

Autism spectrum disorders: students' view of medicine and nursing courses at a public university

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Abstract *The term stigma comes from Greek, being related to the identification of people through a physical mark, which can generate marginalization. The literature points out four types of stigmas: public, institutional, self-esteem, and courtesy. People with Autistic Spectrum Disorders are stigmatized in various cultures and societies. This study describes the view on stigma regarding Autistic Spectrum Disorder among undergraduate medical and nursing students. This is a cross-sectional study of a qualitative approach, whose data were collected through two focus groups, one with medical and another with nursing students, from a public university in Alagoas, Brazil. A script with eight questions for discussion in the focus groups was used. The speeches were recorded, transcribed, and analyzed with the IRAMUTEQ software, based on content analysis. The Descending Hierarchical Classification showed five categories related to the disorder, which were: 1 - Approach to the person with the disorder; 2 - Experience of Stigma; 3 - Segregation of People with Disorders; 4 - Care of the Person with the Disorder and Class; 5 - Challenges faced by the people affected.*

Key words *Stigma, Autistic Spectrum Disorder*

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Introduction

The term stigma originated from a Greek concept related to the practice of physically marking, through cuts or burns, people as criminals, traitors, and slaves, so that they could be easily identified and socially avoided. Today, such physical marking has resulted in the attachment of a certain attribute to a negative stereotype disqualifying the full social acceptance of the devalued individual¹.

Stigma might be visible or not, pointing to a condition in the subject, that disqualifies him/her from acceptance by society, causing attitudes of discrimination from other people².

There are four types of stigma, *public stigma* being that which is revealed through society's reaction to a person who is assigned a certain stigma. Another type is *institutional stigma*, which occurs through the legitimization of stigma by institutions in society. The third type is *self-stigma*, which occurs in the face of the psychological and social impacts that the stigmatized person attributes to himself/herself due to the suffering of the public stigma to which he/she has been subjected. The fourth type is the *courtesy stigma* or *stigma by association*, which is the community's way of reacting toward an individual linked to a stigmatized subject³.

People may suffer the impact on their mental health when subjected to a situation caused by stigma, which can cause damage to the society in which the individual lives and to the stigmatized individual him/herself. By exposing him/herself to this situation, the subject can be inhibited in seeking care; if he/she presents any mental disorder, the situation worsens due to the fear of exposing him/herself in an attempt to seek support⁴. People are stigmatized in a context that encompasses culture, political history, economy, and social aspects. Thus, stigma reflects the society where the subject is inserted in a given time, but also moral, intellectual, and cultural tendencies⁵.

Autism Spectrum Disorder (ASD) is a biologically based neurodevelopmental disorder characterized by impairments in two main domains: (1) deficits in communication and social interaction and (2) repetitive and restricted patterns of behavior, interests, and activities⁶. About one in 54 children has ASD, according to estimates from the Centers for Disease Control and Prevention (CDC); 4.3 times more prevalent among boys⁷. The diagnosis of ASD is considered a spectrum, which means that there is a varied clinical presentation of characteristics in these individuals.

Thus, there are people with different abilities and difficulties in their communication, social interaction, and behavior patterns⁸.

It is important to note that the attributes described are not intrinsic to the people, but conferred by society itself. The stigma, therefore, is not rooted in the ASD, but in the categorizations made by society, using its outputs, its works, its memories, its conversational elements, and its speech⁹.

The literature points out that stigma can often cause distance between people. Such a situation denotes the importance of studying stigma among medical and nursing students in order to contribute to their future education by recognizing their difficulties and lack of knowledge, especially in the case of ASD, which has been increasing its prevalence in recent times¹⁰⁻¹².

Therefore, in view of the aforementioned findings, this study was conducted to investigate whether there is evidence of stigma about ASD among undergraduate medical and nursing students at a public university in the state of Alagoas, Brazil. The research question is: Do medical and nursing students have a stigmatized view of people with ASD?

Method

Study design, study site, and participants

This is an observational study, of qualitative approach, carried out through two focus groups with medical and nursing students in a public university in Alagoas.

