].

The proposed change with the new network configuration for the health care network of people with disabilities faces the challenge of integrating and, simultaneously, meeting the inherent specificities, not only from each disability and its rehabilitation, but, above all, from each subject and their needs.

In this perspective, considering the work organization model in health in care networks and focusing on newborn care, this study investigates children's hearing health care based on the therapeutic itinerary of a deaf child attending a Hearing Rehabilitation Center of high complexity.

Methodological Route

This qualitative and case study research was conducted taking an urban-industrial municipality with more than 200,000 inhabitants as its starting point, in the urban area of Campinas, in São Paulo State, whose health care network provides assistance in all levels of complexity.

The study included an in-depth interview with the mother of a child with moderate bilateral hearing loss, aged 1 year and 3 months at that time, who was assisted at the Hearing Rehabilitation Center, which is landmark for the health care area of the municipality. The *Hearing Rehabilitation Center* is qualified by the Ministry of Health as a high complex institute according to the *Brazilian National Hearing Health Care Policy*[7], and it was incorporated into the *Care Network for People with Disabilities* with the creation of the new policy. The service structure includes: *Hearing Health Clinic* of a university hospital and a *Specialized Center*, both with assistance and academic capabilities, located on the same university campus.

The in-depth interview aimed to identify the route taken in order to have care for the child with hearing loss, including the waiting times, the mother's experience in the search for care, as well as the impact of this process on the life of the child and the family. The interview was conducted at the *Specialized Rehabilitation Center* on the same day of a follow-up visit with the speech-language pathologist and lasted approximately 40 minutes.

The interview was recorded and later transcribed, and then the first version of a narrative was constructed, following Ricoeur's theoretical framework[9]. This narrative was presented to the mother who could contest, correct or validate what the researcher had understood about her speech. Then, the text was improved to allow the reconstruction of the therapeutic itinerary in the form of a narrative. Nunes *et al.*[10] report that, in this way, the "raw data of the interview" is transformed into "processed narrative data"; that is, the information is transformed into knowledge. The construction of a narrative is a methodological resource of interest in the study of therapeutic itineraries associated with chronic conditions, such as hearing loss[11].

Semi-structured interviews were also conducted with 10 professionals involved in management and assistance, in order to understand the arrangements of the assistance to hearing impaired people in the municipality and region, as well as the formal flows agreed by the management. Chart 1 shows the distribution of the interviewed professionals according to their role and the care service to which they are linked.

Chart 1. Distribution of the professionals interviewed by position and facility

Position	Facility
Manager of the Regional Regulation	Regional Regulation Center
Technical Support of the Planning Department	
Manager of the Municipal Regulation Center	Municipal Regulation Center
Technical Support of the Municipal Regulation Center	
Assistance to the management	Municipal Health Department
Speech-language pathologist, technical responsible of the Hearing Health Clinic	Hearing Rehabilitation Center – high complexity
Otorhinolaryngologist, technical responsible of the Hearing Health Clinic	
Otorhinolaryngologist of the Hearing Health Clinic	
Speech-language pathologist and teacher of the Specialized Center	
Speech-language pathologist, responsible for the Newborn Hearing Screening	State Hospital - Maternity Ward

The thematic analysis of the empirical material allowed to discuss the main elements related to children’s hearing health care, particularly with regard to the role of the health care institutions that comprises the *Care Network for People with Disabilities* aimed at this population, namely, the *Maternity* in Neonatal Hearing Screening, the *Hearing Rehabilitation Center* and the *Primary Health Units*.

The research was approved by the Ethics Research Committee (CAAE no. 0724.0.146.000-11).

Results

This study focuses on child hearing health care and presents its results in two parts: the line of hearing health care for the newborn/infant defined and agreed upon by the municipal and regional government (Figure 1) and the narrative on the therapeutic itinerary of João Victor, a child with moderate bilateral hearing loss, aged 1 year and 3 months at the time of the interview with his mother.

