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Characterization of a service in speech-language therapy to individuals with Autism Spectrum Disorder

Caracterização de um serviço de referência no atendimento fonoaudiológico a indivíduos com Transtorno do Espectro do Autismo

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ABSTRACT

Purpose: This study characterized and analyzed data about children and adolescents that received language assessment and intervention in the last 21 years, in a service where clinical care is systematically associated with research and vocational training covering both at undergraduate and postgraduate levels. **Methods:** It is an *ex-post-facto* research based on an empirical exploratory longitudinal methodology that used data recorded in paper and digitally. **Results:** Only 12% of the individuals started intervention before completing 4 years old, or before this age, 74% started between 4 and 9 years and 14% after their 10th year. Among the 340 individuals, 81 (24%) were in therapy process for less than one year. **Conclusion:** It was possible to verify that the mean age on therapy onset is delayed, the amount of dropouts is significant and that there is no association between this data. The number of dropouts on speech-language therapy is 36% of the sample. A limitation to be considered in this study is that the age of the individuals analyzed corresponds to the time at which they were brought for speech-language evaluation in the LIF-DEA and not to the age at which they were diagnosed.

Keywords: Autism; Children; Language; Speech therapy; Longitudinal analysis

RESUMO

Objetivo: Buscou-se caracterizar e analisar os dados relacionados ao atendimento fonoaudiológico dirigido a crianças e adolescentes que realizaram avaliação e atendimento nos últimos 21 anos, em um serviço em que o atendimento clínico é sistematicamente associado à pesquisa e à formação profissional nos níveis de graduação e pós-graduação. **Método:** Trata-se de uma pesquisa *ex-post-facto*, baseada na metodologia empírica exploratória longitudinal, com a utilização de prontuários para a coleta de dados. **Resultados:** Somente 12% dos pacientes iniciaram o atendimento com 4 anos, ou antes desta idade; os que iniciaram o atendimento entre 4 e 9 anos representaram 74% e 14% iniciaram a terapia fonoaudiológica com mais de 10 anos de idade. Dentre os 340 pacientes analisados, 81 (24%) realizaram um ano ou menos de terapia. **Conclusão:** Foi possível observar que a média da idade no momento de busca pelo serviço tem ocorrido tardiamente; o número de desistências/abandonos do atendimento fonoaudiológico foi de 36% da amostra e a idade em que a criança iniciou não esteve relacionada à maior adesão ao tratamento. Uma limitação a ser considerada neste estudo é que a idade dos indivíduos analisados correspondeu ao momento em que foram trazidos para a avaliação/terapia fonoaudiológica no LIF-DEA e não à idade em que foram diagnosticadas.

Palavras-chave: Autismo; Crianças; Linguagem; Fonoaudiologia; Análise longitudinal

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INTRODUCTION

In 1986, a service that for many years would be the only speech therapy service in a psychiatric hospital in Brazil was implanted, together with a psychiatric service of childhood and adolescence[1,2]. After reformulation and curricular restructuring, this service began to integrate teaching, research and clinical care activities.

As well as the service described, which presented several changes and evolutions, the concept of autism has evolved greatly since its first description in 1943, by Kanner, who resorted to the notion introduced by Eugen Bleuler in 1911. Only in its third version, the Diagnostic and Statistical Manual of Mental Disorders (DSM-III[3]) started to include autism among childhood psychiatric disorders, suggesting specific diagnostic criteria. In its latest version, DSM – 5[4] proposes the classification of Autism Spectrum Disorder (ASD), replacing that of Global Developmental Disorders (GDD), previously adopted.

The prevalence related to ASDs has also demonstrated changes over times and, recently, the scientific literature and the media, in general, have mentioned an increase in the prevalence of ASDs. According to Centers for Disease Control and Prevention (CDC), currently, one in every 59 children in the United States of America (USA) is included in the autism spectrum[5]. The growth of this prevalence may be related to the improvement of diagnostic tools, increasing awareness about the disorder and/or growth of its incidence over times[6].