Sixteen students participated in the research, ten from the medical major and six from the nursing major. Fictitious names were created to present the students' speeches, aiming at anonymity.

Data collection procedures

Data collection occurred in April 2019, through the focus group technique – applied at two moments, on different days and locations, one with medical students and another with nursing students. Two groups were conducted due to the understanding that the experiences and curricula in each one present specific aspects of the area. The groups were conducted by a previously trained facilitator, assisted by three observers, also previously trained. Initially, all participants were given the Free and Informed Consent Term

(FICT) to read and sign, and then the discussions started. All the speeches were recorded and then transcribed in a free-access text editor (Open Office - <http://www.openoffice.org>). The norms of Resolution No. 466, dated December 12, 2012, were followed. The project was approved by the Research Ethics Committee (CEP) of the Federal University of Alagoas, according to the protocol - Process No. 77609417.2.0000.5013.

Instrument

A script with eight open-ended questions was used: understanding of stigma, approach to the topic during undergraduate studies; experience of stigmatizing situations, knowledge about ASD; knowledge about the family life of children with autism and the presence of stigma; challenges of children with ASD; suggestions for approaching the two topics during undergraduate studies.

Data Analysis

A computerized textual analysis was carried out using the IRAMUTEQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* - <http://www.iramuteq.org>). It is a GNU GPL (v2) licensed software that allows doing statistical analysis on textual data and is anchored in R software (www.r-project.org) and Python language (www.python.org). IRAMUTEQ allows different types of textual data analysis, whether simple, such as basic lexicography which covers lemmatization and word frequency calculation, as well as multivariate analysis such as hierarchical descent classification, correspondence factor analysis, and similarity analysis.

This software is based on calculations performed on the co-occurrence of words in text segments, aiming to gather them into classes according to their similarity and dissimilarity. It aims to obtain a number of classes, through a statistical classification of simple utterances from the analyzed *corpus* (here are answers given by the participants), according to the distribution of words within the utterance, in order to apprehend the words that are more characteristic to them, that is, more significantly present by the association coefficient [$\chi^2(1) \geq 3.84, p \leq 0.05$] of the word to its position in the text¹³⁻¹⁵. Furthermore, by means of the Factor Correspondence Analysis (FCA), a description is possible, crossing the vocabulary and the classes, by means of a graphic representation, in which the axes allow

visualizing the relations and/or oppositions between the classes^{16,17}.

IRAMUTEQ decomposes text into text segments and performs a classification according to vocabulary distribution. Initially, the statistical analysis performed consists of a Descending Hierarchical Classification (DHC), with the objective of calculating the partitions into lexical classes and presenting their relationships in the form of a tree (dendrogram). Next, a Correspondence Factor Analysis (CFA) is performed to visualize, in a Cartesian plane, the relationships and/or oppositions resulting from the DHC. Computerized text analysis organizes the structured content from a statistical analysis into a DHC, which aims to establish a division among the Classes as clearly as possible.

The dendrogram allows one to verify the relationship between the classes [strong connection (proximity) or weak (distance)] and the representativeness of each class, from the explanation percentage of the evaluated corpus that enables the understanding of the interrelationship between the classes^{13,15,18}.

The Reinert method (DHC) and the parameterization "SIMPLE SUR SEGMENTS DE TEXTE", which corresponds to the smallest meaningful text fragment – equivalent to an analysis of the text segments delimited by the software (Standard Analysis) for long answers, that is, more than three lines of each text - were adopted.

Results

The *corpus* of this study consists of 84 texts divided into 269 text segments - corresponding to 74.31% of the total (362 text segments). After text analysis, five classes were listed: care, coexistence, stigma, challenge, and knowledge (Figure 1).

The classes were named according to the words that best define them that is, with the highest χ^2 value and the highest percentage – for example, 100% means that the word was mentioned only within its own class. Class 1 comprised 20.1% of the *corpus*; Class 2 corresponded to 18.2%; class 3 to 14.9%; class 4 to 19.7%; and, class 5 to 27.1% of the *corpus*. To understand the relationship between the classes, the dendrogram of Figure 1, was divided (1st partition or iteration) into two *sub-corpus*, splitting classes 4, 3, and 2 from classes 5 and 1. Then, the larger *sub-corpus* (classes 4, 3, and 2) was divided, splitting class 4 from classes 3 and 2 (2nd partition or iteration).

