SURVEY PROTOCOLS AND DIAGNOSTIC METHODS APPLICABLE IN THE AUTISM SPEECH THERAPY CLINIC: A LITERATURE REVIEW

Levantamento de protocolos e métodos diagnósticos do transtorno autista aplicáveis na clínica fonoaudiológica: uma revisão de literatura

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ABSTRACT

The speech therapy, as the health science that studies human communication, plays a major role both on the diagnosis and on the treatment of people with autism. However, there are only few speech therapists who make regular publications on the theme - revealing that this is an area where more studies need to be made. The autistic disorder is characterized by a developmental deficit on social interaction, communication and behavior. The diagnosis must be substantial and the three fields above are to be taken into account. Frequently, the speech therapist is the first professional the parents look for; thus, such professional must be able to identify those cases. The objective of this research was to assess methods and protocols of assessment and diagnosis of the autistic disorder, available in Brazilian literature, that could be applied to the clinical speech therapy. Based on several references, ten protocols were found: seven were translated and validated from a foreign language into Brazilian Portuguese and three were developed in Brazil. No Brazilian publications were found using four out of the ten instruments that aimed at screening or diagnosing suspected cases or under risk of autism. It is also clear the minor participation of the speech therapist in such process. Additionally, none of those instruments was considered accurate enough to diagnose such disorder. It is of major importance stressing the need of a critical point of view regarding the reality of things that still happen in the process of diagnosing autism.

KEYWORDS: Autistic Disorder; Diagnosis; Tracking Programs; Methods

INTRODUCTION

The speech therapy, as the health science that studies human communication, plays a major role both on the diagnosis and on the treatment of people with autistic disorder. The Autistic Disorder is characterized by a developmental deficit on social interaction, communication and behavior — which is often restrictive and repetitive. Appearing during

the early childhood, it is developed by children no older than three years old¹. The manifestation of the disorder varies from child to child, according to their level of compromising and their age².

According to the International Disorders Classification¹-tenth edition –, the childhood autism is one of the Global Developmental Disorders, which also includes atypical autism and Asperger syndrome. In the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition² – DSM IV, the autism is one of the Pervasive Developmental Disorders (PDD), in a category named Autism Spectrum Disorder. Both manuals for the classification of mental diseases (DSM-IV and ICD-10) have the same objective: to establish criteria for the classification of diseases. ICD-10 is put together by American researchers, while DSM-IV is organized

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by European researchers. Therefore, the terminology may be different in some instances.

The etiology of this disorder is subject of several discussions. Currently, there is a group of researchers - mainly from France - who agree that it is of a multifactorial origin, with genetic predisposition not well established and environmental influences for the development of autism3.

The person responsible for making the diagnosis of autistic disorder is, in principle, the psychiatrist4. However, because it is added to the International Classification of Diseases (ICD-10), it may be applied by any capable physician. However, a multidisciplinary team, with the presence of a speech therapist, is required to assess the patient before the diagnosis is made. Because, more important than to tell the parents that their child has an autism condition is to make the child's characteristics evident, in general, by emphasizing their abilities to increase their global development.

The early diagnosis is extremely important for an intervention in time to change the child's development. Since autism appears in the very first years of life - otherwise it is not autism -, the earlier the stimulation begins, the better will be the change indices in the disorder's conditions. Thus, a differential diagnosis is necessary, because organic examinations cannot identify the autism by themselves3; a multidisciplinary approach is very important. Additionally, the assessment has to be performed with deep details in order to dissolve any doubts on the potential comorbidities, such as autism and deafness, autism and Down's syndrome and autism and blindness⁵. Usually the first complaint made by parents of children with autistic disorder is little or no pre-verbal and verbal communication from their child. It is also common that the parents suspect that their autistic child has hearing loss only6.

Some scholars have created their own methods and assessment/diagnosis protocols for autism; some of those may be applied by several knowledge areas, which speech therapy is a part of^{7,8}.

In this context, this study aims at surveying the methods and assessment/diagnosis protocols of the autistic disorder, available from the Brazilian literature, whose application may occur during the clinical practice of the speech therapy.