Even though, there are some options for tracking signals and updates in the main diagnostic manuals, but it still occurs late[7-9] and, often, the speech therapist is the first professional to be sought by the guardians who suspect that the child may have a diagnosis included in the autism spectrum[8,10].

Both at the time of evaluation and during intervention, it is essential to consider that individuals with autism present a wide variety of manifestations and symptoms. Overall, the treatments are mainly focused on interaction or social communication deficits, restricted and stereotyped behaviors, sensory issues or challenging behaviors, which affect the development of functional skills and independence[6].

Among the manifestations and symptoms, the incidence of alterations in the language that coexist with ASD is high, thusthe speech therapist plays an important role in the diagnostic process and treatment[11].

Several authors have agreed that speech therapy is among the most common and most frequently interventions carried out by people with autism[12,13].

The treatment, regardless of the theoretical-clinical line chosen, should begin as soon as possible and be adapted to the specific needs of each child and family. The intervention in the first years of life has a significant impact on the performance of many autistic children, and the participation of parents, as co-therapists in some intervention programs, is crucial[14].

Taking into account the changes occurring and the importance of evidence-based practice, the objective of this research was the use of a single sample provided by a referral service, which conducts and uses the research as the basis of its care. The service has a consistent history and systematic record of data from a significant number of children from January 1997 to December 2017. In other words, from the presentation and analysis of data related to this service, this research aimed to contribute towards reflection about the importance of historical records systematization, which provide evidence to improve the professional practice.

METHOD

This is an *ex-post-facto* research, based on the empirical longitudinal exploratory methodology with medical records for data collection.

The research was developed at the *Laboratório de Investigação Fonoaudiológica nos Distúrbios do Espectro do Autismo* (LIF-DEA) and was approved by the *Comissão de Ética para Análise de Projetos de Pesquisa da Faculdade de Medicina da Universidade de São Paulo*, with Protocol No. 224/16.

The records of patients who underwent speech therapy in the LIF-DEA in the last 21 years were selected from the archive, i.e., from January 1997 to December 2017.

The inclusion criteria involved the medical records of all individuals who attended for evaluation and speech therapy. Data from 2011 are computerized in a system specifically developed for LIF-DEA (IDEA).

The exclusion criteria involved individuals who interrupted care in LIF-DEA before January 1997 and/or those who initiated their care after January 2018, besides patients who came to the first care, were evaluated and were not diagnosed with ASD.

RESULTS

Due to the longitudinal analysis, some data collected appeared in an unsystematic way and, therefore, it was necessary to exclude some information, opting to keep the data obtained in the total sample, such as age, gender, time of attendance and reason of interrupting the treatment.

The statistical analysis was based on the data sample of 340 individuals, 73 females and 267 males.

The age range of care beginning ranged from 0 to 20 years old. Of these 340 individuals, only 12% initiated care at 4 years old, or before this age; those who started care with ages between 4 and 9 years old accounted for 74% and 14% started speech therapy with more than 10 years old. Figure 1 shows the characterization of this sample based on the age group in which the care started.

Information regarding the age of therapy beginning did not show a decrease in the age range over the years, that is, last years analyzed did not report age reduction at the time the patients seek care service.

It could observed that the average age of therapy beginning was 6 years old and the individuals remained in care service for approximately 3 and half years (Figure 2).

It was possible to observe that, over the 21 years analyzed, there was a variation in the age at which the evaluation and speech-language pathology began, however, by comparing the year 1997 and 2017, the average age was similar.

When reflecting on the age at which the patient was taken for evaluation/treatment, this evaluation/treatment is related to the child's gender, and it could be possible to notice that the age of the male patients was lower (peak at 4 years old) comparing with female patients (peak at 5 years old). In addition, after 13 years old, there was no evaluation of the female gender while males demanded the service until 20 years old.

