

Original Article

Artigo Original

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From suspicion to intervention in deafness: characterization of this process in Campinas/SP

Da suspeita à intervenção em surdez: caracterização deste processo na região de Campinas/SP

ABSTRACT

Purpose: To identify and detail the current situation of diagnosis and assistance to deaf children in two cities belonging to the administrative region of Campinas (SP). **Methods:** It was conducted a survey of 320 medical records of patients diagnosed with prelingual deafness in the period between 1996 and 2005, in two institutions located in the region of Campinas: a university clinic and a clinic specialized in the assistance to deaf individuals. **Results:** Regarding the suspicion of hearing loss, the average age of the subjects was 1 year and 9 months. The mean age of children referred to medical or speech-language pathology service was 3 years and 6 months; the mean age for deafness diagnosis was 4 years and 3 months; the mean age for the beginning of clinical intervention was 6 years and 1 month; and the mean age for hearing aid adaptation was 7 years and 5 months. **Conclusion:** Suspicion of deafness, the first visit to a doctor, diagnosis, intervention and hearing aid adaptation were all delayed when compared to current recommended diagnostic standards and conditions of access to services. In addition, there was a significant delay between each stage, especially in the period between the suspicion of deafness and the beginning of clinical intervention. Although Campinas region is well developed in economic terms, offering a broad network of health assistance services, this network was little efficient regarding assistance to deafness.

RESUMO

Objetivo: Identificar e detalhar a situação do diagnóstico e atendimento de crianças surdas de dois municípios que pertencem à região administrativa de Campinas (SP). **Métodos:** Foi realizado levantamento de 320 prontuários referentes à pacientes com diagnóstico de surdez pré-lingual no período de 1996 a 2005, em duas instituições localizadas na região de Campinas: uma clínica especializada no atendimento à surdez e uma clínica universitária. **Resultados:** Quanto a suspeita da perda auditiva, a média de idade foi de um 1 e 9 meses. A média de idade da primeira consulta com o médico ou fonoaudiológico foi de 3 anos e 6 meses; para o diagnóstico da surdez 4 anos e 3 meses; para o início de intervenção clínica 6 anos e 1 mês; e para a adaptação de aparelho de amplificação sonora individual (AASI) 7 anos e 5 meses. **Conclusão:** A suspeita, primeira consulta médica, diagnóstico, intervenção e adaptação de AASI ocorreram tardiamente, se considerados os padrões diagnósticos e de acesso aos serviços preconizados na atualidade. Além disso, há um intervalo de tempo importante entre cada uma das etapas, destacando-se principalmente o período entre a suspeita da surdez e o início da intervenção clínica. A região de Campinas é bastante desenvolvida economicamente, dispõe de uma ampla rede de serviços de saúde, mas se mostra pouco eficiente no que se refere ao atendimento em surdez.

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INTRODUCTION

Hearing is one of the senses that offer relevant information to human development. Therefore there are many implications resulting from hearing losses, especially those related to the development of language and oral communication.

The earlier the deafness is diagnosed, the greater the possibilities of intervention and support to the subject's social cognitive development. Hearing is essential to thought organization and to the comprehension of the world and of others, being part of one of the human's superior mental functions, i.e. communication^(1,2).

Studies conducted in 1998 and 1999⁽³⁻⁵⁾ has shown that children who had been diagnosed before 6 months of age and who soon (2 months) were enrolled in intervention processes were within normal expressive and receptive language measures when they were reassessed at 26 months of age. Children who were diagnosed after the 6th month of age and that therefore were later enrolled in intervention programs presented significant delays (12 to 14 months) in expressive and receptive language, when compared to hearing children.

Studies also points out to the relevance of intervention before six months of age to a better language development prognosis. Children whose hearing disorders diagnosis were detected prior to the 6th month of age have better language, speech and cognitive development than the ones that received the diagnosis after this period⁽⁶⁾.

The central nervous system presents a great plasticity when early stimulated, specially until 6 months of age, leading to an increase of nervous connections and therefore to better rehabilitation of the hearing path⁽⁷⁾. This way until the 6th month of age, the central auditory system undergoes positive or negative changes depending on the amount and quality of stimuli presented and perceived⁽⁸⁾. Deafness' early detection is essential because it increases the probability of obtaining the better potential of expressive and receptive language, academic performance and social and emotional development^(9,10).

