

The public health system and the place of autism

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ABSTRACT

Purpose: to characterize the population with autism spectrum disorder and the Psychosocial Care Network.

Methods: a study conducted with patients presented with autism spectrum disorder up to 18 years old treated at the health network in Taboão da Serra, Brazil. Participants' data were collected from medical records of the Psychosocial Care Network for Children of that city, authorized by the Municipal Department of Health, and quantitatively analyzed.

Results: altogether, there were 237 patients with autism spectrum disorder in the said health network by April 2019. Of these, 188 were treated at the Psychosocial Care Network for Children, 110 of them with weekly therapy. There was a predominance of males (73.63%), age range from 3 to 10 years, with a higher percentage of 5-year old (17.27%) patients, and a mean treatment time of 32 months. The youngest age was 2 years old. Half the sample (50%) had weekly therapy and received homeopathic medication; 24 users (21.81%) were referred by speech-language-hearing therapists and 19 (17.27%), by the school they attended.

Final Considerations: although the Psychosocial Care Network for Children is the reference in the region, it is known that this facility alone cannot meet all needs of individuals with autism spectrum disorder. A service network coordinated according to patient's individual needs and the region's reality would ensure their expected rights, decrease public spending, and enable these users to occupy not only one but many places in society.

Keywords: Autism Spectrum Disorder; Unified Health System; Public Health Systems Research; Health Policy; Mental Health Services

Study conducted at Department of Physical, Occupational, and Speech-Language-Hearing Therapy of the Medical School at Universidade de São Paulo, in São Paulo, SP, Brazil.

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INTRODUCTION

Despite the public policies in favor of children with autism spectrum disorder (ASD) and the many years since they have been promulgated, patients with this condition still face countless difficulties identifying their place in the public healthcare system. This is highlighted by the worldwide discussions on the topic that reach no consensus. Ensuring their acquired rights and spaces is still a challenge posed to this population. Each Psychosocial Care Network (PSCN) unit must provide access and different healthcare modalities to understand and respond to the needs of people presented with ASD in their life contexts¹.

Reference services accredited by the Public Health System (SUS, in Portuguese) to care for ASD encompass Psychosocial Care Centers (PSCC), Specialized Rehabilitation Centers (SRC), and community health centers (CHC), which direct the care service. The coordination of these units with one another and with the other levels of the health system and related areas form a cooperative network between sectors – that is necessary to comprehensively meet the patients' needs².

However, are these facilities apt to provide the care recommended by the Ministry of Health? A well-functioning network means it offers services aligned with each institution's functions, with clearly defined roles³.

ASD has a high prevalence, affecting 1.5% of the world population. In March 2020, the Center for Disease Control and Prevention (CDC) published 2016 data updating the prevalence numbers: 1/54 children 8 years old, in 11 states – a 10% increase from the previous 1/59⁴.

Practical considerations on the lines of healthcare for people with ASD in Taboão da Serra, SP, Brazil, lead to reflections that can help understand the place these users desire, respecting the principles of SUS.

Thus, this paper aimed at characterizing the population with ASD and the RAPS in that city.

METHODS

This project was approved by the Research Ethics Committee of the Medical School at the *Universidade de São Paulo* (USP), Brazil, under evaluation report no. 3.622.331 and CAAE 04886818.0.0000.0065. This descriptive, exploratory, quantitative, retrospective, observational study resulted from a Master's dissertation presented to the Medical School at USP.

The inclusion criteria for participants were as follows: being a user of the healthcare network in Taboão da Serra, being diagnosed with ASD (according to ICD-10), and being up to 18 years old. There were no exclusion criteria.

The study encompassed the municipality of Taboão da Serra, located in the Southwest region of Greater São Paulo, with an area of 20,388 km². It has the second-greatest population density in the state of São Paulo, with 12,049.90 people per km². It is characteristically urban, with 244,528 inhabitants, and ranks 238th among Brazilian municipalities in the Municipal Human Development Index⁵.

Its health system is regionalized and hierarchical, working per region, with a minimum mental health team in each CHC. The PSCC for children and youth (PSCC-CY) is the pediatric and adolescent mental health representative.

The study had various stages. Firstly, it mapped the mental health services and human resources in the healthcare network, based on data from the Municipal Department of Health. Then, a questionnaire was sent via e-mail to CHC and SRC directors to survey the individuals with ASD who attend these units. Also, characterization data (sex, age, time and type of treatment, origin, and referrals) were surveyed from the medical records at PSCC-CY. The parents/guardians of individuals treated at PSCC-CY answered a questionnaire on socioeconomic aspects⁶ – which, however, were not collected regarding the individuals treated in the other units.

During the coronavirus (COVID-19) pandemic, another group was also recruited to participate in the research. Limited to 30 people, they were selected as they came for outpatient care at PSCC-CY, with the following criteria: being diagnosed with ASD and having been discharged from therapy groups. The parents/guardians of this group of 30 individuals answered a questionnaire developed for the research, based on the Primary Care Assessment Tool (PCATool)⁷, surveying their perception of healthcare. It was sent via WhatsApp message application in the PSCC-CY group, along with an informed consent form – which was signed by all participants.