METHOD

Aiming at complying with the study's objectives, searches were made on the following databases: SciELO; LILACS; Portal Periódicos da Capes; BIREME, Portal Domínio Público; and Biblioteca Digital Brasileira de Teses e Dissertações, from

August 2011 to July 2012. The keywords Autism, Assessment and Diagnosis were used.

The inclusion criteria were Brazilian articles, theses and dissertations in Portuguese language published in the last 20 years. Any publication that did not address the autism diagnosis as main focus and whose contents were not from a speech therapy study were deleted.

REVIEW OF LITERATURE

Based on several references, only ten literatures published in Brazil were selected, which methods and protocols are validated in and address as a central theme the diagnosis of autism, and that may be applied in the speech therapy practice. It is worth mentioning that most are protocols that were translated and adapted from English into Brazilian Portuguese.

The first one is Childhood Autism Rating Scale (CARS), published in 1988, whose study lasted for 15 years and relied on 1,500 autistic children for validation in the United States of America (USA)7. It is able to demonstrate the difference between levels of severity in autism: mild, moderate and severe. Since it is also possible to differentiate the autism from mental retardation, and due to the fact that it is applied to children from two years old on, it has been widely used. Thus, in 2008, its translation and validation into Brazilian Portuguese was published and named as CARS-BR9.

Such scale scores items from 15 fields: Relationship to People, Imitation, Emotional Response, Body and Object Use, Adaptation to Change, Visual Response, Listening Response, Taste-Smell-Touch Response and Use, Fear and Nervousness, Verbal Communication, Non-Verbal Level, Activity Level Communication, Consistency of Intellectual Response, and General Impressions. Each subitem may score the child from one to four, achieving a minimum score of 15 and a maximum score of 60. The higher the score, the closer the approximation and severity of autism. If the child scores 15 out of 30 points, it may be considered non-autistic; between 30 and 36, mildly to moderately autistic and 36 to 60 as severely autistic.

Communication is a field to be assessed by this scale, which is the primary study object in speech therapy - thus we believe that the speech therapist may use it in their clinical practice. However, this is not proposed explicitly. Additionally, no other specific professional able to use this tool is indicated. It was created by physicians and it must be applied by interview with the child's parents or guardians, as well as direct observation of the child.

The cons of this tool are that it tends to diagnose children with learning deficit as autistic in the age group between two and three years old 10, or even those whose corrected mental age is equal to that age group¹¹. In order not to make mistakes, the interview must be applied by a trained professional. because the interpretation may be confusing and erroneous12.

That tool may only be applied to children aged at least two years old, and it is reliable for children from three years old on. Thus, this is a tool that does not provide early diagnosis, since researches have been indicating the identification of early signs and characteristics of autism in the early months of life^{8,13,14}.

The interdisciplinary assessment based on the program named Treatment and Education of Autistic and Related Communication of Handicapped Children - TEACCH¹⁵ (translated into Portuguese as Tratamento e Educação para Autistas e Crianças com Deficits Relacionados à Comunicação) for autistic children is meant to evaluation only - and not for diagnosis -, which could comply with such purpose regarding the classification used.

That evaluation method is comprised of four protocols subdivided into several criteria, evaluating Social Interaction, Communication Functions, Cognitive Aspect and Behavior. Each criteria may obtain as an answer: Pass (P), Emergent (E) or Fail (F); numerically, that corresponds to P=3, E=2 and F=1. The quantification is not aimed at classifying the level of autism (mild, moderate, severe), even though it may be interpreted as such. Such tool lists the abilities the person applying it must be aware of and develops strategies to assess those abilities when it comes to the child's answers.

One of the principles of the TEACCH program is that the professional who helps the child with autistic disorder is to be generalist and multidisciplinary¹⁵. In other words, it does not matter their specialization area: the physician must be able to deal with all and any manifestation caused by autism, being completely responsible for the person they are supposed to follow. Thus, this evaluation method may be used by any professional dedicated to study and capacitate to deal with children with autistic disorder; this was the only tool found by this survey that relied on the participation of speech therapists during the creation.

The interesting in this evaluation methodology are the several criteria assessed regarding the abilities impaired by the autistic disorder. However, its denominations may create ambiguity to the person applying it, if they are not familiarized with the terms; thus it may be complex and require capacitation of the professional in the area. Additionally, it does not mention the strategies that may be used to make those criteria easier to assess. Apparently, it restricts a few functions to a given aspect.

