

BRAZILIAN SCIENTIFIC OUTPUT ON AUTISM SPECTRUM DISORDERS

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ABSTRACT

OBJECTIVE. This systematic review sought to conduct a general analysis of the Brazilian scientific output on autism spectrum disorders (ASD) published between 2002 and 2009.

METHODS. A literature search was conducted in the scientific databases PubMed, SciELO, and LILACS and in the CAPES portal, using keywords such as “autism” and “pervasive developmental disorders”.

RESULTS. A total of 93 articles were identified, most of which were authored by researchers from Southeast Brazil and affiliated with public universities. Approximately one-third of all articles were published in journals with an impact factor ranging from 0.441 to 3.211; most were based on small sample sizes. Furthermore, 140 theses and dissertations were identified, 82.1% of which were master’s theses. Interventions for ASD were the predominant research topic.

CONCLUSION. Brazilian researchers are clearly interested in the topic of ASD; however, a substantial portion of their scientific output is limited to doctoral dissertations or master’s theses. A minority of articles was published in journals with a high impact factor. These findings suggest the need for studies with larger sample sizes, which could produce higher-impact findings and thus increase visibility of the Brazilian scientific output in the field of ASD research.

KEY WORDS: Autistic disorder. Review. Impact factor. Databases, Bibliography. Brazil.

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INTRODUCTION

In 2007, the Brazilian Ministry of Health established a working group for autism care within the framework of the Brazilian Unified Health System, highlighting the importance of this issue. One of the points discussed by the working group was the need for producing evidence-based knowledge to serve as a basis for the development of proposals for care of autism spectrum disorders (ASD)¹, the range of manifestations of which autism is a form.

ODiagnostic criteria for ASD have changed over the various editions of mental disorder classification manuals;

both the World Health Organization’s International Statistical Classification of Diseases and Related Health Problems (ICD, currently in its tenth revision)², and the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM, currently in its fourth text revision)³, no longer classify it as a psychosis, but rather as part of the concept of pervasive developmental disorder. This conceptual shift has contributed to the variability of results reported by published studies—such as in prevalence rates reported by various international epidemiological studies⁴⁻⁷. Reported increases in the frequency of ASD may also be largely due

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to improved recognition and detection of the autism spectrum, particularly in cases in which there is no intellectual disability.

However, the vast majority of population-based data on ASD were obtained in developed countries. This limited knowledge of the reality of autism in developing nations is a further challenge that must be faced by the Autism Working Group. It is now accepted that the prevalence of ASD may vary according to the genetic background of study populations.

The overall scientific output of Brazilian researchers has increased over the past few years, and the field of mental health is no exception^{8,9,10}. The availability of local data on the mental health of the Brazilian population is essential for the development of adequate public health policy. Thus, the general objective of this study was to carry out an analysis of the Brazilian scientific production on ASD, in an attempt to gauge the current scientific scenario in this field. The specific objectives of this review were: a) to identify all ASD-themed articles, master's theses, and doctoral dissertations authored by Brazilian researchers between 2002 and 2009; b) to classify articles and thesis/dissertation abstracts into broad categories according to research subject; c) to find out the impact factors of the journals in which these articles were published, and the bibliographic databases in which these journals were indexed; and d) to compile data on the institutional affiliation of the lead authors of articles, theses, and dissertations.

METHODS

Article and abstract selection: Inclusion criteria were as follows: i) articles and thesis/dissertation abstracts published between 2002 and 2009, ii) having at least one Brazilian researcher listed as an author, iii) studies with empirical data from case reports or field research. Review articles (including theoretical and systematic reviews) and preclinical research conducted on animal models were excluded.

Databases, search terms and quality of journals, dissertations and theses: Articles were identified through a search of the major biomedical literature databases: PubMed (maintained by the United States National Library of Medicine at the National Institutes of Health); Scientific Electronic Library Online (SciELO); c) and Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS). The following search terms were used, alone and in combination: "autism", "pervasive developmental disorders", "assessment", "diagnostic criteria", "Brazil", and "Brazilian" (in Portuguese, autismo, transtorno invasivo do desenvolvimento, distúrbios do desenvolvimento, avaliação, critérios diagnósticos, Brasil, brasileiro). For thesis and dissertation abstracts, the only search terms used were "autism" and "pervasive developmental disorders", alone and in combination.

Journals indexed by more than one database were ranked in order of quality criteria (hence, PubMed first, followed by SciELO, then LILACS). Articles were also classified by impact factor of the journal in which they were published, as reported in the 2008 Journal Citation Report (JCR). Dissertation and thesis abstracts were obtained from

the CAPES website (<http://www.capes.gov.br/avaliacao/cadastro-de-discentes/teses-e-dissertacoes>), which does not list any quality criteria.