Data were statistically analyzed by a professional specialized in the science in question. As for the descriptive statistics, qualitative variables were presented in their frequencies and percentages.

RESULTS

Taboão da Serra has the two facilities (PSCC-CY and SRC) indicated by the Ministry of Health to assist patients with ASD, as well as the minimum mental health teams in each CHC, with a psychologist, a speech-language-hearing therapist, and a psychiatrist.

Altogether, the health network had 237 patients with ASD by April 2019. Of these, 110 attended PSCC-CY in weekly therapy groups, 78 attended PSCC-CY in individual outpatient visits to the psychiatrist, 76 attended other units (68 attended CHC and eight attended SRC), and 27 attended therapeutic services along with PSCC-CY.

In April 2019, 174 users were attending PSCC-CY in weekly therapy groups – 110 of them were diagnosed with ASD (63.21%).

There was a predominance of males (73.63%), C2 socioeconomic class (49% with an average income of R\$ 1,625.00), and a mean treatment time of 32 months.

PSCC-CY users in Taboão were concentrated in the age range from 3 to 10 years, with a predominance of those 5 years old (17.27%). The youngest age was of 2 years, with 3%.

As for the type of treatment, Chart 1 shows that 55 users attended therapy groups and were treated with homeopathy (50%), followed by 48 users who attended therapy groups and were treated with both homeopathy and allopathy (43.63%). Only five users were treated with allopathy and the therapy groups (4.54%).

Of the 78 users discharged from therapy groups, 41.02% continued with allopathy and homeopathy; 2.05%, only with allopathy; and 26.92% only with homeopathy (Chart 1).

Chart 1. Distribution of types of treatment conducted at the Psychosocial Care Centers for Children and Youth

Treatment	Number of users	Homeopathy	Allopathy	Homeopathy + Allopathy
Therapy Group	110	50%	4.54%	43.63%
Discharged from Therapy Group	78	26.92%	32.05%	41.02%

Concerning their origin, 24 users (21.81%) were referred by speech-language-hearing therapists, followed by 19 users (17.27%) referred by the school, and 18 users (16.36%) referred by services from outside the municipality.

Of the 30 patients whose parents/guardians answered the questionnaire after therapy group discharge, 53.33% continued the treatment in PSCC-CY with homeopathy, while 30% used homeopathy combined with allopathy.

Their parents/guardians considered the treatment adequate, with good results. Half (50%) of the users were referred to other services, of whom only 36.66% were immediately admitted.

Speech-language-hearing therapists were the professionals who received the most referrals after the discharge from weekly groups (six referrals), followed by psychologists (five referrals).

DISCUSSION

There was a discrepancy between the number of PSCC-CY users (188) and CHC and SRC users (76),

which may indicate that PSCN is a reference in the region for this population's healthcare and treatment. This movement is related to the PSCN guidelines: ensuring access to quality service with multiprofessional comprehensive care. Social rehabilitation and reinsertion in the society of individuals with mental disorders are among the specific goals of this network.

The percentage of ASD patients in treatment at PSCC-CY was higher than in other studies⁸⁻¹¹, demonstrating the preference for this line of treatment in the region. This may happen either because professionals and families do not know the services focused on caring for autism or services other than PSCC-CY lack specialized human resources.

The predominance of males corroborates the literature; likewise, the age was similar to that in other pieces of research^{8,11}. The treatment time was shorter than the reported in previous research¹¹, which was of 40.7 months.

Speech-language-hearing therapists stand out as important professionals in the referral to specialized attention. Due to these children's communication

difficulties (one of the main symptoms of their atypical development), speech-language-hearing therapists are among the first specialists that families seek – which makes them essential in the treatment. They are also among the main professionals in the counter-reference of PSCC-CY concerning the ASD care network for language rehabilitation. They have the necessary scientific knowledge of communication and language to outline detailed individual profiles of skills and difficulties, enabling them to construct unique therapy planning according to each person's needs and family and social contexts¹².

There were few referrals to other sectors outside the field of health, which weakens the care network, and impairs the comprehensiveness of care.

FINAL CONSIDERATIONS

The study showed that the network in Taboão da Serra meets the recommendations of the Ministry of Health regarding attention to individuals with ASD, concerning both its facilities and professionals, ensuring universal care. Even though PSCC-CY is the reference in the region, it is known that this facility alone cannot meet all needs of individuals with ASD. There is little participation of primary health care and SRC and little coordination between these services.

The few or altogether absent records on network coordination open an important gap. The cooperative network between sectors is what actually makes treatment happen and ensures essential SUS principles – comprehensiveness and equity.

The cooperativeness between sectors appears when unique therapy projects are developed for each user, which must meet their needs according to the different realities in the region.

Individuals presented with ASD have acquired legal rights, which, however, have not yet ensured practical changes. Investment in ASD research must encompass not only studies on treatments but also the accessibility to them.

The existence of services does not ensure effective treatment; rather, it requires coordination between services. Cooperative sectors, encompassing both health and others, can share their knowledge and ensure that SUS principles are carried out, helping individuals with ASD become active citizens, occupying not only one but many places in society.

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VM: study design, data collection, analysis, writing original draft;

MS-Z, DRM-A: study design, analysis, writing original draft.