Due to the importance of early diagnosis of deafness and information about language development in deaf children, it is necessary to examine the reality of identification and early diagnosis. This way it will be possible to propose procedures to prevent language delays in deaf children.

This work aimed to identify and detail about the general situation of diagnosis and speech therapy for deaf children in two cities that belong to Campinas administrative region (SP).

METHODS

This study was authorized by the Ethics Research Committee of Universidade Estadual de Campinas, protocol 600/04, referring to a retrospective analysis.

The research is a retrospective study conducted in two institutions: a specialized clinic in Campinas and a school-clinic in Piracicaba⁽¹¹⁾. These institutions are very important because they provide free assistance or charge according to the patient's

economic level. They offer services to individuals of any social level, but most of the patients have a low income.

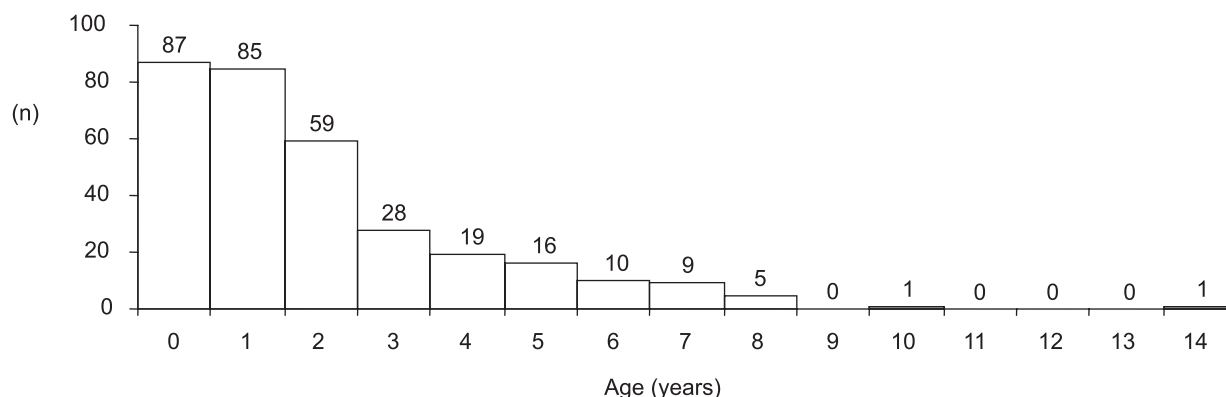
Data were collected from the protocols of patients treated from 1996 to 2005, diagnosed with pre-verbal deafness. In the school-clinic we considered the information referring to 114 of patients treated during the investigation period. This service is not equipped to perform a complete diagnosis of deafness (there is no equipment for evoked otoacoustic emissions – EOAE – or brainstem auditory evoked potentials – PEATE) and when these assessments were needed the patients were referred to other services, most frequently in the city of Campinas, where there are major hospitals and specialized services. The focus of the school-clinic is speech and language therapy and it also provides selection and hearing aid fitting services. However, it does not provide the hearing aids, referring the patients to proper services.

In the specialized clinic data about 206 patients were used for this study. This institution was founded in the city of Campinas in the late 1980's with the aim providing services to families of deaf children that didn't had other resources. Nowadays, it operates in its own building, has infrastructure with classrooms and offices, and provides assistance in the areas of Social Services, Otorhinolaryngology, Audiology, Speech and Language Therapy and Learning, being considered a reference center in Campinas and surrounding cities as regards deafness. It receives people of all ages, with a large number of elderly and an increasing number of children and adolescents. Moreover, at the time of data collection the selection, adaptation and provision of the hearing aids by the public health system (SUS) was being performed in a joint effort by two of the cities universities.

Thus, the data gathered in both institutions refer to 320 patients. Patients' protocols of both services were divided according to the multidisciplinary team, and analyzed according to: registration form, social service, speech and language therapy anamnesis, otorhinolaryngologic assessment, speech-language assessment involving indication and/or hearing aid adaptation, and speech and language therapy. A specific protocol was used to register all data (Appendix 1).

The following information were studied: gender; parents' education and occupation; city of origin; age of suspicion of deafness; how this happened; who suspected; age when the patient visited the physician or the speech-language pathologist for the first time; type and degree of the hearing loss (per ear); cause of deafness; age at speech evaluation; age of intervention onset; other medical services after diagnosis before being treated in the institution; education beginning and end; age of hearing aid adaptation and if was still using hearing aid or not by the time of the study.