The narrative allows the identification of the strengths and weaknesses of the health care network, as well as the waiting times and the journey experienced by the child and his mother in the search for care. The research decided to report the TI in full, in a narrative, not excerpts, since it is a more appropriate methodological tool to deepen the understanding of the path taken by users in the health care network, according to the framework adopted in the study. Fictitious names were used for the mother and the child.

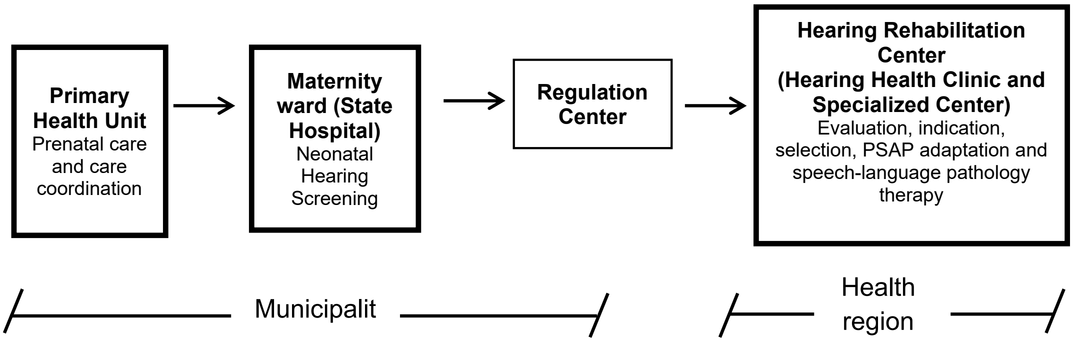

Figure 1. Care line to user/infant (hearing care)

Narrative on the therapeutic itinerary taken by João Victor

Ruth is 40 years old and she was born in Minas Gerais, where she left her family to live with her sister in the São Paulo State. Then she married and, eight years later, she had João Victor, who is her only son. The pregnancy was “*wonderful, it couldn’t be better”.*”. She had prenatal care at the *Primary Health Unit* and went into labor at midnight, going straight to the *maternity* ward, where she waited until 8 am, when she underwent a cesarean section. She believes that the hospital waited too long, since João Victor “*choked and swallowed the dirt from the birth*”. She said, with her eyes filled with tears, that he spent 14 days in the Neonatal ICU and that she “*almost lost*” João Victor. Still in the *maternity* ward, he did the “baby hearing screening”, which detected a hearing problem. So she was asked to go to the regulation center to get referrals to make the BERA test. The test was conducted at the *Specialized Center*, one or two months after João Victor’s discharge, and it confirmed the suspected impairment rose at the *maternity* ward. So the mother understood that João Victor’s hearing ability was “*neither bad nor good*”. Ruth was worried, but she learned that the use of hearing aids is indicated in such cases, and that the procedures would be provided in this same service. She reports that several professionals assisted her son: an otolaryngologist, psychologist, social worker and several speech-language pathologists – one performed the BERA test, while another provided the hearing aid and another had weekly conversations with Ruth on the development of João Victor. He received the hearing aid after 12 months of life, but the mother believes that he hears well even without the device: "*he does not hear (everything) he needs to hear (...), he listen to the television, when we call him (...) he looks at us when we call him...*". As for the *Specialized Center*, she said that it was all wonderful, since there are several professionals available. She had no difficulty in scheduling follow-up visits, nor does she wait on visit days. In addition, she always has the help she needs, such as transportation assistance. With regard to the service provided by the *Primary Health Unit* (UBS), she says "*it is terrible, very bad*". There is a lack of doctors, vaccines and professionals to apply them and it is difficult to schedule a visit. One of the professionals, being aware that the child was treated at the *Specialized Center*, said that she could not miss this service, since it is very important. However, she does not feel to be supported by the *UBS*, since she did not have the answer she expected, when she needed. The speech-language pathologist once asked her to take João Victor to the *UBS* to remove the excess earwax; then, when she arrived at the unit, she was informed that this procedure was not available there and she was referred to the municipal specialized clinic, being included in a huge waiting list. Given the need, she decided to pay for a private consultation, so the family decided to make a health plan for the child. João Victor also requires other care services, since he "*does not walk, does not drag, and that his leg is soft*". She undergoes physical therapy at the hospital linked to the SUS, after being referred by the *Specialized Center* staff in a visit to take care of hearing. About her son, Ruth says: "*It is a life lesson, since you learn many things, new things, and you learn to live. Now, I just want to dedicate myself to him, so whatever I can do for him, I will do, until the last day of my life*".