Classes 3 and 2 are closely related, as are classes 5 and 1. Likewise, classes 5 and 1. Class 4 is the most isolated, but is closer to the *sub-corpus* composed of classes 3 and 2. It is not by chance that the classes are related in this way. Class 4 comprises the identification and the first consultation or search for help/care (it was named “Care”). Classes 3 (“Coexistence”) and 2 (“Stigma”), contemplate the importance of having lived with someone with ASD to be able to identify characteristics (specific to people with ASD) and the existence of stigma. Classes 5 (“Challenge”) and 1 (“Knowledge”) understand how students perceive the insertion of the person with ASD in society (challenges they will have to deal with) and how they build their knowledge on the subject in their academic training.

Below are some text segments that exemplify each category, which resulted after content analysis.

- Category 1 - Approaching the person with ASD.

I think that in general there could be more publicized campaigns because I don't know which ones there are, I didn't know about them, they should have greater visibility, and also that health courses should have at least one class dealing with the matter and that one day this would be addressed (Carlos).

I think that talking about it and exchanging experiences with other people is already a good thing because they are different people with different perspectives, so this debate, hearing the other person's opinion, is also very important (Florença).

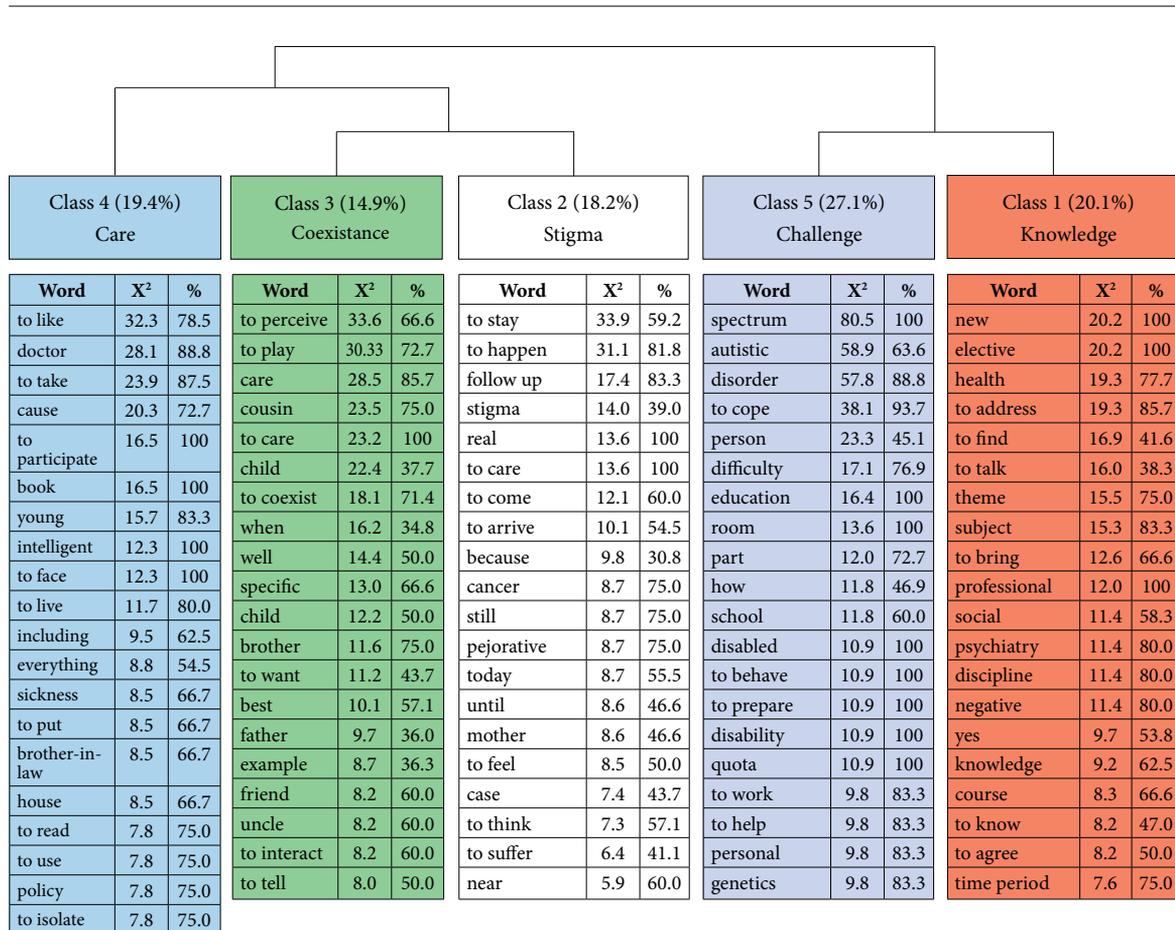


Figure 1. Top-down Hierarchical Classification Dendrogram.

Source: Authors.

- Category 2 - Experiencing Stigma among the interviewed students.

For example, the stigma over the humanities student today is that they are a liberal, laid-back students who smoke marijuana, which can happen in some cases, but this generalization, this stigma is not valid (Roberto).

I suffer a lot with stigma for being fat, for being an atheist, for being homosexual, for studying Nursing. People say "If you studied a little more you would get into medical school, you would be so beautiful if you lost weight", and the girls say "oh, if only you liked it [the female sex/gender]" (Lucio).

- Category 3 - Coexistence and segregation of a person with ASD.

I remember when I was a kid and I saw him for the first time. I realized that no one in the family communicated with him, interacted with him, and I asked why we couldn't play with him (João).

I realized by the family's movement, by the family's dynamics, that his family core was distancing itself from the rest of the family because of the child's behaviour, which was not an exaggerated, showy behaviour, it was perhaps a way for the family to protect itself from more not-so-close relatives (Vitoria).