The analysis of data was mainly quantitative and based on these results the qualitative aspects were discussed. The tables present the results of the statistical descriptive analysis of the data, with the arithmetic average, standard deviation and minimum and maximum percentage values. The software used was the Statistical Package for Social Sciences (SPSS) 7.5⁽¹²⁾ for Windows. As data did not present a normal distribution, a non-parametric test (Mann-Whitney's U test) was used.



Legend: n = sample size

Figure 1. Distribution of cases regarding age of suspicion of hearing loss

RESULTS

Hearing loss suspicion age ranges from two months to 14 years and in 34 cases (10.6%) there was a suspicion of deafness. The average age was 1.9 years. Figure 1 shows the distribution of cases in years by age of hearing loss suspicion.

The mean age of subjects in the first appointment with the physician or speech-language pathologist was 3.6 years. Deafness was diagnosed from 1 month to 20 years, with a mean age of 4.3 years. Both subjects that were diagnosed at one month had been submitted to neonatal hearing screening. The age of intervention onset varied from 6 months to 28 years, with an average age of 6.1 years.

In what refer to the hearing aid adaptation the age variation was from 11 months to 42 years with a mean of 7.5 years, as shown in Figure 1. Data about minimum, maximum and median age from the moment of suspicion to the hearing aid adaptation is shown in Table 1.

Table 1. Data distribution regarding subjects' age from deafness suspicion to hearing aid adaptation

	n	Mean	SD	Minimum	Maximum
Suspicion*	320	1.9879	2.1228	0.2	14.00
Doctor visit	320	3.6371	3.3489	0.2	19.00
Diagnosis age	320	4.3305	3.5531	0.1**	20.00
Intervention	320	6.1795	4.3507	0.6	28.00
Hearing aid age	320	7.5153	6.2845	0.11	42.00

*34 cases no suspected; **newborns who were submitted to hearing screening
Legend: n = sample size; SD = standard deviation

Data about the moment of suspicion, first appointment with physician, diagnosis, intervention and hearing aid fitting are presented separately to allow the comparison between the two services. The mean age of deafness suspicion was higher in the specialized clinic (Table 2).

As regards the age at diagnosis, it was also verified that specialized clinic's patients were diagnosed later than those at the school-clinic as shown in Table 3 (Table 3).

Using Mann-Whitney's U test it was observed that there is a relevant difference between the mean ages at diagnosis in

Table 2. Data distribution regarding subjects' age when deafness was suspected, in each institution

Institution	n	Mean	SD	Minimum	Maximum
University clinic	114	1.5610	1.7506	0.2	1.0
Specialized clinic	206	2.2242	2.2728	0.2	14.0

Legend: n = sample size; SD = standard deviation

Table 3. Data distribution regarding subjects' age when deafness diagnosis occurred, for each institution

Institution	n	Mean	SD	Minimum	Maximum
University clinic	114	3.8168	3.7223	0.1	18.00
Specialized clinic	206	4.6148	3.4321	0.5	20.00

Legend: n = sample size; SD = standard deviation

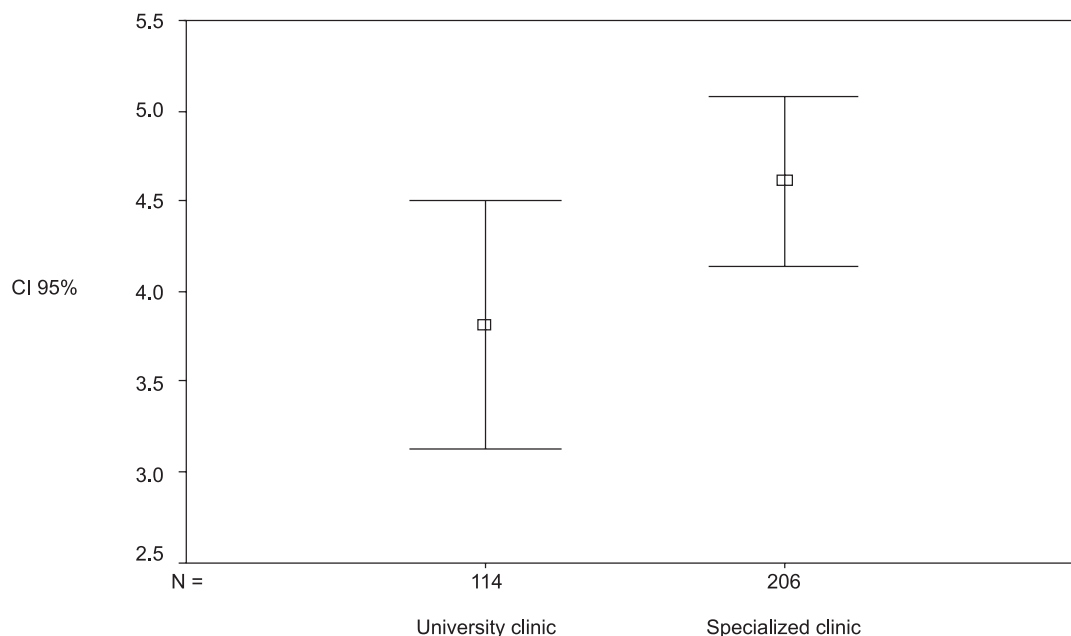
the two institutions, as Figure 2 shows.