In the field of communication functions, for example, the ability of a comprehensive language limits to the situations in which something is requested from the child and if the child reacts or not to the request. The comprehensive language is far more complex than the execution of actions. It is about understanding any communication media, such as language, body expressions and music. Ultimately, to capture and interpret the message that people and the environment convey¹⁶.

The Scale of Autistic Traits (ATA) scale was translated, adapted and validated to be used in Brazil in 1999¹⁷ and a new validity study was carried out in 2008¹⁸. This is a screening protocol with easy applicability, which may be applied by any professional. It may be used to identify cases of autism and also to follow-up the course of those being treated. Its translation, adaptation and validation to be used in Brazil also considered the DSM-IV diagnosis criteria, because when it was created19. the DSM-IV had not been published yet, having as reference DSM-III. DSM-III-R and ICD-10.

ATA is considered sensitive to identify suspected cases of autism, since is strongly correlated to CARS, which is used internationally²⁰. Its advantage is that it seems more sensitive when differentiating the mental retardation conditions versus autism, but it may be too early to affirm that.

The research sample in which it was validated in Brazil was the age group between two and eighteen vears old10. CARS is little sensitive to children in the age group between two and three years old. Additionally, between the two validity groups, the cut-off point where the most sensitiveness is detected to identify autistic disorders was dissonant, being fifteen on the first one¹⁷ and twenty three on the second one¹⁸.

The Modified Checklist for Autism in Toddlers (M-CHAT) was translated into Brazilian Portuguese as Escala de Rastreio Precoce de Autismo²¹. It is comprised of 23 questions that must be answered by the parents or guardians of children under risk of autism, whose age group is from 18 to 24 months old. The answers may be answered in few minutes, because they are of the positive (yes) or negative (no) type, considering its observations on the behavior of those children, in order to early identify those with autistic disorder.

The application of the M-CHAT scale is not exclusive to a medical doctor; thus, the speech therapist is allowed to use it. However, M-CHAT has no diagnosis power; its use aims at selecting suspected cases of autism for a detailed assessment.

That scale was created in United States of America and its validation was comprised of a sample with 1,293 children, out of which only 171 were followed-up by services specialized in early checking, which implied satisfactory values of specificity and sensitivity²².

There are no studies on the applicability of M-CHAT to the Brazilian version, in addition to the study that have it translated. However, international studies indicate that such tool is capable of identifying suspected cases of autism between 20 and 40 months old²³. Another study concludes that M-CHAT is able to classify more precisely children with Pervasive Developmental Disorder (PDD), who have lower intellectual and adaptive functioning²⁴.

There are researches that conclude that such tool tends to indicate as false positive cases in which children were born with a low weight and preterm²⁵. The same applies to cases of children with cognitive, sensorial and motor deficits^{25,26}.

The interview Autism Diagnostic Interview Revised (ADI-R) was translated in 200927, as a tool to diagnosing autism to be used in Brazil. It contains six sections, subdivided into 93 items. The first session collects data referring to the patient and their family, encompassing aspects of diagnosis process and education. The second session investigates the development and its benchmarks. The third encompasses questions on communication; the fourth is about social interaction and the fifth is about repetitive and stereotyped behaviors. The last session is related to overall behaviors.

For this interview, the child is required to have a mental age equivalent to a two-year old, because a false autism diagnosis may be obtained in cases of children with severe mental retardation. With this scale, three diagnoses may be obtained: autism; non autism; and autistic traits, with no classic autism.

However, the tool is not capable of specifying the severity of the condition. It may be applied by a specialized professional to parents and/or caretakers that have followed-up and still follow-up the child since their birth until they turn five years old. The time required to complete the interview is from one hour and a half to two hours and a half.

Just like M-CHAT, no Brazilian literature or research have used the translated version of ADI-R. In international literature, there are researches investigating the validity of such interview in its original version²⁸. They provide data that affirm that CARS is more sensitive than ADI-R to identify younger children with autistic disorder, because ADI-R is more appropriate when the children demonstrate severe symptoms and the IQ is relatively lower²⁹. ADI-R has no strong relationship with other scales investigating autism. However, when the behavioral domain is excluded, the relationship gets stronger, which makes us believe that in ADI-R the items related to the stereotyped behaviors and interests are not relevant for the diagnosis aspect³⁰.