- Category 4 - Caring for the person with ASD.

The school pedagogue already faced a big challenge because she said that the work was not hers alone, she had to take him to the doctor, so the mother said she had taken him, but they said he was sick (Fabio).

The same thing happens with my aunt's cousin, who is a psychologist [the aunt], but she would rather believe that he doesn't have anything and neglect more specialized care. I think this complicates the autistic person's situation even more (Cicero).

- Category 5 - Challenges presented by people with ASD.

So if children grew up with other people who have autistic spectrum disorder, it would become normal and we would learn to deal with the situation (Rubia).

He had difficulty relating, but the biggest difficulty was people approaching him because they thought he wasn't ready to communicate (Marcia).

In the Correspondence Factor Analysis (CFA) we observed the relationships among the categories that are presented in Figure 2.

It is clear that categories 2 (Stigma) and 3 (Coexistence) are highly related, with a greater mix of the defining words. The others present themselves with a lesser mix of words.

Discussion

Category 1, *Approaching the Person with ASD*, presents the opinion of the students surveyed about the need to learn the several aspects of ASD. Not only the biological knowledge but also the ways of dealing with it in everyday life, aiming at the possibility of reducing fears, difficulties in relationships and treatment, as well as the stigma about this disorder.

The lack of information enhances discriminatory and prejudiced attitudes and hinders the learning process focused on mental health. The provision of information on the subject during graduation, in the most diverse forms – seminars, elective courses, conversation circles, dialogue with parents and caregivers of people with ASD, and even the subjects who are in this condition – would make it possible to differentiate and understand what a disorder is and the possible absence of it. Only with quality information can the stigma pertaining to the health of the mind be overcome⁴.

The general population, including medical and nursing students, when they have little knowledge about ASD, can cause suffering through stigmatizing processes, most often for those with ASD¹⁹.

The Stigma suffered by those surveyed, appears in the category below.

Category 2, *Students' Experiences of Stigma*, through reports of some incidents experienced by them. We identified stigmatizing situations related to not being part of the local culture, i.e., being from another state, having a different sexual orientation from the majority of the class, being obese, and attending more free-thinking courses, such as courses in the humanities area.