As regards age of hearing aid use, the average age in the specialized clinic was higher than in the school-clinic (8.2 years and 7 years, respectively). Mann-Whitney's U test has shown relevant differences between the average ages ($p < 0.05$) (Figure 3).

DISCUSSION

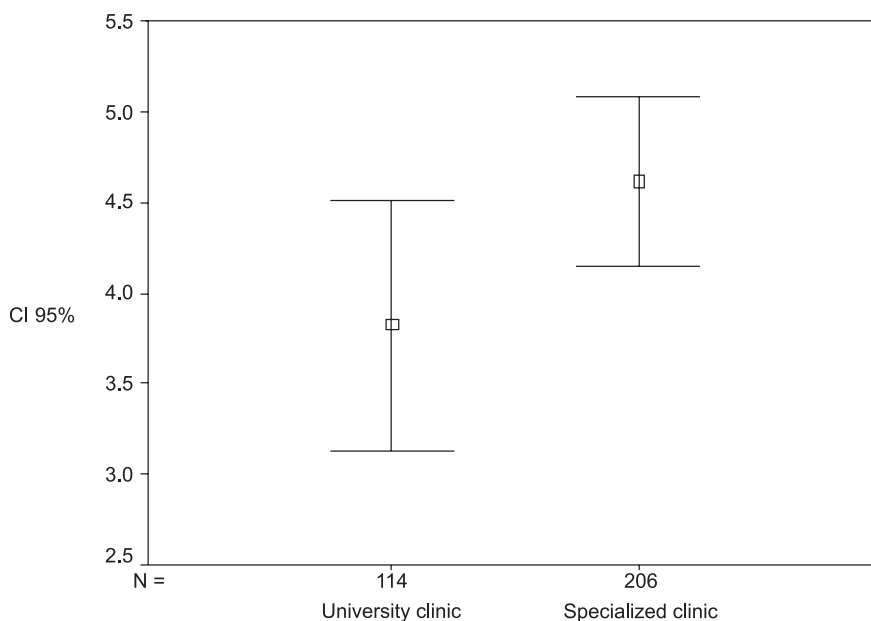
Results show that the average age of suspicion, the first appointment with physician, diagnostic, intervention and adaptation of hearing aid occurred later than in other researches or standards determined by national and international committees, which recommend that the diagnosis occurs around the 3rd and 4th month of a baby's life, and the intervention before the 6th month^(13,14). It is important to consider that this study, as compared to others, covered a larger, more heterogeneous, population as concerns age and maybe this has influenced the results⁽¹⁵⁻¹⁹⁾.

It was observed that deafness suspicion occurred mostly in family situations with the consequent mobilization to the diagnosis, what was also found in other researches⁽¹⁵⁻¹⁹⁾. This is an alarming finding, because the number of suspicions raised by health professionals was extremely low even for children assisted in public health administration for vaccines and child care. It also happened in other studies^(9,20,21).



Legend: CI = confidence interval

Figure 2. Confidence interval of 95% of the age (in years) when deafness diagnosis occurred



Legend: CI = confidence interval

Figure 3. Confidence interval of 95% of the age (in years) when the use of hearing aid began, for each institution

It was possible to notice a relationship between time of suspicion and type of loss: profound losses were suspected around 1.9 years, severe losses around 2.8 years and moderate losses around 9.8 years, a result also found in another study⁽¹⁸⁾.

There was a great time span from parent’s suspicion to deafness diagnosis. This may be related to uncertainty by the family about deafness and at the same time the fear to confirm this suspicion. Another possibility is related to health service procedures, which deals with this demand referring patients

to audiologists and hearing assessment, and these are not able to diagnose all children immediately due to the great number of referred cases.