Articles and dissertation/thesis abstracts were classified by research subject, with some being included in more than one category. The institutional affiliations of the lead authors of each article and thesis abstract (student authors) were also recorded. Finally, the scientific output of Brazilian researchers was compared with that of authors from other countries by means of a PubMed search using the term "autistic disorder" plus any MeSH subheadings consistent with each of the research categories defined for the present study. The following limits were used for this search: date of publication between 2002 and 2009, no Brazilian articles, and no review articles or animal studies.

RESULTS

The inclusion and exclusion criteria of this systematic review yielded 93 articles and 140 abstracts (25 theses, 115 dissertations). Twenty-seven articles were published between 2002 and 2004, 26 between 2005 and 2007, and 40 between 2008 and 2009; therefore, the number of published articles having ASD as a theme has increased in recent years (Chart 1). Conversely, thesis and dissertation output declined in 2008 and 2009 after a period of growth (2002, 17 thesis and dissertations; 2003, 19; 2004, 20; 2005, 19; 2006, 21; 2007, 30; 2008, 12; 2009, 11).

All articles, theses and dissertations were classified into one of the following seven research categories:

Intervention studies: A recent review noted that the most frequent interventions for ASD are, in decreasing order: administration of antipsychotic agents, hyperbaric oxygen therapy, applied behavior analysis, and others¹⁸. Intervention studies, particularly randomized controlled trials and those including pre- and post-intervention assessment to analyze efficacy of the intervention, are usually highly complex¹¹. We were therefore surprised to find that this category included most ASD-themed articles authored by Brazilian authors between 2002 and 2009: 25 journal articles¹²⁻³⁶, and 46 thesis and dissertation abstracts. These studies were most commonly conducted to test the following interventions: (1) administration of hormonal agents, (2) improvement of communicative function, (3) clinical psychoanalytical interventions, (4) speech and language therapy, (5) virtual learning environments, and others. Over the same period, over 100 intervention studies published by foreign authors were indexed in PubMed.

Communication patterns and family relations: This category included studies on: communication and social interaction; the communicative profile of the ASD as defined by various theoretical approaches, such as psychoanalysis, behaviorism, and phenomenology; and quality of life and stress among relatives of people on the autism spectrum. Of the 93 articles identified, 21 were classified into this category^{13,33,37-55}. Of the 140 relevant abstracts found in the CAPES database, 46 fell into this category. A PubMed search

yielded 250 articles authored by non-Brazilian researchers that would have been included in this category.

Neurobiological and genetic bases of ASD and comorbidities in the autism spectrum: Studies grouped under this category addressed various conditions commonly associated with the phenotypical spectrum of autistic disorders, including cytogenetic and molecular markers associated with ASD, correlations between anatomical and functional CNS changes and ASD, and possible associations between neurological conditions and psychiatric disorders and ASD. Twenty articles⁵⁶⁻⁷⁵ and nine dissertation abstracts fell into this category. A PubMed search combining the term autistic disorder with subheadings relevant to this category yielded over 330 international studies published between 2002 and 2009.

Phenotype and endophenotype studies: Phenotype studies focus on the clinical manifestations of ASD, the clinical, behavioral, cognitive, communicative, and social interaction-related aspects of which are usually observable. Endophenotype studies aim to identify a measurable variable that adjusts to neural circuit-based models and thus mediate the gene-disease relationship^{76,77}. Many articles fell into this category (18 of 93 published between 2002 and 2009)^{14,33,34,41,78-91}. The CAPES database contained 17 thesis and dissertation abstracts in this category, and over 60 PubMed-indexed articles in this category by foreign authors were published during the study period.

Psychometric properties of ASD assessment instruments: Standardized assessment instruments are of great importance in diagnosing diseases, and are particularly useful for identifying individuals with ASD⁶ because the diagnosis is made primarily on the basis of clinical criteria. Assessment instruments must have features that ensure their reliability and validity in order to allow their proper use and proper inferences from their scores. Instruments developed in a different culture should therefore be translated into and adapted for the population in which they will be used⁹². According to our review, few of the published articles fell into this category, which is considered essential for scientific research: only nine articles and nine dissertations tested the psychometric properties of screening instruments such as the ASQ, CARS, and ABC⁹⁴⁻¹⁰¹. According to a PubMed search, over 70 foreign studies published during the review period tested the validity, reliability, specificity, and sensitivity of ASD assessment instruments.