Discussion

This study aimed to analyze children hearing care as from the therapeutic itinerary of a deaf child using the services provided by a Hearing Rehabilitation Center of high complexity. The limitations of the study are the fact that it reports the therapeutic itinerary of only one child, and the absence of primary care professionals among the respondents.

After presenting the institutionally delimited flows and the narrative on the therapeutic itinerary taken by João Victor, the main elements related to children's hearing health care will be discussed, particularly with regard to the role of the health care institutions that comprises the *Care Network for People with Disabilities* aimed at this population, namely, the *Maternity* in Neonatal Hearing Screening, the *Hearing Rehabilitation Center* and the *Primary Health Units*.

The maternity ward and its role in neonatal hearing screening

The Ministry of Health (MH) recommends that every newborn should be submitted to the Neonatal Hearing Screening (NHS), as part of a set of actions that must be conducted for a comprehensive health care in childhood[4]. Preferably, the maternity ward is the point where the NHS should be conducted in the health care network.

Screening may include tests such as the Otoacoustic Emissions (OAE) test, which is better known as "baby hearing screening", and the Brainstem Auditory Evoked Potential - with automated interpretation (BERA). These are non-invasive tests, which are used to detect possible sensory or neural hearing loss[5]. The NHS aims to investigate all newborns to allow the implementation of more effective rehabilitation measures if hearing loss is identified early.

The Neonatal Hearing Screening Guidelines established by the MH recommend that the screening should be follow specific protocols for newborns with and without a Hearing Impairment Risk Indicator (HIRI); therefore, both test types are required - OAE and BERA[4]. However, institutions have organized screening programs in different ways, using the resources available in order to reach the proposed goal. As reported in the study by Cavalcanti, Melo, Buarque and Guerra[12], this variability in the protocols makes it difficult to monitor and also to define quality milestones.

As the Neonatal Hearing Screening Program analyzed in this study includes only the OAE test, it does not follow the recommendations of the Ministry, which indicate different types of tests for newborns with and without HIRI. Differing from the recommendations, the mothers of the newborns who stay in a rooming-in setting, usually without HIRI, receive a referral at the time of discharge, with the date to conduct an OAE in the hospital outpatient clinic, approximately 20 to 30 days after the birth. On the other hand, neonates with HIRI, who usually require neonatal ICU hospitalization, like João Victor, are screened prior to discharge, in order to reduce absences. When the newborn does not attend the visit, the *maternity* staff contacts the family by phone to schedule a new date.

Still, according to data provided by the speech-language pathologist of the maternity ward in an interview, the number of absences in the screening test in outpatient programs is significant: although the JCIH[5] recommends that a NHS program should be able to screen at least 95% of newborns, absences in 2012 ranged from 13% to 20%. In order to reduce the absenteeism, the screening of every newborn is recommended in the first two days of life, still in the *maternity* ward.[4].

If the newborn does not pass the screening, a retest is scheduled about 15 days later, both for newborns in the rooming-in setting and those in the ICU. Most return for the retest, but if they don't, the staff contacts the family to schedule a new date. Fernandes and Nozawa[13] investigated the reasons that lead to non-return and found that factors such as having more than one child, having attended only one to three prenatal consultations and the mother not having a partner may lead to non-attendance and the need for a new test.