The experiences reported by students as negative situations regarding sexuality, physical appearance, and coming from another place can generate: labelling, stereotyping, separation, and devaluation of the subject, which, together with discrimination, constitute stigma – considering that society tends not to accept human differences, such as skin color, social origin, and sexual orientation, which are stigmatizing aspects. The process of stereotyping occurs through a selection of human differences that matter socially and are rendered undesirable characteristics²⁰.

Socially shared beliefs can generate stereotypes about subjects of a social category, assuming the possibility of group homogeneity and common behavior belonging to the social group, based on propositions about factors that

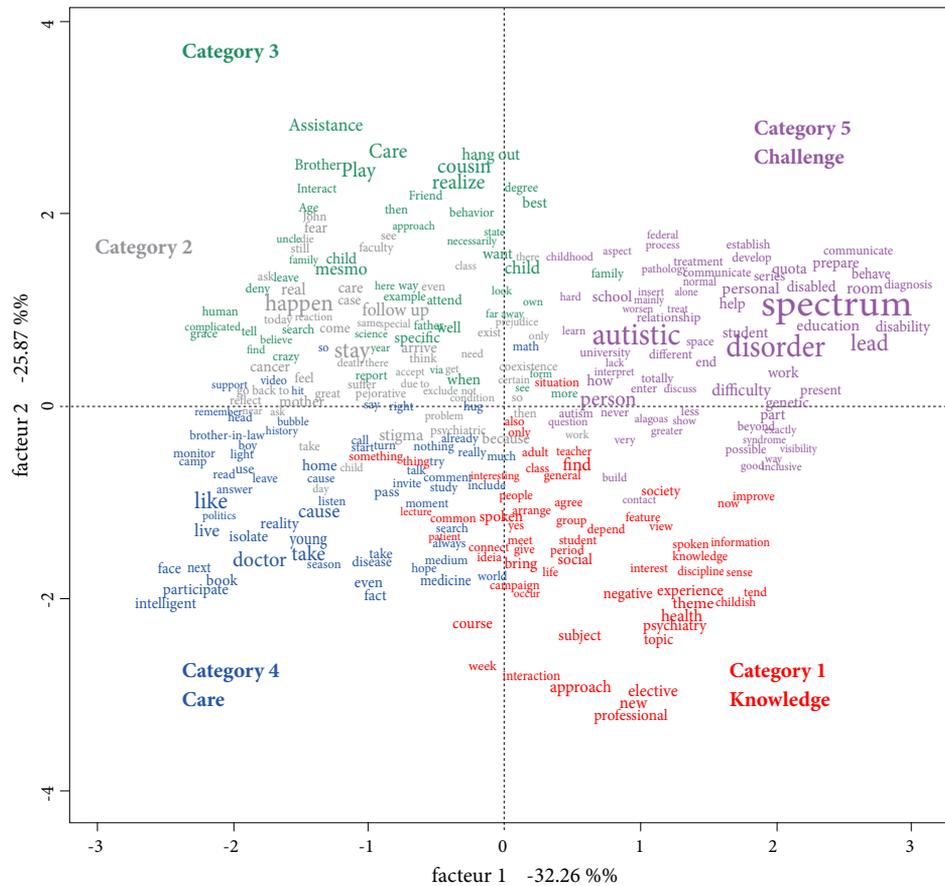


Figure 2. Plotting the classes and defining words.

Source: Authors.

produce models of subject behavior, evidenced in judgments founded on assumptions about the existence of the exchange of psychological traits among members of the same social category²¹.

Category 3, *Coexistence and Segregation of People with ASD*, demonstrate the difficulty of those responsible for including and caring for people with ASD in society and their exclusion in everyday interactions.

Society has norms and values that define the attributes and behaviors that are acceptable for its components. It has forms of social control to ensure that most of them conform to the established norms. Subjects who do not conform to these rules or break social taboos can be socially excluded²², which corroborates the reports of those surveyed here.

