

Expressions during World Autism Awareness Week on Twitter

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Abstract

Introduction

Autism spectrum disorder (ASD) is a condition that influences communication, social interaction, and behaviors. On social media, we find expressions ranging from information about ASD to personal accounts and discussions on inclusion.

Objective

To analyze the expressions of the Brazilian population on Twitter regarding autism.

Methods

This study is qualitative, descriptive, and based on document analysis. We collected data on the social media platform Twitter between April 3, 2023, and April 10, 2023, in Portuguese, the hashtags: #diamundialdeconscientizaçãodoautismo encompassing (#worldautismawarenessday) and #autistas (#autisticpeople). We analyzed 279 tweets using discursive textual analysis, from which two thematic axes emerged.

Results

The results indicate that the inclusion of people with ASD in cultural, sports, and labor market spaces is seen as crucial for promoting citizenship and social inclusion. However, challenges persist in implementing public policies, especially in education, health, and information dissemination, highlighting the need for a more holistic approach and respect for diversity.

Conclusion

Social media reflects a lack of progress in public policies and legislation to include people with ASD in various aspects of social life, such as education, health, and work, which are necessary to promote full citizenship. Despite advances in public policies, significant challenges remain in implementing these initiatives, requiring greater awareness and respect for this population.

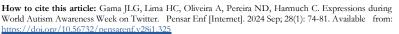
Keywords

Autistic Disorder; Social Network; Public Policy; Social Inclusion.

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Introduction

Autism spectrum disorder (ASD) is a heterogeneous condition that encompasses a group of complex brain development disorders, including those previously known as early childhood autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's syndrome.1 The condition is characterized by impairments in social interaction and communication, as well as restricted and repetitive patterns of behavior, activities, and interests, primarily affecting the neurological development of children. Additionally, individuals with ASD may present a variety of comorbidities, including hyperactivity, sleep disorders, gastrointestinal problems, and epilepsy.²⁻³

The literature highlights that people with disabilities or disorders are generally perceived by society as abnormal, alienated, unrealistic, dangerous, and incapable, often facing prejudice and social stigma. This perception contributes to the lack of appropriate care and attention for individuals with ASD in various areas, suppressing the exercise of free citizenship, which is guaranteed to all citizens.4

In the Brazilian context, although there are no specific studies on the prevalence of ASD, it is estimated that this condition affects approximately two million Brazilians.⁵ In the United States, where there has been significant progress in standardized assessment resources and tools, the incidence of ASD is estimated to be 1 in every 50 children.⁶ Thus, the urgency of substantial investments focusing on various aspects of the lives of this population is evident, aiming at their inclusion and the guarantee of fair and equal rights.

In 2008, the United Nations (UN) declared April 2 as World Autism Awareness Day to raise awareness among society and policymakers about the disorder, provide information, and break down prejudices, recognizing the condition and supporting actions for improving the quality of life of individuals with ASD.7

One of the areas affected by ASD that draws the attention of health managers is social interaction. Relationships established through the internet have exponentially spread over time, helping to overcome physical barriers and enabling communication among social actors anywhere in the world.8 In general, social media can be used to extract information about patterns of interpersonal interaction and opinions, proving to be an important tool for assessing social expressions that occur in various social movements, such as World Autism Awareness Week.9

Therefore, identifying and understanding the main expressions on social media regarding the population with autism is necessary to demystify the topic, thereby allowing for the dissemination of information aimed at guiding the actions of competent authorities and assisting in implementing inclusive public policies nationwide. Thus, the study aimed to analyze the Brazilian expressions on Twitter concerning World Autism Awareness Week.

Methods

We conducted a qualitative, descriptive, and documentbased study. We adopted the Discursive Textual Analysis (DTA) as the methodological framework, an approach that integrates elements from traditional content analysis and discourse analysis, characterized as a self-organized process of construction and understanding, demonstrating an interpretative movement of a hermeneutic nature. 10

Regarding document-based research, studies using this methodology primarily utilize documents without analytical treatment, meaning they have not been previously analyzed or systematized. In discursive textual analysis, both description and interpretation are elements of analysis, with these stages occurring concurrently within the article. From this perspective, interpretation requires a systematic and argumentative understanding of the information.¹⁰

The study setting was the social media platform Twitter, which provides a publicly accessible global database, chosen for its importance as a communication tool between governmental and non-governmental organizations and the general population. We conducted data collection from April 3 to April 10, 2023, considering that April 2 is recognized as World Autism Awareness Day, established by the United Nations (UN) and instituted in Brazil by Law 13,652/2018, marking the beginning of World Autism Awareness Week.

We considered the following inclusion criteria: tweets published between March 3 and March 10, 2023 (filtered using the MAXQDA Plus software), in Brazil, in the Portuguese language (Brazil), and containing the intersection of the hashtags #diamundialdeconscientizaçãodoautismo

(#worldautismawarenessday) [Supplementary Material No.1] and #autistas (#autisticpeople) [Supplementary Material No. 2 and Supplementary Material No. 3], with no profile restrictions. Exclusion criteria included publications that did not represent the research subject. We selected the hashtags based on an analysis of Twitter's trending topics, which are the most frequently mentioned and trending topics at the time of the research.