The Autism Screening Questionnaire (ASQ) or the Social Communication Questionnaire (SCQ)31 is comprised of 40 yes or no questions that involve questions on the current prior history and current life situations relevant to the autistic characteristics. This questionnaire may be self-applied or read by the interviewer. It was translated into Brazilian Portuguese and validated in 2008, and it was named Questionário de Avaliação do Autismo or Questionário de Comunicação Social³².

Such guestionnaire was applied to parents of children suspected of having autistic disorder and who were in the 30-month age group²⁴, lower age to apply such questionnaire. The conclusion of application of SCQ was that, if the cut-off point of the questionnaire is reduced, it would be capable of detecting more accurately children with Pervasive Developmental Disorder (PDD), whose intellectual functioning is lower and adaptive. Used to check preschoolers (three- to five-years old), the SCQ demonstrated being useful to identify children with developmental problems for further specific autism evaluation33.

The tools described so far indicate that, upon intellectual impairment, they often provide false positive results. SCQ, however, demonstrates it may be used as a screening tool in persons with Down's syndrome for the identification of PDD. Thus, we suggest that the SCQ is part of the global assessment of children with Down's syndrome34.

The Autism Behavior Checklist (ABC)35 scale was adapted into Brazilian Portuguese and validated since 2005, called in Brazilian Portuguese Inventário de Comportamentos Autísticos (ICA)36.

That scale is aimed at screening suspected cases of autism based on non-adaptive behaviors. It is made of 57 items to be investigated by means of questions to parents or guardians of the child to be followed-up. The results that may be found are: high, moderate or low probability of autism.

In a Brazilian research³⁷, the ABC - Autism Behavior Checklist - demonstrated that the result may vary according to the person answering the questionnaire - professionals or child's parents - and reveals low agreement between them; the higher level of disagreement is from patients in the private institution.

Another research³⁸, associating ABC and CARS, demonstrated a good level of agreement between them, whether by the replies of parents, whether by the replies of professionals. However, separately, those tools cannot establish a diagnosis. It is worth mentioning that the latter research was carried out by a public institution, which supports the conclusion from the previous research - a higher level of disagreement in the answers from private institutions when compared to public institutions.

The Childhood Follow-Up Card8, a tool split into four age groups (zero to six months old; six to nine months old; fifteen to eighteen months old and twenty four to thirty months old), contains subitems that may lead to three responses: 1-Never; 2-Sometimes; and 3-Always. The method to apply the childhood follow-up card is by interviewing the parents up to the age group which the child is in on the application date. The observation of the child, made by the interviewer, is also a parameter to complete the card, if the child is in the age group being investigated.

This is a tool found in the survey that investigates the expected behavior of children since the early months of life. Thus, it is of great relevance for the investigation and early detection of risk signs for the autistic disorder. It is based on the psychoanalytic theory, which aims at investigating the child-motherfamily relationship. It is proposed that, in cases that are identified risk signs for autism, integrated therapeutic interventions between parents and children are initiated.

In this study, there are no references to cases in which the children present some comorbidity (syndromes, sensitive and motor deficits). It is also not referred to the singularity of the prematurity. The Childhood Follow-Up Card use parameters such as age groups described in the tool, but it is not known if the corrected age is to be used in prematurity cases, taking into account the maturity of newborns. since the scientific literature refers that the delay in the acquisition of certain abilities are often found in pre-term-born babies.

No studies were found to apply this instrument as a screening or diagnosing method for autism. except the one which it was validated against; more studies are required to confirm the sensitiveness and specificity of this tool.

