



REVIEW ARTICLE

Autism in Brazil: a systematic review of family challenges and coping strategies^{☆,☆☆}



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KEYWORDS

Autistic disorder;
Autism;
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Abstract

Objective: To describe the challenges faced by families caring for children with autism spectrum disorder (ASD) in Brazil and the coping strategies employed.

Sources: Systematic review of articles published until September of 2013, without language restrictions, using quality appraisal (AMSTAR and CASP/Oxford instruments).

Summary of the findings: The literature shows parental emotional overload as one of the main challenges faced by families, especially mothers. The main stressors were diagnostic postponement, difficulty dealing with the diagnosis and associated symptoms, and poor access to health services and social support. The predominant coping strategies found included information exchange between affected families and integrated healthcare network for patient and family support.

Conclusion: ASD exerts strong influence on family dynamics, resulting in caregiver overload, especially in mothers. The Brazilian Unified Health System needs to provide comprehensive, continuous, and coordinated care to strengthen the patient-family dyad and promote the full development and societal inclusion of children with ASD.

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PALAVRAS CHAVE

Transtorno Autístico;
Autismo;
Relações Familiares;
Cuidadores;
Sistema Único de
Saúde

Autismo no Brasil, desafios familiares e estratégias de superação: revisão sistemática**Resumo**

Objetivo: Descrever os desafios encontrados pelas famílias na convivência com crianças portadoras de transtorno do espectro autista (TEA) no Brasil e as estratégias de superação empregadas.

Fonte dos dados: Revisão sistemática da literatura com inclusão de artigos publicados até setembro de 2013, sem restrições de idioma. Os artigos incluídos foram submetidos à avaliação de qualidade metodológica através do AMSTAR e CASP/Oxford.

Síntese dos dados: Inclui-se estudos provenientes de São Paulo e Rio Grande do Sul com alta e moderada qualidade metodológica. A literatura mostra sobrecarga emocional dos pais como um dos principais desafios encontrados pelas famílias, inclusive com grande tensão sobre as mães. Dentre os fatores relacionados ao estresse estão: postergação diagnóstica, dificuldade de lidar com o diagnóstico e com os sintomas associados, acesso precário ao serviço de saúde e suporte social. Dentre as estratégias de superação destacaram-se: troca de informações entre as famílias afetadas e assistência integralizada da rede de saúde no atendimento do paciente e suporte à família.

Conclusão: Observou-se que o TEA exerce forte influência na dinâmica familiar com sobrecarga dos cuidadores, geralmente da mãe. O Sistema Único de Saúde necessita prover cuidado integral, longitudinal e coordenado visando o fortalecimento do binômio paciente-família e o pleno desenvolvimento e inserção destas crianças na sociedade.

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Introduction

Autistic spectrum disorder (ASD) is a neuropsychiatric syndrome characterized by behavioral manifestations accompanied by deficits in social interaction and communication, repetitive and stereotyped behavior patterns, and a restricted repertoire of interests and activities.¹ Developmental abnormalities are also characteristic of autism, which can be detected in the first three years of life and persist into adulthood.² Despite its importance, the etiology of ASD remains unknown. It is believed to be multifactorial, associated with genetic and neurobiological factors, i.e., physiological or anatomical abnormality of the central nervous system, innate constitutional problems, and interaction between multiple genes.^{2,3}

Autism represents a pervasive developmental disorder of utmost importance due to its high prevalence. Worldwide epidemiological data estimate that one in every 88 live births has ASD, affecting more male than female individuals. In Brazil, in 2010, it was estimated that approximately 500,000 individuals had autism.³

The diagnosis of ASD is essentially clinical, attained based on observations of the child, parental interviews, and application of specific tools. The criteria used to diagnose ASD are described in the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM).⁴ These criteria have evolved over the years. The DSM-V, launched in May of 2013, is the newest tool to guide medical diagnosis of individuals with ASD.^{1,5} In addition to the DSM-V, there are other screening tests for ASD, such as the Childhood Autism Rating Scale (CARS), the Clinical Risk Indicators for Early Childhood Development, and the Modified Checklist for Autism in Toddlers.^{3,6}

Childhood autism involves severe and early changes in the areas of socialization, communication, and cognition. The resulting scenarios are usually severe and persistent, with large individual variations, but often requiring extensive care and permanent commitments from the families.⁷

Parents of children with ASD are faced with a new situation that requires family adjustment. The fantasized desire of pregnancy must be adjusted to the individual who is born, and who has his/her own characteristics.⁸ Children diagnosed with ASD often exhibit a greater degree of cognitive impairment and difficulty in interpersonal relations. Consequently, they require special care, including adaptations in formal education and upbringing as a whole.

These particularities lead to changes in family dynamics, requiring careful and prolonged care by all family members who live with a child with ASD. Thus, increased levels of stress are frequently reported, which can impact the quality of life of all family members.^{9,10} The child's special condition requires that parents face the loss of the idealized child and develop coping strategies to deal with the new reality. The interaction of parents with specific manifestations of ASD in their children can often lead to the family's marginalization regarding social life.⁸

In 2013, the Brazilian Ministry of Health published the Guidelines for the Care and Rehabilitation of Individuals with ASD, in order to guide health professionals as well as family members in the early identification of autism in children as young as 3 years of age.¹¹

Despite the relevance of this topic, the number of scientific publications on the care of children with ASD from the perspective of their family members is still scarce.⁴ Velloso,¹² in a systematic review, observed that only 93 Brazilian scientific articles on ASD were produced between

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