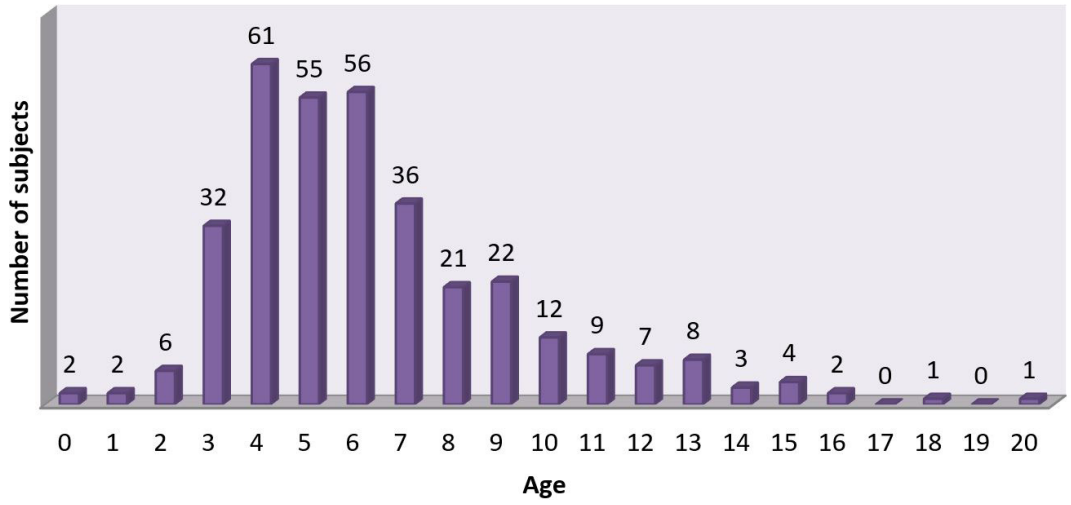

Figure 1. Sample characterization based on age of onset of care

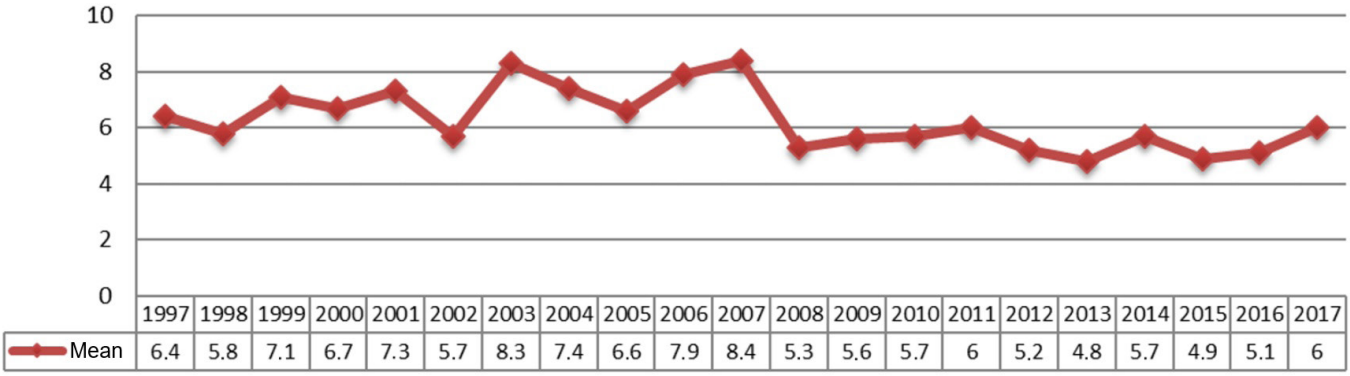

Figure 2. Mean age at beginning of assessment and speech therapy

Table 1. Correlation analysis between the length of service and the age of initiation of speech therapy for the total study sample

Variables		Age of initiation
Length of service	r	-0.072 [-0.160, 0.025]
	value of p	0.184

Pearson correlation test ([a])

Concerning the correlation analysis between the length of care and the age of arrival, for the total sample of the study, the correlation coefficient (r) and *p* value were calculated by means of the Pearson correlation test, since the sample size (n=340) allowed the use of parametric tests, due to the Central Limit Theorem (Table 1).