Diagnostic criteria for ASD: This category included four articles that sought to establish diagnoses of ASD on the basis of clinical criteria (mostly DSM-IV and ICD-10), clinical examination, screening scales, or behavioral observation^{60,75,102,103}. Five Brazilian thesis abstracts met criteria for this category. Approximately 3,000 articles by foreign authors on the development and testing of protocols for the assessment and detection of ASD were published between 2002 and 2009 in PubMed-indexed journals.

Epidemiological studies: These studies play an essential role in determining prevalence rates, identifying high-risk and best-prognosis groups for the development of effective treatment approaches, and providing information on the availability, quality, and accessibility of care services¹⁰⁴. Despite the importance of this line of research to public policies, we identified a mere three articles and three thesis abstracts authored by Brazilian researchers in this category and published between 2002 and 2009. The first study, a dissertation-derived journal article, was a population-based study of the prevalence of ASD among children and adolescents with Down syndrome in the city of Curitiba, Paraná¹⁰⁵. The second article compared quality of life in the mothers of 31 autistic children with the mothers of 31 children with typical development¹⁰⁶, whereas the latest article sought to compare the sensitivity of teachers and health professionals for diagnosis of ASD¹⁰⁷. One master's thesis estimated the frequency of autism in the Brazilian state of Santa Catarina according to data provided by the state Association of Parents and Friends of Handicapped Children (Associações de Pais e Amigos dos Excepcionais, APAE), Friends of Autism Association (Associação de Amigos dos Autistas, AMA) and the State Foundation for Special Education (Fundação Catarinense de Educação Especial, FCEE)¹⁰⁸, and the second study compiled preliminary findings on the prevalence of ASD in a single neighborhood of a municipality in the state of São Paulo¹⁰⁹. A PubMed search of international articles designed as epidemiological studies yielded a vast literature on the subject, with over 560 articles published over the same period.

Chart 1 presents an overview of the 93 selected articles by year of publication. Immediately apparent is the predominance of small sample sizes: 36.6% of articles were single case reports or case series enrolling up to six patients. Nevertheless, the proportion of articles using small sample sizes decreased slightly over the years: 44.4% between 2002 and 2004, 34.6% between 2005 and 2007 and 32.0% in 2008 and 2009. Of the 140 thesis and dissertation abstracts mentioning sample sizes, 46.1% reported data on only one to six participants. Furthermore, sample sizes were quite small and unrepresentative overall: nearly 67.7% of articles enrolled 1 to 30 subjects by nonprobability sampling.

The results of this review show that Brazilian authors have kept up to date; 57 articles (61.3%) had adopted DSM-IV and/or ICD-10 diagnostic criteria. However, only 22 of these (23.7%) employed a standardized instrument for case-finding: 20 used screening instruments and the remaining two used a diagnostic test, the Autism Diagnostic Interview-Revised (ADI-R) (Chart 1).

Classification of journals by indexing database showed that over half (50) of the 93 articles in the sample were published in PUBMED - indexed journals, and were thus available on PubMed; 29 articles were published in journals that met SciELO but not PubMed criteria, and only 14 were published in journals indexed by LILACS alone. The 93 articles were published in 39 different journals, most of which (64%) were Brazilian. According to our review of the literature, the Brazilian journals that most often publish articles on ASD are (1) the Arquivos de Neuro-Psiquiatria,

Chart 1 – Scientific output about ASD of Brazilian authors between 2002 and 2009

Date of publication	Features assessed	No. Of articles
2002-2004	<u>Sample size (N)*</u>	
	1-6	12
	7-30	7
	> 30	7
	Not reported	1
	<u>Diagnostic instruments/criteria</u>	
	DSM-IV or ICD-10	18
	Standardized instruments alone	0
	Diagnosis made by multidisciplinary team or psychiatrist	2
	Not reported	7
	<u>Use of standardized instrument</u>	
	Yes (CARS, ABC, ADI-R)	3
	No	24
	<u>Journal impact factor</u>	
	> 1	4
	< 1	7
	No impact factor	16
2005-2007	<u>Sample size (N)</u>	
	1-6	9
	7-30	7
	> 30	10
	<u>Diagnostic instruments/criteria</u>	
	DSM-IV or ICD-10	15
	Standardized instruments alone	3
	Diagnosis made by multidisciplinary team	1
	Not reported	7
	<u>Use of standardized instrument</u>	
	Yes (ABC, ATA, ASQ, CARS, EAT)	7
	No	19
	<u>Journal impact factor</u>	
> 1	6	
< 1	6	
No impact factor	14	
2008-2009	<u>Sample size (N)</u>	
	1-6	13
	7-30	14
	> 30	13
	<u>Diagnostic instruments/criteria</u>	
	DSM-IV or ICD-10	24
	Standardized instruments alone	4
	Diagnosis made by multidisciplinary team	0
	Not reported	12
	<u>Use of standardized instrument</u>	
	Yes (CARS, ASQ, MCHAT, ABC, ATA, ADI-R)	12
	No	28
	<u>Journal impact factor</u>	
	> 1	9
	< 1	1
No impact factor	30	

* The sample size of one article was not reported.

