Impact of training in autism for primary care providers: a pilot study

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Objective: To evaluate the impact of a training program on autism spectrum disorder (ASD) identification offered to Brazilian health professionals.

Methods: Twenty-two primary care providers participated in five 3-hour weekly training sessions.

Results: The trained providers significantly improved their ASD knowledge after training in comparison with pre-training (mean score, 6.73 vs. 9.18, p < 0.01). Clinical practice also changed: 4 months after the training program, the providers had referred six times as many suspected cases of ASD to a specialized mental health service in comparison with the previous 4 months.

Conclusion: This pilot training model seems a promising, feasible, and inexpensive way to improve early identification of ASD in the primary care system.

Keywords: Autistic disorder; inservice training; early diagnosis; primary health care

Introduction

Early identification is one of the main predictors of functional outcome and social adaptation in patients with autism spectrum disorders (ASD).1 Unfortunately, several studies conducted in developed countries have detected considerably late ASD diagnosis. In Great Britain, for example, only 8% of children with ASD are diagnosed on their first clinical visit. In many developed countries, the mean age at diagnosis is 7 years,2 even though it is best to identify the condition before age 3.

The single paper reporting ASD prevalence in Brazil has estimated a rate of 0.3%,3 which is probably an underestimate. Children with ASD use more health services than children with other medical conditions and children with intellectual disability.4 A recent population-based survey found that most ASD cases in Brazil go undiagnosed and do not receive specialized treatment.5

The Brazilian Unified Health System (SUS) provides free access to health services for all citizens in the country, and is organized at the regional level, encompassing primary through tertiary care. It is intended that first access to the SUS occur through primary health care (PHC) services. In the SUS organization flowchart, psychosocial care centers for children and adolescents (CAPSI) are the health services responsible for providing assistance to children/adolescents with severe and persistent mental illness and coordinating mental health care in a defined catchment area.6

In short, within the SUS, patients with ASD should be detected by primary care providers and referred to local CAPSIs. In this sense, implementation of training programs to improve the ability of primary care providers to recognize ASD is one of the most important steps to scale up psychiatric care to this population, as shown in previous experiences.6 The objective of this study was to evaluate the impact of a training program on ASD for pediatricians and other primary care providers in the city of São Paulo, Brazil.

Method

The training program offered to primary care providers (pediatricians and other health professionals selected by local managers) consisted of five 3-hour weekly training sessions comprising 2 hours of lectures and a 1-hour case discussion. The training program was conducted at a single CAPSI in the Vila Maria/Vila Guilherme neighborhood, in the North region of the city of São Paulo.

The themes of the meetings, given by ASD experts, were ASD epidemiology, symptoms and early signs of ASD including joint attention, diagnostic criteria, evidence-based treatments, and the SUS structure. The main objective of training was to improve detection of
suspected cases of ASD in the primary care units and achieve their immediate referral to the local CAPSI.

To measure knowledge acquisition, a structured questionnaire comprising 13 multiple-choice questions and vignettes of clinical ASD cases was developed by our research team and was administered before and immediately after the course. The survey included questions on DSM-IV diagnostic criteria, diagnosis of atypical cases, comorbidities, differential diagnoses, and treatment. Participant satisfaction was assessed by a structured questionnaire administered at the end of training. All providers signed a written informed consent form before completing the questionnaires. This project was approved by the local Research Ethics Committee.

To identify changes in the clinical practice of the participants, a survey was carried out to find out the number and profile of suspected ASD cases that these professionals referred to the CAPSI 4 months after the conclusion of the course. These data were compared with the records of cases referred by the same professionals 4 months before training. All referrals to the CAPSI were assessed by a child mental health team including a child psychiatrist to ascertain the diagnosis and severity of each case based on DSM-IV-TR criteria. This assessment sought to determine whether the referral should be followed up by the CAPSI, by another mental health service, or if no treatment was required.

All analyses were conducted using SPSS version 18.0. The nonparametric paired Wilcoxon test was used to test the difference in mean total scores of provider knowledge before and after the training program (outcome), at a significance level of 5%.

Results

The training program on ASD was offered to 29 primary care providers from the Vila Maria/Vila Guilherme neighborhood of São Paulo. Twenty-two care providers (16 pediatricians and six general practitioners) completed the knowledge questionnaire before and after the training program as well as the course evaluation questionnaire, and were thus included in the analyses.

Of the 22 providers, 15 (68.2%) were female. Mean age was 46±11.8 years, and mean time since graduation was 20.7±12 years. All participants evaluated the course as excellent/good, 19 (86.4%) considered its length adequate, and only three participants (13.6%) considered the course difficult. All participants found the course didactics excellent/good and relevant to clinical practice. Overall, the participants’ knowledge of ASD increased significantly from baseline: initial and final mean scores on the knowledge questionnaire were 6.73 and 9.18, respectively (p < 0.01). The total number of correct answers increased 37.1%, from 148 at the start of the training program to 203 at its completion.

Analysis of single results from the 22 primary care providers showed that, at the end of the training program, most participants (18 providers, 81.8%) had improved knowledge about ASD. The responses to questionnaire items after training that showed the most significant improvement in provider knowledge concerned epidemiology, etiology, recognition of textbook clinical cases, and evidence-based treatment approaches. In the 4 months preceding training, the Vila Maria/Vila Guilherme CAPSI had received 274 referrals of suspected cases of children with severe mental health problems, 11 of these from members of the training group. Of these 11 referrals, only one was for a child with suspected ASD, the diagnosis of which was subsequently confirmed.

In the 4 months after the course, the same service received 229 referrals, 13 of these from members of the training group. Of these 13 referrals, six were for patients with suspected ASD, all of whom were found to have clinical symptoms consistent with ASD (little visual contact, absence of verbal communication, stereotyped movements) or at least be complex enough to warrant specialized assessment by the multidisciplinary CAPSI team (intellectual disability, impaired language development) (Table 1).