We included all tweets made during the data collection period that met the selection criteria in the study. People worldwide have been using Twitter to discuss issues of great societal interest, such as debates and statements from government organizations, including direct speeches from heads of state.¹¹ Therefore, we decided to use tweets published throughout the national territory, originating from different regions of Brazil.

We considered the number of likes on tweets as interactions sharing the original post, signifying agreement with the content and consent for the publications. 12 Based on this, we used the number of likes to assess the level of agreement with the shared information.

We collected data using the "Import Twitter Data" interface in the MAXQDA Plus 2022 Student software. The subsequent analysis followed the three phases by DTA, encompassing unitization, categorization, and metatexts.

The dataset included information at the tweet level, such as the author's account name, Twitter identifier, account verification status, number of followers at the time of download, date and time of tweet publication, indication of the original tweet or retweet, textual content, hashtags, user mentions, Uniform Resource Locator (URLs), presence of media (images and/or videos), user location, and languages used in the publication.

Initially, we compiled a database of 1,411 tweets, which we refined according to the inclusion and exclusion criteria, resulting in a final database of 279 tweets. We coded the data with the MAXQDA software, and in the first stage proposed by DTA, we assigned 17 meaning units and 275 codings, utilizing the theoretical data saturation technique and a thorough reading of all tweets in the selected sample. Subsequently, we conducted the second analysis stage, constructing four intermediate categories, which we recategorized into two final categories, where we discussed the achieved metatexts. For developing the partial report, we used the visual tools available in the MAXQDA Plus



Figure 1. Word cloud representing the main hashtags. Source: Authors' data. Brazil, 2023.

Next, we analyzed and organized the tweets into two thematic axes: "The importance of social inclusion" and "The governmental perspective."

The importance of social inclusion

The appreciation and approval of spaces designed for people with ASD can indicate a sense of belonging and concern for their well-being and inclusion in society. This sentiment is evident in expressions demonstrating efforts in sports and cultural contexts to promote inclusive practices.

2021 Student software, version 20.4.1, which allowed us to construct the analyzed textual corpus and word cloud, enabling the visualization of results. To refine the word cloud, we established a list of exclusion words that did not influence its presentation [Supplementary Material No.4]. It is important to note that this study involved publications in an institutional open-access database, so it did not require approval from the relevant Research Ethics Committee (REC). However, we emphasize that we followed all ethical research principles stipulated by Resolution No. 466/2012 of the National Health Council and ensured the anonymity of all authors of the analyzed publications. To guarantee the anonymization of the tweet authors, we used only the status of the users' accounts, with the acronym "V" for verified profiles or "NV" for nonverified ones and the number of likes each original tweet received.

Results

We observed that the expressions published on World Autism Awareness Day covered various themes, including inclusion, state, government, and information. This diversity suggests that the population is focused on inclusion and governmental issues, highlighting the need for actions that broadly raise awareness about ASD while considering all associated factors.

Great initiative by @Corinthians in creating a space for #autistas. I hope @Gremio and @SCInternacional in Poa /Porto Alegre] follow this beautiful example. This way, our community can attend the games. Congratulations to the club from São Paulo for this wonderful initiative! (NV-0)

This Wednesday morning, we held the workshop "The Art of Puppetry in an Inclusive Context." The workshop, aimed at educators, was part of BPBL's program for World Autism Awareness Day (...). (NV-0)

Another possible tool to minimize prejudice and stereotypes is disseminating information about the disorder and executing informative campaigns that can provide greater visibility to this issue.

With more than 500 people, a walk was held in Guaíba on World Autism Awareness Day (...). (NV-0)

STRENGTH, GLORY, AND INCLUSION! Our captain will wear the captain's armband in honor of World Autism Awareness Day. (V-0)

Yesterday, we attended a wonderful event at the Latin America Memorial on World Autism Awareness Day. As a mother of a child with ASD, I ask for more public policies, information, and less prejudice. (NV-0)

The expressions regarding including people with ASD in the job market suggest a need for dialogue and awareness on this topic. We believe structural changes (including specific legislation to promote the social inclusion of people with disabilities) are necessary to improve employment opportunities.

During World Autism Awareness Week, Crivelli discusses the inclusion of people with autism in the job market (...). (NV-0)

I suggested a bill to include people with disabilities in the job market. (NV-0)

Actions aimed at including people with disabilities in the job market appear to be limited, and when it comes to people with ASD specifically, they may be virtually nonexistent. Work can be an excellent tool for exercising citizenship, and public policies that encourage hiring individuals with ASD could break down inequalities and foster greater social inclusion.

The governmental perspective

We observed distinct perceptions in the tweets regarding the support provided to individuals with ASD. One tweet criticizes the Unified Health System (SUS) and private health plans for their lack of involvement in autism awareness campaigns and the absence of coverage for treating these individuals, thus reflecting frustration with the healthcare system. In contrast, another message reaffirms a commitment to inclusive education, emphasizing the importance of ensuring that autistic students have their educational rights respected.