As previously reported, the NHS Program investigated is limited only to the OAE test, not including the BERA, which is due to the lack of equipment in the institution where João Victor was born, which reflects the reality of many maternity hospitals throughout Brazil. Although Law No. 12,303/2010 has been an advance in terms of newborn access to the NHS, it has been insufficient, as it only requires the OAE test to be mandatory.

The BERA test is a test of paramount importance and is recommended for direct screening of newborns with HIRI, like João Victor, since it allows the identification of retrocochlear hearing losses, which are prevalent in this population and that are not detectable in the OAE test. This test is also indicated for neonates who did not pass the OEA test and retest, to avoid unnecessary referrals for diagnostic evaluation tests[4].

This means that a percentage of newborns with hearing loss may not be detected by the program, which was only avoided in the case investigated because he did not pass the OAE test, and so was directly referred for diagnostic evaluation.

The lack of equipment for complete screening is still a reality in many Brazilian maternity hospitals, with only 625 BERA tests recorded in the Brazilian National Database of Healthcare Facilities (CNES) in the country, of which 596 are in operation, and there are only 4,148 maternity hospitals in the country[14].

The concern with the installed capacity of hearing assessment equipment was one of the goals of the *Living Without Limits Plan*, which intended to equip 175 maternity hospitals by 2014[15], but that goal was only partially met. This topic was discussed again in the federal public administration in 2015, due to the unexpected increase in the incidence of newborns with microcephaly associated with the Zika virus. Since microcephaly was considered an emergency public health issue that may be associated with hearing loss, the federal government released the *National Plan to Combat Microcephaly*[16], which aimed to equip 737 maternity hospitals with the equipment required to conduct BERA tests in 2016; however, this has not been achieved. Therefore, this is a real problem and, although it has been recognized for some time by the federal government, the Ministry of Health has not yet published a national policy in order to regulate the Newborn Hearing Screening, including the subsequent diagnosis and intervention[17].

The essential factors to increase the coverage of the NHS would include the availability of adequate equipment, hiring of qualified professionals to conduct the tests and in sufficient numbers to maintain the daily coverage of the working shifts, as well as the encouragement of family members to participate. When analyzing the evolution of NHS coverage in the country, Paschoal, Cavalcanti e Ferreira[18] identified that the growth observed in the coverage rate from 2008 to 2015 was not uniform in all regions, with better rates in the South and Southeast, to the detriment of the North and Northeast regions, which can be justified by the existence of municipal or state laws on NHS even before the federal law itself.

The publication of the NHS law at national level seems to have influenced the increase in the coverage rate in the years following its publication, reaching 21.8% in 2011[19] and 31.8% in 2015[18]. However, efforts are still needed in order to bring coverage closer to the ideal rate, since the actual rate is still very far from the recommended 95% coverage.

The role of the Hearing Rehabilitation Center

The Hearing Rehabilitation Centers of medium and high complexity are part of the specialized care component of the *Care Network for People with Disabilities*, as well as the CER with hearing facilities. In total, the Hearing Rehabilitation Centers have 221 services enabled by the Ministry of Health to perform Hearing Rehabilitation (50 on medium and 77 on high complexity) and 94 CER with hearing facilities[14].

The Hearing Rehabilitation Centers of medium and high complexity follow the regulations in force at the time of their qualification, according to the former *Brazilian National Policy on Hearing Health Care*[7], in addition to the *Care Network for People with Disabilities* guidelines that were incorporated into the regulations.

The Hearing Rehabilitation Centers of medium complexity must provide specialized diagnostic and therapeutic care actions; screening and monitoring of hearing of newborns, preschoolers and schoolchildren; diagnosis, treatment and rehabilitation of hearing loss, including the adaptation to a Personal Sound Amplification Product (PSAP) in children from three years of age, young people, adults, including workers, and the elderly. The services provided in high complexity institutions have the same tasks as medium complexity ones, except for screening and monitoring the hearing of newborns, assisting children under three years of age and patients who have other associated conditions and/or unilateral hearing loss[7].

