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## Review Article

### THE STIGMA OF AUTISM AND ITS MULTICULTURALISM: A REVIEW

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#### ABSTRACT

Carry out a bibliographic search about the stigma of Autism Spectrum Disorder (ASD). Its implications and how different its manifestations can be in a diversity of cultures. Point out similarities and differences on the perception of the autism stigma and bring up data about its manifestations. After analysis, 15 national (Brazilian) and international articles have been selected. These articles were published between the years of 2011 and 2016 on research platforms, which met the inclusion criteria. Among the analysed articles, it was confirmed that the stigma lived by an autistic child and/or families is still existent in the American, African, European, Asian and Oceanic continents, and they emerge in different ways due a cultural variety but with high prevalence rates until today. It was concluded that an intervention with a proposal of de-stigmatisation of autism is needed in different cultural spheres, aimed at fighting the stigma still present in ASD.

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#### INTRODUCTION

According to the new DSM-5 edition (American Psychiatric Association – APA, 2013), the Autistic Spectrum Disorder is a neurodevelopmental disorder characterized by weakness in social communication and social interaction and for repetitive and stereotypical patterns of behaviour that can be presented on 3 levels of support, and with behavioural characteristics that are reported during early childhood.

The concept of stigma, according to Goffman (1988) refers to attitudes of derogatory nature that are expressed on interpersonal relationships, and they can be break into three categories: overt or external deformities, known deviations in personal traits, and tribal stigma. Due to prejudice, families with autistic child have been confronting many difficulties, not feeling welcomed by society as a political subject independent of which social sphere they belong to; which makes them often unable to take action on behalf of their child needs (Machado and Ansara, 2014).

It is known that the discovery of a distinctive pathology on a child will certainly bring consequences especially into the family with an autistic child (Segeren and Françoso, 2014).

These families are faced with the great challenge of being part of one of the groups that have little space and attention in a conventional society, a scenario that arises from the existing stigma (Machado and Ansara, 2014).

The identification of prejudice and other discriminations suffered by autistic individuals and their family could be used as motivation to change this paradigm (Machado and Ansara, 2014). Taking in consideration the importance of identification and the awareness about the stigmas currently present in our society and daily experienced by autistic individuals and their families, it is clear that a bibliographic search is extremely necessary in order to both guide future researches and to cooperate on the reduction of paradigms and segregations caused by the stigma of autism.

According to the DSM-5, the Autism Spectrum Disorder (ASD) is defined by a condition of neurological characterised by impairment in social communication besides the presence of restricted, repetitive or stereotyped patterns of behaviour together with a restricted repertoire of activities and interests (APA, 2013).

Little is known about the aetiology of autism, although studies have already showed evidences linked to epigenetic

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phenomena such as exposure to chemical components during pregnancy (Arif *et al*, 2013) and others unspecific risk factors like advanced parental age and babies born underweight (APA, 2014).

Autism can emerge isolated or associated to predefined genetic conditions such as the Fragile-X syndrome, Tuberous Sclerosis and Down syndrome. Besides that, studies show that epilepsy can be present at 20% of autistic patients (Marchezan, Gonçalves and Riesgo, 2014).

ASD diagnosis is essentially a clinical and interdisciplinary work, based on interview with parents, application of specific instruments, reports from school and therapists, as well as a close look at the patient's recreational and social activities (Muskat, *et al*, 2014).

According to the DSM-5, impaired hearing, severe psychosocial deprivation, intellectual disability, mixed receptive-expressive language disorder, Landau-Kleffner syndrome, extreme separation anxiety, selective mutism and schizophrenia can still define differential diagnosis.

The DMS-5 shows that age and the onset pattern are important and must be taken into consideration. The symptoms can be usually observed during the second year of life, although it is also possible to be diagnosed earlier that age in cases where the child shows severe development delay.

According to DSM-5, behavioural characteristics can also be observed during early childhood, where one of the main observed behaviours is the lack of interest on social interactions during the first year of life, besides a development delay on language, atypical patterns during playtime and very uncommon patterns of communication.

The prognostic of the Autism Spectrum Disorder is given by the presence or absence of intellectual disability and language impairment, besides other health problems such as epilepsy (APA, 2014).

The use of the word "spectrum" is given due the manifestations of the disorder that can vary significantly depending on the severity of the autism, the level of the development, and the chronological age. In this way, the Autism Spectrum Disorder encompass what it was once called Early Infantile Autism, Childhood Autism, Kanner's Autism, High-Functioning Autism, Atypical Autism, Global Development Delay, Childhood Disintegrative Disorder, Asperger Syndrome (APA 2014).

Regarding the treatment of patients with ASD, interventions and compensations, besides current support, can be used to mask the symptoms; yet those symptoms can still be present and even worst, they can be the ones responsible for causing social and professional functioning damage, besides affecting other areas that are important in patient's life (APA, 2014).