The average age of deafness diagnosis confirmation was around 4.3 years and it has relevant implications regarding language acquisition. During the nervous system development all sensory systems, especially nerve pathways, mature at the same time as the motor system and mental processes. Thus, if there is a hearing deficiency at the stage of maturation (between

0 and 3 years of age) there will be impairments that are unlikely to be corrected later and that can impair children's development in school, family and social domains⁽²²⁾. Diagnosis occurs very late for this population, revealing a reality that deserves more attention from those interested in health and life quality.

There were statistically relevant differences between the mean ages at diagnosis: patients of the specialized clinic were diagnosed later than those of the school-clinic. This is an unexpected data because the school-clinic is not a diagnosis center, but a care center, as it is not equipped to audiologic procedures. Specialized equipment is rare in the region, and this often requires some time of waiting before exams are performed. We must emphasize that the specialized clinic has equipment which patients at the school-clinic in Piracicaba are referred to for a complete hearing assessment. Thus, it would be expected that this deafness diagnostic center would be faster as regards early diagnosis but the data did not confirm this hypothesis.

We must emphasize that Campinas, the place of the specialized clinic, is a city with many resources that concentrates a large number of state-of-the-art industries and has a metropolitan way of life, and is considered, according to Department of Economy and Planning of São Paulo Government an area having a huge number of health services able to do almost all exams and procedures⁽²³⁾.

In Campinas, Law 10759, 02/16/2004, make it mandatory that all hospitals and health services detect deafness in newborns during the neonatal period or until 60 days of birth, and according to Decree 432, 11/14/2000, procedures carried out in TANU (Universal Neonatal Hearing Screening). This are high complexity programs that must be authorized by the proper agency (APAC), but the service is not available to all users in many maternity hospitals.

The average age of hearing aid adaptation may also be considered as occurring later than recommended, for it is later than the ideal age, which is around 6 months^(3,4,9,21). Hearing aid adaptation must be conducted as soon as the diagnosis is concluded⁽²⁴⁻²⁵⁾ as a resource to prevent a longer period of sensorial privation and to begin speech and language intervention.

CONCLUSION

Results allow us to conclude that deafness suspicion, first physician appointment, diagnosis, intervention and use of hearing aid occurred very late considering modern recommended standards. There was a long waiting time to start early speech therapy, indicating a lack of public resources which cause delays, hampering the process of rehabilitation for deaf children.

Despite official approval of hearing screening programs, the population is not well assisted in regard to detection of deafness, not to mention diagnosis, intervention and hearing aid adaptation before six months of age. The relevant difference between average age at diagnosis of deafness and patient use of hearing aid devices reveals a worrisome situation, indicating that assistance services to deafness were not able to perform the necessary procedures at the right time. This shows the need for a more detailed investigation of the reality about the assistance

to deafness to promote a more appropriate care standard in a more structured way.

The National Policy of Assistance to Auditory Health was implemented in a more structured way in the region of Campinas since 2004, something that would change this reality. However, collected data has not shown the impact of this recent measure.

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Appendix 1. Protocol for data collection

Graduate Program in Child and Adolescent Health / CIPED
Data survey – deafness
Institution: _____

Date: _____ () Archive () Patient assistant
Name: _____ Age: _____
Birthdate: _____ Education: _____
Mother occupation: _____ Mother education: _____
Father occupation: _____ Father education: _____
City: _____
Deafness suspicion date (child's age): _____
How was deafness suspicion: _____

Who suspected: _____
Child's age at first doctor visit/speech-language pathologist: _____ Speciality: _____
Diagnosis: RE / LE () sensorineural () conductive () mix () normal
RE () light () moderate () severe () deep () deafness
LE: () light () moderate () severe () deep () deafness
Deafness ethiology: _____
Audiologist evaluation date: _____ Child's age: _____
Starting intervention date: _____ Child's age: _____
Have you searched another doctor after diagnosis?: _____
Scholar starting and/or finishing date: _____
Institution's leaving and cause date: _____
Hearing aid: () Yes () No Since? _____
() RE () LE () BE
Hearing aid use yet?: () Yes () No Last datum: _____

Current time: Deafness suspicion and first visit to the doctor: _____
First visit to the doctor and diagnosis: _____
Diagnosis and beginning of intervention: _____

Observations: _____