In this study, the investigated patient, João Victor, experiences an important part of his therapeutic itinerary in a *Hearing Rehabilitation Center* of high complexity. This Center has a particular form of organization, consisting of a *Hearing Health Clinic* and a *Specialized Center*, located in different locations within the same university campus. Table 1 shows the set of actions aimed at the newborns/infants that must be carried out in high complexity institution and how they are allocated in the *Hearing Rehabilitation Center* investigated.

Table 1. Distribution of agreed actions and procedures focused on the hearing health of newborns in the facilities that make up the hearing rehabilitation center of the study

Actions*	**Hearing Rehabilitation Center of high complexity**	
	Hearing Health Clinic	**Specialized Center**
Medical evaluation for the purpose of diagnosis	X	-
Audiological evaluation for the purpose of diagnosis	X	-
Transient evoked OAE test	X	-
Distortion product OAE test	X	-
Short-, medium-, and long-latency BERA test	X	-
Medical consultation for treatment purposes	X	-
PSAP indication, selection and adaptation	X	-
Speech-language pathology therapy	-	X
Evaluation and psychological therapy	X	X
Social service care	X	X
Family counseling	X	X

OAE, Otoacoustic Emissions; BERA, Brainstem Evoked Response Audiometry; PSAP, Personal Sound Amplification Product.
*Source: Directive SAS/MS 587/2004[7]

As shown in Table 1, both services - the *Hearing Health Clinic* and the *Specialized Center* - work together in order to provide all actions of a *Hearing Rehabilitation Center* of high complexity.

It should be noted that the *Specialized Center* conducts hearing evaluation for the purpose of diagnosis, as well as indication, selection and adaptation of PSAP and it is not shown in Table 1 because this actions are not within the scope of a formal reference of the municipality investigated.

Confirmation of hearing loss

The *Hearing Rehabilitation Centers* are responsible for the diagnostic evaluation, which is essential for newborns with suspicion of deafness. The main barrier found by the investigated therapeutic itinerary refers to the difficulty of accessing the diagnosis of the BERA test. According to the regulations of the regional regulation center, this test should be conducted at a *Hearing Health Clinic*; however, the test was conducted at the *Specialized Center*, which although it is part of the *Hearing Rehabilitation Center*, is not the recommended facility.

There was a context that made it difficult the access of newborns to the *Hearing Health Clinic* in order to perform the diagnostic evaluation. The municipal regulation received a negligible monthly limit (from zero to four) from the regional regulation to meet all the demand for cases with suspected hearing loss, from newborns to the elderly. Due to the huge waiting list, especially the elderly, the municipality had already arranged to conduct an otorhinolaryngologal evaluation at the municipal specialized outpatient clinic and to perform the audiological evaluation in an accredited service for patients referred by Primary Care. In this way, the municipal regulation center was able to organize a waiting list for those who would have a PSAP indication and thus optimized the limit assigned to them. If they referred newborns with suspected hearing loss, these newborns would compete with patients whose need for hearing aids was already set and an application for hearing aids would have been "wasted."

With respect to the long waiting list of hearing loss patients awaiting for PSAPs, the *Technical Support Representative of the Municipal Regulation Center* reported: "*(There are many patients) waiting for the device. They have been coming here (regulation central) periodically and our answer is always* "*you must wait.*" *This is very unpleasant, but it is our reality. And we depend on the Regional Center, since our unique reference is the Hearing Rehabilitation Center (...) They (DRS) claim that other municipalities also have it (waiting list). And they do, do you know it? (...) including it all there, (another city in the region) there are more than 500 people in the waiting list. (...) we have 200 in our waiting list. There are still 45 people waiting since 2009, another 18 people waiting since 2008 (...). They are young, with an active professional life and in the work and study stage. (...) So, if you go to see other municipalities in the nearby, we're fine. Amazing as it might seem!*"