However, other investigation protocols of early signs of autism based on psychoanalytic theory have been applied and are constantly being researched. IRDI - clinical risk signs of childhood development – was created based on a multicenter research in Brazil, mainly observing the behavior of children in a day-care setting. It contains 31 items, subdivided into age groups (0 to 04 incomplete months, 04 to 08 incomplete months, 08 to 12 incomplete months and 12 to 18 months), which are assessed by capable professionals in the area39. The Preaut research is aimed at identifying early the communication disorders that may be associated to the autistic spectrum on the two first years of life. Preaut investigates two signs (S1 and S2) related to the drive circuit, which is involved in the subject constitution process. Preaut was meant to validate a set of tools to establish the early disturbances of communications from four to nine months old and to assess the risks of developing autism. After that period of time, other tools may complement the Preaut, such as the communication evaluation questionnaire (QDC), by 12 months old, and CHAT, by 24 months old⁴⁰. The signs indicated by Preaut are the no search for the mother's eyes by the baby and the no joyful reactions caused by the baby to the mother⁴⁰.

During the clinical speech therapy practice, it is often observed that this professional is sometimes the first to be attended to by those responsible for children with autistic disorders, whose main complaint is absence of speech. The speech therapist must be capable of identifying the characteristics of the disorder and of directing the case to other professional areas, such as Medicine, Psychology, Occupational Therapy, etc. Thus, it should collaborate to establish the Autistic Disorder diagnosis, as well as integral service to the subject. However, only the doctor, whether psychiatrist, neurologist, pediatrician or any other specialist, may confirm the diagnosis of such Pervasive Developmental Disorder. Then, it is common that the speech therapy clinical observation or even the subject's own language is little valued, because there is a trend to consider only the protocols as diagnostic methods, and for several of them there is not even the need of direct contact between the professional and the child. However, as demonstrated by this study, those protocols are not accurate on their own and it is necessary to use them associated to clinical observations from all professionals involved in helping a person with autistic characteristics.

CONCLUSION

By evaluating those tools and assessment/ diagnosis protocols for the autistic disorder, it is realized that only three of them were created in Brazil, not being adapted and validated translations. Additionally, a speech therapist participated in the assessment methodology based on the TEACCH program only. None of the tools mentioned in this study is able to establish precisely on its own the diagnosis of the autistic disorder.

This is justified by the complexity and variability of that Pervasive Developmental Disorder. However, the professional may use those tools to identify the risk signs for autism.

There were few national researches that used those tools aiming at screening or diagnosing the autistic disorder. And the researches made in Brazil used only six out of the ten protocols presented in this study.

The speech therapy has a long journey to travel in the research of autistic disorder, thus helping in the diagnosis and treatment of people with autism.

It is critical to continue with the researches in that area, because it constitutes the subjectivity of a person, which is directly associated to the autism condition.

It is necessary to criticize the reality of what still happens in the process of diagnosing autism. The criteria in the mental diseases manuals and the assessment protocols are often highlighted. The clinical observation from the speech therapist and the language used by the child are often in the background of the assessment process.

RESUMO

A Fonoaudiologia, no âmbito das ciências da saúde que estudam a comunicação humana, assume grande importância tanto no diagnóstico quanto no tratamento daguelas pessoas com autismo. Entretanto, ainda são poucos os fonoaudiólogos que publicam regularmente sobre o tema, o que demonstra ser uma área que necessita de mais estudos. O transtorno autista caracteriza-se por um prejuízo no desenvolvimento da interação social, da comunicação e do comportamento. Seu diagnóstico deve ser criterioso e considerar os três campos acima. É comum o fonoaudiólogo ser o primeiro profissional procurado pelos pais de crianças autistas; portanto, ele deve saber identificar esses casos. O objetivo da pesquisa foi levantar métodos e protocolos de avaliação e diagnóstico do transtorno autista, disponíveis na literatura nacional, cujas aplicações possam ser da prática clínica fonoaudiológica. A partir de várias referências, encontraram-se dez protocolos: sete traduzidos e validados da língua estrangeira para o português brasileiro e três desenvolvidos no próprio Brasil. Não foram encontradas publicações nacionais que utilizassem quatro dos dez instrumentos apresentados para fins de triagem ou diagnóstico de casos suspeitos ou com risco para autismo. Evidencia-se, também, a pouca participação do fonoaudiólogo nesse processo. Além disso, nenhum desses instrumentos foi considerado preciso para diagnosticar esse transtorno. É importante salientar que é necessária uma reflexão crítica à realidade do que ocorre, ainda, no processo de diagnóstico do autismo.

DESCRITORES: Transtorno Autístico; Diagnóstico; Programas de Rastreamento; Métodos

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