CARS, Childhood Autism Rating Scale; ASQ, Autism Screening Questionnaire; MCHAT, Modified Checklist for Autism Toddlers; ABC, Autism Behavior Checklist; ATA, Autistic Trait Assessment Scale; ADI-R, Autism Diagnosis Interview-Revised.

with 14 studies (15% of the total) and an impact factor of 0.44, and (2) Pró-Fono, with 12 articles (12.9% of the total) and no JCR-assigned impact factor until 2009.

Of the 39 journals in which articles by Brazilian authors were published, 17 had impact factors. Of the 93 articles identified through our literature search, 33 (35.5%) were published in journals with an impact factor, which ranged from 0.441 to 3.212. Narrowing the sample to articles published in journals with an impact factor >1 yielded 19 articles, i.e., only 20.4% of the total. Analysis by date of publication showed that 41% of the 27 articles published between 2002 and 2004 were published in journals with an impact factor, with 15% being published in journals with an impact factor >1. A slight increase in this rate was observed between 2005 and 2007, both in number of articles published in journals with any impact factor (46%) and in articles published in journals with a higher impact factor (23%). In 2008 and 2009, the percentage of articles published in journals with any impact factor declined to 23%, whereas the rate of articles published in journals with an impact factor >1 increased slightly to 25% (Chart 1).

Analysis of the institutional affiliation of Brazilian authors showed that ASD-related scientific output is focused in specific regions of the country. The lead authors of 89% of all articles published between 2002 and 2009 were affiliated with universities in the Southeast Region of Brazil (specifically, in the states of São Paulo and Rio de Janeiro) and in the South of the country (particularly in the state of Rio Grande do Sul). When journal quality was considered, 21 (63.6%) of the 33 articles published in journals with an impact factor had their lead authors affiliated with institutions in the state of São Paulo. Likewise, there was a clear predominance of studies performed at public universities (81.3%), particularly among those published in journals with an impact factor: the lead authors of only four of these 33 articles (12.1%) were affiliated with private institutions.

Over 60% of the thesis and dissertation abstracts included in this review were authored by graduate students attending universities in the Southeast Region of Brazil, mainly in the states of São Paulo and Rio de Janeiro. The remaining output was distributed among universities in the South of the country and few graduate programs in the Southeast, North, Northeast, and Center-West regions of the country (particularly the Brazilian Federal District and the state of Minas Gerais). Public universities accounted for most (roughly 80%) of the scientific output on ASD produced as part of master's or doctoral degree programs. Seventeen abstracts did not disclose the size of the study sample; of the remaining theses and dissertations, 46.2% had samples of up to six participants and only 8.5% enrolled more than 50 participants.

DISCUSSION

This review reflects the state of the art regarding the Brazilian scientific output on autism spectrum disorders, and can serve as a guide for students and professionals in the field. The scientific community clearly has an interest in the

subject of ASD, even though this interest is still expressed more fully in the form of theses and dissertations (140) than as scientific papers (93). A countervailing element is evident on analysis of the Brazilian scientific output on the theme in two distinct periods — 2002 through 2007 versus 2008 and 2009. The total number of theses and dissertations about ASD published in the latter two years was less than half of the number authored between 2002 and 2007, whereas the average number of articles published rose to 20 per year from only nine in the earlier period. This suggests that Brazilian researchers are becoming increasingly interested in publishing research results in peer-review journals to provide greater visibility and quality.

Analysis of the line of research of these studies showed a curious predominance of so-called “intervention studies” (25 articles), which are considered methodologically complex.¹¹ However, as the present review did not assess article quality, one can safely presume that many articles classified as such were not those with more robust methodologies, such as randomized controlled trials. Also evident is a reversal of priorities in Brazilian scientific output from the public health standpoint. Basic studies required as guidance for public policy, such as epidemiological studies or those seeking to validate instruments used in ASD screening and diagnosis, are among those least frequently published (three and nine articles respectively).

The predominant theme of graduate theses and dissertations was “communication patterns and family relations” (46 dissertations/theses), which probably reflects the influence of speech therapists on the development of Brazilian research on the autism spectrum disorders.