For this reason, when a child is diagnosed with ASD, family members may receive it with great impact and a range of emotions. From now on, a totally new perspective for the future has to be draw – expectations and dreams that were once reality are now affected by numerous contradictory feelings (Givigi *et al*, 2015).

Parents and family now will have to deal not just with those feelings but also with a radical change of lifestyle, besides discrimination and segregation still present in modern society, defined as stigma.

In this way, it is of great importance that stigmas present in society and in different cultures around the world become known by the general public - in order to take into account the implications that these stigmas impose on autistic children and their families, in order to fight against the perpetuation of stigma in autism.

The concept of stigma started in Greece, to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier (Goffman, 1988, p.1).

GOFFMAN (1988), the pioneer of stigma-related studies, define stigma as a phenomenon whereby an individual isn't fully accepted socially. The author defines the term as a derogatory, weak and handicapped feature, classified into three different types: overt or external deformities, known deviations in personal traits (dishonesty, mental disorders, alcoholism, homosexuality, etc.), and tribal stigma (related to nationality, religion). The author state that in all these types, the stigmatised individual could go unnoticed in everyday relationship, yet it has a particular trait that stands out and prevents attention to other attributes that this person might have. This attribute that makes him different from others is what is called stigma.

In one of their studies, MACHADO and ANSARA (2014) showed a civilisation patch concerning handicapped people and their family. The authors point out how those families suffered from a slow process of evolution concerning the way there are seeing and treated by society. The handicapped individual was kept away from social contexts, preventing the contact of society with these individuals and their families, which resulted in many decades of social segregation. The social inclusion of people with disabilities is a recent event that started just a few decades ago.

Being that, the stigma has been present in society since ancient times, when child neglect and extermination were legitimized. Things have changed with Christian doctrine claiming that children with birth defects had the right to live. The 20<sup>th</sup> century saw the rising of social movements against the criminalisation of mental disability, and it was when the disabled were recognised and legitimised by The Declaration of Human Rights (Machado and Ansara, 2014).

The autistics were considered as mentally disable or psychotics for a long period of time and kept away from any social attention or public policy. In Brazil, the ASD was one of many terms kept only in mental health publications. The majority of people would never have heard about the term, yet ASD would have no identity or face (Machado and Ansara, 2014).

Despite actions in defence of ASD, autistic individuals don't cease to suffer from forms of social segregation. Mothers of autistic children state that there is a lack of awareness in all-social spheres, even to negotiate interests of their child. These families are not recognised as a political subjects by society; aside from facing challenges in everyday life, they fear the uncertainty about the future of their children (Machado and Ansara, 2014).

Families also report that “practical aspects of daily life are difficult, and the lack of considerable efforts to put in action effective political policies, besides moral and symbolic accessibility, contributes to the absence of families of autistic children into public spaces; getting isolated in virtue of society’s reaction” (Machado and Ansara, p. 526).

The stigma therefore has been found to cause deep impacts on the emotional health for those caring for someone with disability, reducing coping effectiveness and leading them to greater isolation (Cantwell, Muldoon and Gallagher, 2015).

In this way, this present study intends to analyse the aspects that involve ASD stigma in a variety of socio-cultural realities, besides analysing the perception of stigma in ASD and the consequences suffered by caring families in a diversity of cultures.

## METHODOLOGY

The present study involves a cross-sectorial approach. For the review of literature, works that have been published at Pubmed, Scielo and Lilacs, between the years 2011 and 2016, were analysed. The key words used for the search and gathering of those articles were, in Portuguese: estigma e autismo; estigma, autismo e países; estigma, autismo e culturas; followed by their equivalents in English: stigma and autism; stigma, autism and culture; autism and world; stigma; autism; stigma, autism and cultural differences.

The selected articles were chosen according to the following criteria: articles that were published in Portuguese or in English, articles linked to the stigma of autistics, and/or articles which talked about how family members see the stigma in autism.

Among the variables, one point that is taken in consideration is studies that show research results where the stigma in ASD was evaluated together with other developmental disorders. The collected data was qualitatively analysed.

## RESULTS

In the database referred above, 37 articles were found, from which 23 were pre-b selected. After reading and analysing those ones, it was concluded that only 15 of them met the objectives and criteria of this review.