Moreover, only two of the six patients with suspected ASD were aged over 4 years, indicating that providers are improving identification of earlier cases. It should be noted that, in addition to these suspected cases of ASD, only one child younger than 4 years was referred to the CAPSI in the same time period.

Discussion

In this setting, the training of non-specialized health professionals to identify early cases of ASD improved their knowledge of these disorders and increased referrals of potential cases. The program contributed to a change in providers’ practices, significantly increasing the number of correct referrals. These results suggest that a simple and feasible training program aimed at pediatricians can optimize the distribution of (currently scarce) human resources to manage ASD and might improve early diagnosis.

Early signs of autism are identifiable before age 24 months.7 However, late identification of ASD is a well-known problem, even in developed countries.8 A recent review article including data from 42 studies (from 1990 to 2012) showed that the mean age of ASD diagnosis ranged from 38 to 120 months.9 In Brazil, data on the age at ASD diagnosis and on the ability of primary care providers to detect ASD are practically nonexistent. A single pilot study in a community sample showed that 75% of children with ASD from ages 7 to 10 had not received an accurate diagnosis.3 Even when parents suspect the condition and seek assistance, there is usually a delay until proper diagnosis and care are achieved.10

Pediatricians and general practitioners are the first health providers to have contact with young children, but many studies have shown that they are not trained to identify ASD.5 This is also the case in Brazil, where mental health issues occupy only 5% of a total of 8,602 hours during the whole of a physician’s training prior to graduation, including the pediatrics residency.11
Although the present study reports promising results, it has some limitations. It is a pilot study, conducted in a single region of the city of São Paulo, with a small sample size that limits generalization of the data obtained. ASD diagnoses were based on DSM-IV-TR criteria, without use of structured instruments. Furthermore, the results on the acquisition of specific knowledge are limited, because the questionnaire contained few items on each subtheme of training and may have been rather poorly sensitive to quantify knowledge improvement.

The training program described herein achieved its aim of increasing knowledge about ASD and promoting adequate referral of ASD cases by primary care providers. This short-term, limited initiative was well received and well evaluated by the program participants, and can be used as a model for the public health system in other Brazilian regions. It is noteworthy that these results can benefit ASD patients directly, since early referral to a specialized service may contribute to a better outcome for persons with ASD.

**Disclosure**

The authors report no conflicts of interest.

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**Table 1** Profile of the six suspected ASD cases referred to CAPSI Vila Maria/Vila Guilherme after the training course

<table>
<thead>
<tr>
<th>Child (gender, age)</th>
<th>Main complaints that motivated referral</th>
<th>Main symptoms identified at CAPSI</th>
<th>Final diagnosis*</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male, 2 years 5 months</td>
<td>- Suspected autism - Request for psychiatric assessment</td>
<td>- Difficulty socializing with other children - Little visual contact - Aggressiveness - Does not verbalize - Instrumental use of the mother’s hands - Altered sleep - Irritability, crying - Toe-walking - Distress from loud noises - No delay in NPD</td>
<td>ASD</td>
<td>Accepted to CAPSI for treatment by the multidisciplinary team</td>
</tr>
<tr>
<td>Female, 2 years 8 months</td>
<td>- Suspected autism - Request for psychiatric assessment</td>
<td>- Does not verbalize - Points at the desired object - Inattention - Enjoys music - Repetitive gestures - Good visual contact - Shares objects and interests - Looks for other children to play with - No delay in NPD</td>
<td>Suspected hearing impairment</td>
<td>Referred to speech-language pathologist at the local primary care unit</td>
</tr>
<tr>
<td>Male, 5 years</td>
<td>- Delayed language development - Suspected ASD</td>
<td>- Incomprehensible speech - Interaction with other children exists, but is inappropriate - Delay in NPD (walked and spoke at 3 years) - Impaired motor coordination - Disrupted sleep, social smile - Good visual contact - Attempts to communicate with people and to share interests - Semi-dependent for ADLs</td>
<td>Intellectual disability and impaired language development</td>
<td>Accepted to CAPSI for speech therapy only</td>
</tr>
<tr>
<td>Male, 8 months</td>
<td>- Lack of response to the mother</td>
<td>- Good visual contact - Responds to his own name - Social smile - Joint attention</td>
<td>Difficulties in mother-infant relationship</td>
<td>Mother was given advice on developing relationship and instructed to return if necessary</td>
</tr>
<tr>
<td>Male, 3 years</td>
<td>- Difficulty using language - Unusual behavior - Suspected ASD</td>
<td>- Language exists, but is non-functional - Pronoun reversal, decreased visual contact - Stereotyped movements - Difficult relationship with peers and relatives - Lack of attention, irritability - No delay in NPD</td>
<td>ASD</td>
<td>Accepted to CAPSI for treatment by the multidisciplinary team</td>
</tr>
<tr>
<td>Male, 12 years</td>
<td>- Diagnosed with autism at 9 months: request for diagnostic confirmation</td>
<td>- Walked at 3 years, good visual contact - Adequate and functional language - Never exhibited stereotypy - Good social skills - Much difficulty at school</td>
<td>Intellectual disability</td>
<td>Referred to the regional Basic Health Unit</td>
</tr>
</tbody>
</table>

ASD = autism spectrum disorders; CAPSI = psychosocial care center for children and adolescents; ADLs = activities of daily living; NPD = neurological and psychomotor development.

Data obtained from referral forms.

* In accordance with DSM-IV criteria, by a multidisciplinary CAPSI team, including a child psychiatrist with extensive experience in ASD.
References