Many of the articles, theses and dissertations were based on studies of small samples (six participants or fewer in 36.6% of articles and 46.1% of theses and dissertations). Some reflection on the impact of single case reports and case series — namely, in describing new or rare diseases, unusual presentations of known diseases, etc. — would therefore be in order.¹¹⁰ The wealth of scientific knowledge already available on the autism spectrum disorders suggests a need for studies with more complex designs that may yield bolder findings, such as epidemiological studies seeking to establish the prevalence rate of ASD in the Brazilian population.

Epidemiological studies play an essential role in public policy planning and in helping organize population-wide health care systems.¹⁰⁴ However, population-based, ASD - specific epidemiological studies conducted in Brazil are practically nonexistent: only three epidemiological studies authored by Brazilian researchers had been published as of 2009. Although a single master’s thesis presented preliminary data on a possible ASD prevalence rate for Brazil,¹⁰⁸ there are still no robust or nationwide data. This is a striking finding, particularly in light of the wealth of epidemiological evidence produced in other countries and published in PUBMED - indexed journals⁶: 560 articles describing the findings of ASD-related epidemiological studies were published between 2002 and 2009, showing the need for urgent action in this field.

One positive finding of this review was that most articles (57, 61.3%) adopted DSM-IV or ICD-10 criteria for diagnosis of ASD (Chart 1). However, the number of Brazilian studies based on systematic assessment by means of standardized, validated, gold-standard instruments for ASD screening and diagnosis (the Autism Diagnostic Observation Schedule—ADOS and/or the Autism Diagnostic Interview—ADI) is practically negligible.⁷ The lack of standardized instruments validated for the Brazilian reality forces research conducted in the country to rely on less-objective clinical assessments, which in turn makes it less likely for these articles to be accepted by high-impact factor periodicals. Furthermore, no systematic protocols for early detection of ASD have been tested in Brazil, despite the fact that integration of these protocols and guidelines into the Brazilian Public Health System (SUS) framework would undoubtedly be highly useful.

Another promising finding of this review is that Brazilian studies have achieved international visibility: 54.8% of articles were published in PUBMED - indexed journals. The interdisciplinary nature of Brazilian research on ASD was also an interesting finding. The articles included in this review encompassed various fields of education and health care, including psychiatry, neurology, psychology, pediatrics, and speech therapy. On the other hand, over 70% of articles were published in a set of 25 Brazilian journals, which, apart from the Arquivos de Neuro-Psiquiatria and the Revista Brasileira de Psiquiatria, have not yet been assessed by the Institute for Scientific Information (ISI) and have thus not received impact factor ratings. Accordingly, approximately one-fifth of all articles were published in journals with an impact factor >1. One of the recommendations of this review is therefore to encourage that Brazilian researchers expend the time and effort required to publish in domestic and international journals with higher impact factors, the intense competitiveness of first-tier journals and the challenges of writing or translating articles into a foreign language notwithstanding.

This review also shows a striking discrepancy in Brazilian scholarly output by region and institutional affiliation. Research activity is massively concentrated in the Southeast and South regions of the country and in public universities, accounting for 81.3% of all articles and 85.7% of theses and dissertations. We believe that national-level research funding agencies, such as CAPES and CNPq, have helped bridge this inequality by assigning several grant quotas to the North, Northeast, and Center-West regions of the country. It bears noting, however, that little has been done specifically for the ASD topic; grants aimed at supporting research in this area are almost nonexistent.

Limitations of this review include: (1) no analysis of the quality of published articles was attempted — therefore, the methodological quality of the studies described herein was not assessed or called into question; (2) the only institutional affiliations considered were those of lead authors, which may have led to overestimation of the regional concentration of research activity; and (3) our analysis of theses and dissertations was exclusively abstract-based.

CONCLUSION

There is a dire need for evidence that can contribute to the development of ASD detection and intervention programs in Brazil. Public policies for the health sector depends on the results of robust methodologies studies that are expected to be published in high-quality domestic and international journals. The data compiled over the course of this review show that the scientific output of Brazilian researchers does not correspond to the country's demand for scientific data; particularly lacking are epidemiological studies conducted on large, population-bases samples and studies seeking to validate early diagnosis and screening instruments that can play a role in the establishment of public policies for the development of targeted intervention and care programs for people with ASD and their family members.

Expansion of knowledge across the various regions of Brazil and over a broader range of research institutions also appears to be key elements for the further development of domestic scientific output. Training multi-professional teams in the fields of health care and education to provide diagnosis and care — by expanding center of excellence networks, for instance — may help consolidate scientific research on ASD, reversing the current scenario in which research and care opportunities are highly focused in certain regions of the country and at public universities.

Conflicts of Interest: none

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