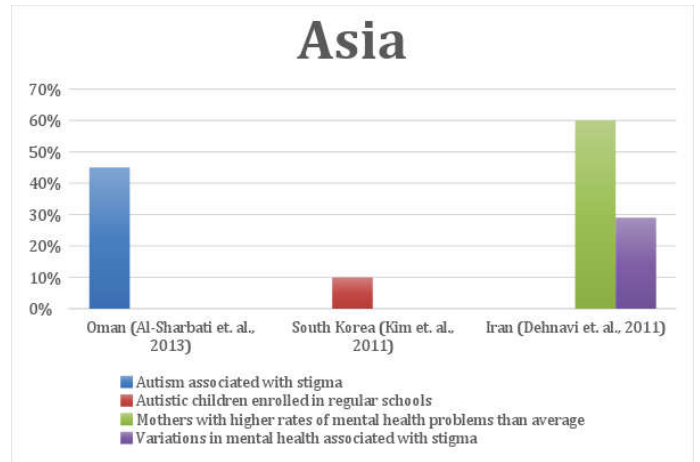


Chart 1

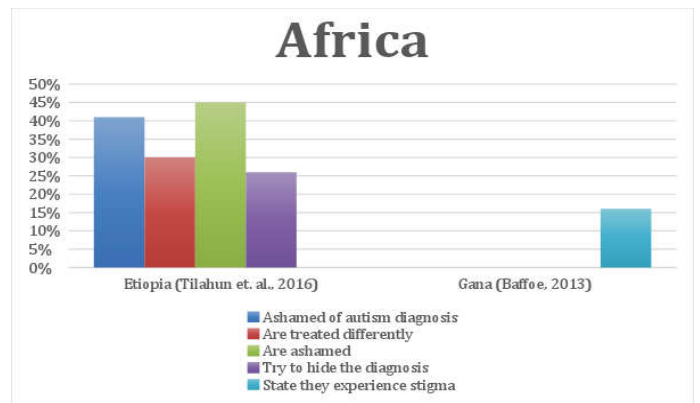


Chart 2

Table 1

Autors	Place/date	Title/description
Tilahun <i>et al.</i>	Etiópia, 2016	Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional, facility-based survey
Jensen <i>et al.</i>	Dinamarca, 2015	What do the general population know, believe and feel about individuals with autism and schizophrenia: Results from a comparative survey in Denmark
Lilley, R	Austrália, 2013	Crying in the park: Autism stigma, school entry and maternal subjectivity
Segeren&Francoso	Brasil, 2014	As vivências de mães de jovensautistas (The experiences of mothers of autistic children)
Russell & Norwich	ReinoUnido, 2012	Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders
Givigi <i>et al.</i>	Brasil, 2015	Implicações de um diagnóstico: o que sentem as famílias dos sujeitos com deficiência? (The Implications of a diagnosis: what do relatives of disabled people feel?)
Milacic-Vidojevic <i>et al.</i>	Sérvia, 2012	Tendency towards stigmatization of families of a person with autistic spectrum disorders
Cantwell <i>et al.</i>	Irlanda, 2015	The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities
Durand-Zaleski <i>et al.</i>	França, 2012	A first national survey of knowledge attitudes and behaviors towards schizophrenia, bipolar disorders and autism in France
Tait K <i>et al.</i>	Hong Kong, 2014	Raising Young Children with Autism Spectrum Disorders in Hong Kong: The Impact of Cultural Values and Stigma on Chinese Parents' Coping Strategies
Kim <i>et al.</i>	Coréia do Sul, 2011	Prevalence of Autism Spectrum Disorders in a Total Population Sample
Gona <i>et al.</i>	Australia, 2016	Challenges and coping strategies of parents of children with autism on the Kenyan coast
Al-Sharbati <i>et al.</i>	Omã, 2013	Awareness about autism among school teachers in Oman: A cross-sectional study
Dehnavi <i>et al.</i>	Irã, 2011	The Share of Internalized Stigma and Autism Quotient in Predicting the Mental Health of Mothers with Autism Children in Iran
Baffoe, Michael	Gana, 2013	Stigma, Discrimination & Marginalization: Gateways to Oppression of Persons with Disabilities in Ghana, West Africa