In order to solve this problem, and aware of the relevance of the early hearing loss detection in newborns, the municipality started to refer them informally to another service - the *Specialized Center* - through the Regulation Center. After analyzing the request from the speech-language pathologist of the *maternity* hospital, the social worker of the municipal regulation center contacted this service directly, creating another route of access, different than the route formally agreed. Regarding this situation, the *Manager of the Municipal Regulation Center* said:

(Before, we tried at the Hearing Health Clinic), we used to call, talk, fight, and even cry with them. (...) Priority cases were always approved. But then we had this difficulty, this door of the BERA test, especially for children in the maternity ward. This one (from the Specialized Center) has always done the job. (...) then, maternity ward identified among our babies (the suspicion of hearing loss) and we always managed to have access (to tests) through it (Specialized Center).

Represented by the manager and the technical support representative, who played an active role and with relative autonomy in the search for solutions, the Municipal Regulation Center was essential to connect services, aiming to ensure the flow of users and correct inequities in access.

These measures have been decisive either to confirm or deny the hearing loss as early as possible, before the first six months of life, as happened with João Victor. The reconstitution of the child's therapeutic itinerary made it possible to identify a weakness in the line of care for newborns/infants, which has not become even more evident due to local management initiatives to overcome barriers.

Hearing rehabilitation

As shown in Table 1, all rehabilitation actions are expected to be conducted at the *Hearing Rehabilitation Center* (*Hearing Health Clinic* and *Specialized Center*), according to the regulations of the Ministry of Health[7]. Therefore, the indication, selection and adaptation of PSAPs; speech-language pathology therapy; psychological evaluation and monitoring; and social service assistance must be conducted at the *Hearing Rehabilitation Center*.

The speech-language pathology therapy is managed by the *Specialized Center*; however, according to the professionals of the *Hearing Health Clinic*, the speech-language pathology therapy should be managed by the municipality where the patient lives, so it can be closer to the user. Sometimes, the institution has already adopted this practice when referring the patient to municipal health services that provide speech-language pathology therapy.

As shown by the study of Youssef, Mendes, Costa, Ficker and Novaes[20], the professionals also reported that the distance from the users' residence to the institution may represent an obstacle to their adherence to the rehabilitation process..

In Minas Gerais State, for example, there was a decentralization of the speech-language pathology therapy through the creation of specific services to provide this care in order to overcome this problem[21]. This allows greater access by reducing the geographical barrier and providing services closer to people, with consequent greater adherence. This measure relieves the burden of specialized services, which can focus their efforts on the evaluation, selection and adaptation of PSAPs[22].

In addition, users generally use the public transportation provided by municipal management when they need to move to another city, which implies a cost to ensure user's access to the service. This means that the farther the service is from where the user lives, the greater the financial implications for the municipality[23].

The *Hearing Health Clinic* is trying to work on this issue by referring users to speech-language pathology therapy in their cities; but not all municipalities have an adequate service. It should be added that, although it is preferable for the user to have a speech-language pathology therapy closest to their home, if not possible, every *Hearing Rehabilitation Center* must ensure such follow-up.

However, distance is not the only barrier to the access to speech-language pathology therapy. Often, speech-language pathology therapy is not provided in the same proportion as the hearing aids, even though it is precisely the speech-language pathology follow-up that will assist with the effective use of hearing aids and with practices aimed at the full development of deaf children[24].

In the context investigated, the speech-language pathology therapy provided at the *Specialized Center* is part of a broader program aimed at the newborn and their caregivers, which is called the *Deaf Children Family Orientation Program*. This program is aimed at parents of children from birth to three years of age and aims to provide psychological and social support to caregivers, as well as to expand the child's communication possibilities, through speech-language pathology practice and the learning of the Brazilian Sign Language (BSL), when indicated and asked by the family. In this program, the parents had weekly meetings with the speech-language pathologist to discuss issues related to the impacts of hearing loss in childhood, forms of intervention, importance of PSAP adaptation and the learning of BSL by family members. There is also psychological and social support.