Disability in any aspect of human life can lead to the suffering of stigma, a procedure in

which different subjects are marginalized, segregated, and belittled by society for having values, characteristics, or practices distinct from the dominant culture²³. The segregation reported by students regarding people with ASD is brought by history through the various ways of treating the “different” individual. For a long time, there was the marginalization and segregation of those who were considered different from others, but as human rights have been consolidated, the way to look at people who are different has changed²⁴.

It is understood that it is important that society knows how to live with diversity among its members because no human being (especially those with ASD) should be condemned to segregation, either by misinformation or prejudice. Understanding the disorder enables the recognition of the difficulties that these people face, whether they are children, adolescents, or adults,

leading to work for their inclusion in society, enabling the pursuit of their citizenship, and also offering support to family members to overcome the challenges²⁵.

In Category 4, *Care for the Person with ASD*, the speeches show how people have difficulty accepting the diagnosis, which is shown in the various spaces attended by individuals with this condition to seek their treatments and mental health care, specifically those with ASD.

The first social institution and through which the child has access to society is the family, thus being the main space for socialization. Family members, as important social members in the child with ASD's life, should provide basic care according to their needs, playing an important role in their development and growth²⁶.

Studies conducted in Brazil on ASD show an increase in Brazilian scientific production, however, these publications do not specifically focus on actions that promote the improvement of autism care. Efforts are needed in this direction so that the studies can contribute more to the definition of public policies for the disorder²⁷.

The data found brings the students' perspective on the involvement and family relationship with people with ASD. The family is the place where the child begins his/her socialization, and it is also the main structure of his/her care, which embraces his/her needs and is predisposed to contribute to the development of his/her potentialities. The appearance of a chronic situation can lead to the fragilization of the family when it is trying to manage this challenge²⁸.

Category 5, *Challenges faced by People with ASD*. This category demonstrates the potential of the students' sensitivity towards these people, in addition to the need for openness to new learning, so that the relationship between the subjects with ASD can happen and thus they can develop anti-stigma interventions during the degree.

Characterized mainly by relationship deficits, sometimes ASD can lead to intellectual deficits, which is a common comorbidity, causing challenges in the lives of people with the disorder and their families/caregivers. In recent years, there has been an active participation in movements involving people with low-severity ASD, highlighting the greater activism of their parents. Even so, the challenges are still many²⁹.

Since there is no biological marker that genetically determines ASD, and since it has a broad picture, the presence of a multidisciplinary team

with experience is important, both to act in the identification of cases and in the care process, being each practitioner responsible for their actions, but with an eye on the individual as a whole³⁰.

The variability of symptomatology contributes to the complexity of diagnosis, evaluation, and follow-up requires experience and knowledge of professionals from various specialties. Studies show different qualifications among the professionals involved, varying from one place to another. For the necessary care, the participation of reference professionals from various spatialities is important, which contributes to early diagnosis³¹.

To alleviate this situation, it is important that the person with ASD be assisted by a multi-professional team that intervenes early on, enabling the best performance and achievement of skills. This requires the use of specialized therapies, such as those aimed at social integration, to improve sensory processing and behavioral organization³².

Social contact is the most effective type of intervention for improving knowledge, information, and attitudes related to stigma in the short term. However, there is evidence of long-term benefits from social contact to reduce stigma. Given the magnitude of the challenges that result from stigma and discrimination in mental health, a collaborative effort is needed to fund methodologically strong research that provides robust evidence to inform investment decisions to intervene and reduce stigma³³.

Through contact theory, it is recommended that increased social contact can attenuate stigma, especially internalized stigma³⁴.

Conclusion

It can be concluded that the surveyed students recognize the existence of stigma and that they propose strategies to demystify this conception resulting from the society they belong to.

It was clear that the education system still does not have enough tools to break the barriers and provide nursing and medical students with a better relationship, understanding, and care for the person with ASD.

Thus, approaches to ASD need to be shared among the university, students, caregivers, and people with ASD, with a social and not merely welfare view.

Collaborations

MGMM Taveira worked on the research design, data collection, data analysis, and final writing of the paper. DS Correia worked on the data analysis and final writing of the paper. JAPM Coelho worked on the data analysis. CT Miranda worked on the final revision of the paper.

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