The results in Table 1 show that there was no statistically significant correlation between the length of care and the age of arrival. Therefore, the length of stay (LOS) in the service did not correlate with the age at which the treatment began.

It was observed that the abandonment/withdrawal rate of treatment was very high. Among the 340 patients analyzed, 81 (24%) carried out 1 year or less of therapy, without relying on the 48 subjects excluded from the analysis, because they attended only the first evaluation session. Most of treatment interruptions were due to abandonment and withdrawal, for several reasons.

DISCUSSION

Regarding the results found, it was possible to observe similar data on the proportion between the prevalence in males and females in other studies[5,15].

A limitation of this study is related to the age of the individuals analyzed corresponded to the moment they were brought to the evaluation/therapy in LIF-DEA. However, no data were found/collected/described in relation to those who had previously undergone therapies, whether they were in the diagnostic process or if they already had a defined diagnosis, at the time they arrived at the service.

In a study on global data[11], the typical age of the diagnosis was 3 years old, one year less than what was observed in this research, regarding the characterization of the sample based on the age range of the care beginning. The vast majority started after 4 years old, only 12% started before this age.

Research with data collected only in Brazil showed a different reality[9,16], reporting that Brazilian children tend to be diagnosed when they are between 5 and 6 years old.

Even presenting similar data in the proportion between sexes, according to the prevalence found in this study and to what is reported in the literature, this information is in the opposite direction compared to what Baio et al., 2018 presented[5], which

illustrated an increase in the proportion of females in the cases diagnosed with ASD.

Studies indicated that ASD, in some girls, might be unnoticed by the current diagnostic procedures, considered as gold standard. Thus, these girls receive fewer diagnoses when compared to males[17,18].

A study that analyzed the relationship among continuity, treatment adherence and the result of intervention mediated by the caregiver, for families of low-income children with ASD [19], demonstrated that families with lower socioeconomic status address treatment abandonment (TxA) more frequently. However, it is important to emphasize that this attitude is not part of the service culture where this research was performed to include data related to race/ethnicity and purchasing power of families during anamnesis and data collection, and therefore, it could not be found information regarding these aspects in the analyzed medical records.

Other results[20] showed that adherence to drug treatments is higher than therapy (independent of the model), and it is important to analyze the interference of therapy in the family dynamics/routine. Over the last years analyzed, especially after the introduction of medical records in computerized system, it was possible to observe data regarding the use of medication by patients, but in most medical records, the information regarding this issue is unsystematic, which does not allow their analysis.

With regard to information on interruptions and abandonment, it is essential to consider that one of the service proposals is to collaborate with families in the search for clinical services and schools near their homes. Thus, the indicative data for care interruption also include the situations in which this objective was achieved.

CONCLUSION

In view of the data volume of patients in the 21 years analyzed, this study aimed to characterize the age, gender and age at which care began in one of the oldest speech-language pathology services specialized in individuals with ASD in the country, suggesting the importance of systematic historical records for the construction of evidence and improvement of professional practice.

It was possible to observe that the average age for patients seeking care service was high; the proportion of dropouts/abandonment of speech therapy was considerable, that is, 36% of the sample, and the age at which the child started the treatment was not related to greater adherence to treatment.

Considering these aspects is fundamental for proposing new studies illustrating the Brazilian reality, as well as providing data to care services focused on this population, seeking to contribute to the efficiency of these services, guaranteeing the improvement of available resources.

One of the strategic objectives of the American Speech Therapy Association (ASHA) is to obtain objective data regarding the work of the speech therapist and the population this professional takes care. This study showed the need for systematic records of the work performed, preferably with computerized databases. It was observed a limitation in the characterization of data and reduction data loss after digitalization, thus ensuring that, in the future, other studies can offer more precise and specific data on speech therapy.

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