It is also important to notice that the monitoring with deaf children is not restricted to them, as it also includes their respective families, as recommended. A study by Lima, Souza, Santos, Carvalho and Brazoroto[25], that evaluated the effectiveness of an intervention program for families of deaf children, showed that there were significant changes in communicative interactions between mothers and their children after 8 months of intervention.

The *Specialized Center* offers BSL instructors who work with children and parents to learn this language, as children are expected to have contact with this language from the first months of life and that they will learn Portuguese later or simultaneously. As the children grow, they will be assisted in two other sets of actions, the *Children's Program: Language and Deafness* and the *Deafness and Education Program*.

It is also noteworthy that the therapeutic follow-up provided to the newborn with hearing loss meets the regulations for the qualification of the assistance and still includes the BSL as a possibility in the therapeutic process, which is not provided in any directives of the MS and that may serve as an example for other services with the same qualification.

Returning to João Victor's journey, the suspicion of his hearing loss occurred in a timely manner, still in the first month of age, when he did not pass the hearing screening. The NHS was performed in the first month of life, but the intervention that started with the adaptation of the PSAP took place shortly after 12 months of life.

To allow hearing rehabilitation in a timely manner, an early diagnosis of hearing loss is necessary. It is well documented in the literature that the first years of life are a critical period for the development of auditory skills. In fact, therapeutic intervention should be started in this period, in order to provide the necessary conditions for language development[20]. The early identification of hearing loss is essential and must occur up to three months of age, while the therapeutic intervention must start until six months of age, in order to enable the adequate development of the child[26;27].

The study by Rovere, Lima and Silva[28], which analyzed two groups of deaf children and adolescents who started rehabilitation early and late, pointed out that the group whose members were diagnosed with deafness and started the rehabilitation program early showed greater development in communication skills, making spontaneous use of Sign Language and a more effective communication with family members, when compared with the group of children who started late.

Once the hearing loss was confirmed and the PSAP adaptation process started, the child entered the *Deaf Children Family Orientation Program*. It was possible to observe the lack of the BSL in the therapeutic itinerary of João Victor, which is probably due to the fact that his ability is very close to the standard of normality according to his auditory skills associated with the use of PSAP. Thus, it is possible to notice that the access to BSL learning does not mean that it will be an option for every patient, as the choice of parents must be considered, above all.

The role of the Primary Health Unit

In Primary Care, teams are expected to perform a set of actions to promote hearing health, prevention and early identification of hearing disorders, as well as informative, educational and family counseling actions, and referrals to specialized services, when required[7]. The UBS is often the place where hearing impaired users will report their complaint, or where such a complaint may be perceived by professionals during the provision of some assistance.

Primary Care must be very integrated with the NHS Programs and *Hearing Rehabilitation Centers*, as it is responsible to check if the NHS was performed, if there was a need for a follow-up visit to perform the retest or if the patient attended for diagnostic evaluation, when necessary, in addition to supporting the PSAP adaptation processes. The study by Fernandes and Nozawa[13] reported that the effectiveness of a NHS program depends, among other factors, on the involvement and participation of family members throughout the process. This study also found that one of the reasons for the non-adherence of families to the program is due to the mothers' belief that doctors, during childcare consultations, will be able to assess any needs related to the child's hearing.

There is insufficient awareness that newborns, especially those with HIRI, must go through monitoring of hearing and language development[4] in Primary Care, even in cases where the newborn obtains a result of normal functioning of outer hair cells in OAE tests, as progressive or late onset hearing loss may occur[5].

However, actions in the daily routine of Primary Care are generally restricted to the prevention of problems that can lead to hearing disorders, such as vaccination campaigns and the control of arterial hypertension and diabetes mellitus, even though its relationship with hearing health is not clearly perceived. Although they are prerogatives of Primary Care, it is not common to find actions specifically focused on the early identification of signs that indicate a hearing problem, on monitoring hearing development and on hearing care for newborns and children. Generally, professionals are requested after a complaint is submitted, restricting themselves to referral to specialized services.