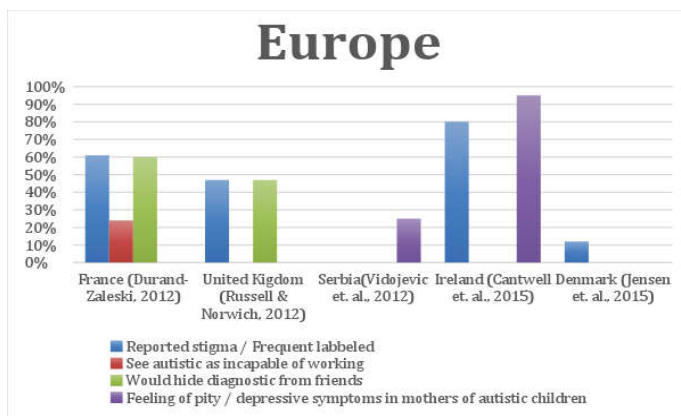


Chart 3

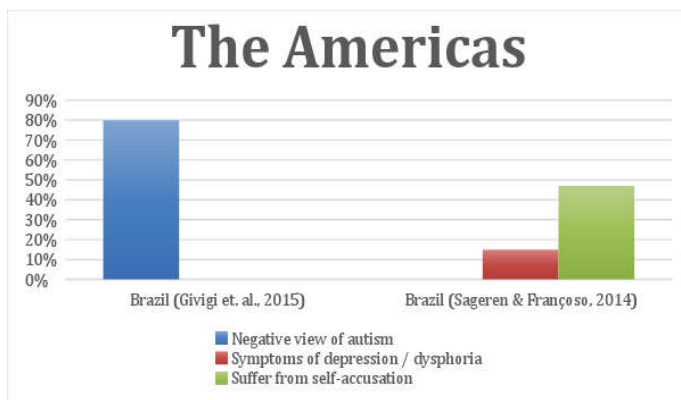


Chart 4

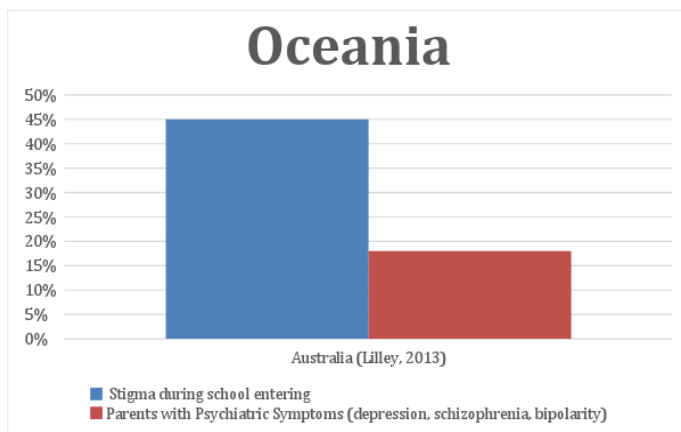


Chart 5

## DISCUSSION

The present research showed that even though studies about the stigma of ASD are limited, it shows clearly that there are gaps in the knowledge of such reality. The presentation of the analysed studies shows that the stigma in autism has been perpetuated in different cultures around the world, at different levels and at different contexts.

In this regard, many of the studies here analysed suggest the need of social interventions, especially regarding autism awareness, in order to reduce the social segregation that exists today due to stigma.

In the American continent, more precisely in the Brazilian scenario, data indicated that stigma is expressed mainly through the negative view of the population towards neuropsychological deficiencies, usually expressed through

feeling of rejection, fright, struggle and prejudice coming from relatives of individuals diagnosed with ASD, and though social isolation of these families who wants to avoid prejudice (MACHADO and ANSARA, 2014; GIVIGI *et al.*, 2015).

On the other hand, results from the Asian researches show that stigma exists due to taboo still present in society regarding neurological disorders in general. Since Asia has a culture of individualisation and retention of personal problems away from society, stigma leads families of individuals with ASD to hide the diagnosis and to behave in fear while in public, resulting in a lack of public awareness about ASD and other neurological disorders, besides increasing the levels of taboo and stigma. (ANDO, 2013; AL-SHARBATI *et al*, 2013; KIM *et al*, 2012; DEHNAVI, 2011).

In African countries, studies have showed that stigma is more related to the difficulty of people with ASD to live “normal lives”, specially concerning their working capacity, which leads local population to exclude those who are perceived as different, besides often treating people with mental disorders with disrespect. (BAFFOE, 2013; TILAHUN *et al*, 2013).

Researches carried in Oceania, in their turn, showed that stigma in ASD occurs mainly in the labelling and exclusion of autistic individuals and their family members, high level of prejudice, and parents with psychiatric disorders of depression, bipolarity and schizophrenia (Lilleley, 2011).

In addition, interrelations between the surveys were found.

In this way, it is understood that the stigma of ASD is perpetuated in different cultures, levels and contexts. Proposals for social empowerment are necessary in order to reduce social segregation.

## CONCLUSION

This study covered a multicultural perspective of ASD and its perceptions, and thanks to its bibliographic search, it was confirmed that stigma occurs in numerous cultures and manifests itself in a number of different ways. It can be concluded that historical-cultural aspects also influence on the manifestation of stigma, leading to the understanding that ASD awareness is still low and its implications, little known.

It is also understood that stigma is usually presented linked to other factors such as prejudice, pity, shame, rejection, social exclusion and myths derived from the lack of knowledge about the condition.

The intervention with a proposal of de-stigmatisation of autism is clearly necessary in different cultural spheres, aiming to combat the still present stigmatisation of people with Autism Spectrum Disorder.

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