Therefore, it is imperative that Primary Care fulfill its coordinating role, closely monitoring cases that are in hearing rehabilitation and providing the necessary support to solve possible problems arising in the process.

A simple procedure was required in João Victor's therapeutic itinerary in order to remove excess earwax to allow the PSAP adaptation. However, the user was referred from the UBS to the specialization clinic in the municipality, joining a long waiting list, without any analysis of the priority level of the situation and the consequences that a late adaptation of the hearing aid would cause in his development. The situation highlights the importance of well-defined rules of referral to specialists, with risk assessment to ensure greater resolution of the system.

This is not an isolated fact since, as reported by the *otorhinolaryngologist at the Hearing Health Clinic*, it is not uncommon for patients to be referred from the municipalities to the *Hearing*

Rehabilitation Center of high complexity in order to remove excess earwax.

"*We receive referral from the city's emergency department: 'Please remove the patient's ear wax'. So, the patient comes from another city to a tertiary or quaternary hospital just to remove earwax!?*"

This is a relatively simple procedure, which must be performed by an otolaryngologist, but it can also be performed by a family doctor or general practitioner. The availability of adequate material in health units and the training of primary care physicians (clinicians, pediatricians, family health doctors) could help to reduce the demand for the specialization clinic of the municipality, reduce the waiting list of the otorhinolaryngologist and increase the system's resolution, while considering that there may be cases in which the referral is necessary.

The difficulty in accessing this simple procedure faced by João Victor is not a particular aspect of health care for people with disabilities. A study by Cecílio et al.[29] showed the great difficulty faced by users to access specialized care, which is also faced by Primary Care teams that lack the means required. Due to problems like this, users like João Victor's family resort to the private sector.

The permanent training of professionals in the primary care network can be conducted by the staff of the municipality's specialization clinic or by the *Hearing Rehabilitation Center*, which has this role provided in its regulations[1;7]. These professionals could work in a logic of matrix support[30], providing technical-pedagogical support to the reference teams of Primary Care, seeking to increase their autonomy and response capacity.

Permanent training may be stimulated and coordinated by municipal management in order to overcome these issues, in addition to being a powerful device to cause changes in work processes and to increase the provision of care. Given its potential for transformation, this initiative is a guideline and goal of the Care Network for People with Disabilities[1].

Final considerations

The reconstruction of the therapeutic itinerary proved to be a significant methodological tool to analyze the health care comprehensiveness, making it possible to understand the user's actual trajectory in the search for care in health systems. In this sense, the reconstruction of the journey taken by the patient, from the initial perception of the health problem to the provision of the required care, allow us to know the true operation of the health care network.

Although still under construction, the *Care Network for People with Disabilities* has been a major advance in improving the lives of people with disabilities, since it clearly presents the requirements for the implementation of a new network and the link between its facilities.

A significant step towards a comprehensive care was to bring together more than one type of disability in the Specialized Rehabilitation Centers, making an integrated management by demand and need and not by type of disability. The Hearing Rehabilitation Center investigated in this study is still a facility that works with the former logic, prior to the creation of the care network. Therefore, when the user needs a service that performs auditory rehabilitation, they will need another service that provides physical rehabilitation. The narrative of the therapeutic itinerary presented proves the need to overcome this model, which is expected from the expansion of the *Care Network for People with Disabilities*, allowing children to be cared for in a single specialized service, even when they have more than one type of disability.

The *Care Network for People with Disabilities* has advanced in many aspects, especially by providing that disabled people are users of the SUS not only for rehabilitation, but for any and all services provided, depending on the need. This network is relatively new in the NHS and further research on its implementation process, aimed mainly at contributing to advancing the quality of care provided to users with disabilities is essential for its consolidation.

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