Where are the SUS and other health plans in the World Autism Awareness Day campaign? Oh, I forgot that neither covers treatment for autistic people. (NV - 9).

On World Autism Awareness Day, we reaffirm our commitment to inclusive education, thereby ensuring students' right to education is respected. (NV-0).

Public authorities should expand the responsibility for developing and implementing informative initiatives about autism. We can highlight official events organized by municipal and state departments, focusing on training professionals to better meet the needs of autistic individuals.

This week, the city of São Paulo (SP) hosted official events organized by the municipal and state departments to mark World Autism Awareness Day. These events included training sessions for professionals across various fields (...). (NV-0)

The Parliamentary Front of the Caxias Legislature promotes a meeting with parents of autistic individuals. The action is in honor of World Autism Awareness Day. (NV-2)

These expressions can be seen as a recognition of the efforts made in public policies and legislation. However, challenges seem to persist, particularly concerning education, law enforcement, and the support provided to schools, suggesting a lack of genuine commitment to inclusion.

(...) In Brazil, despite advances in legislation to guarantee rights, parents still frequently resort to legal action, especially to enroll their children in school. (NV-7)

I am shocked by the number of councilors [...] who posted on social media yesterday about World Autism Awareness Day and today voted in the chamber against school mediators for autistic people and people with disabilities. Doesn't this shock you? (NV-3)

Thus, these expressions reveal a recognition of the efforts in public policies and legislation to include individuals with ASD, but they also highlight persistent challenges, especially in education. Improvements in law enforcement and support for schools are identified as necessary measures. The tweets emphasized the responsibility of public authorities in developing informative initiatives about autism.

The content also allows us to identify that some strategies are necessary, such as disseminating basic information about the disorder, expanding knowledge, and consequently minimizing prejudice and stereotypes. Therefore, social inclusion actions, active participation, and educational measures aimed at improving the development of individuals with ASD are declared essential.

Additionally, we observe a need to address these individuals comprehensively, respecting the individuality, specificity, and human needs of people with ASD.

Discussion

The lack of knowledge or misconceptions about ASD highlights the importance of disseminating accurate information to society, particularly to those without direct contact with this population.¹³ Awareness campaigns aim to educate the public, promote discussions, and increase the visibility of conditions, thereby supporting the dissemination of scientific and technical advancements and aiding in early diagnosis.14

Individuals with ASD face a series of social prejudices compounded by the absence of physical traits that typically characterize the syndrome. This lack of visible signs often contributes to these biases, even though everyone is equal under the law and has the right to freedom, equality, and security for a healthy life. 15 The first step toward addressing this issue is to ensure social inclusion and provide opportunities for individuals with ASD to live without discrimination welcoming appropriate environments.15

Experiences of violence, whether verbal or physical, on the internet or in other contexts, represent a clear form of perceived stigmatization.¹⁷ In a study involving individuals with ASD, this variable emerged as a significant predictor of quality of life, both in general and specific terms. 16 These findings corroborate previous research that identified stigmatization as a crucial factor in the health of autistic individuals, explaining the health disparities between minority and majority groups due to social disadvantages and associated stigma.17

Given that stigma can be understood as the opposite of acceptance, lower acceptance of ASD from external sources is associated with poorer mental health outcomes, which in turn negatively impact these individuals' lives. 18 Additionally, since a sense of community can moderate the effects of discrimination and stigma on psychological distress and well-being, it is important to develop and implement programs that help autistic individuals strengthen their sense of community.¹⁹

Public policies play a fundamental role in shaping the practical realities faced by individuals with health conditions like ASD, influencing both public opinion and the pathways to identification and treatment of the condition. Historically, ASD was absent from major federal policies, particularly during the 1960s and 1970s, a period marked by significant legislative advances in the rights of people with disabilities. Examples include Rehabilitation Act of 1973, which prohibited discrimination against individuals with disabilities in federal programs, and the Education for All Handicapped Children Act of 1975, which ensured a free and appropriate public education for all children with disabilities.²⁰

The importance of equal and inclusive education for autistic children has been consistently reflected in the formulation of global educational policies, which guarantee these children's rights to education. The United Nations established a fundamental policy to protect and promote these rights in the Universal Declaration of Human Rights,²¹ which asserts that everyone has the fundamental right to an education to fully develop the human personality the human personality. Since its ratification, this declaration has been the foundation for policies, strategies, and human rights actions in subsequent decades.²²

The inclusion of individuals with ASD in subsequent policies has provided additional protections in the areas of education and employment. However, research estimated that 80% of young people with ASD do not receive adequate transition services during the critical period from adolescence to adulthood, resulting in various unmet needs such as employment, schooling, and housing.²³

A study revealed a variety of obstacles that individuals with autism expected to face and indeed encountered. The findings mentioned difficulties such as filling out job applications, finding work, and communicating and interacting with supervisors.²⁴

In Brazil, SUS provides most services for individuals with ASD, mainly at the levels of Primary Care and Specialized Care. Among specialized services, the Psychosocial Care Centers (CAPS) stand out. These open and communitybased services should offer daily care, provide efficient and personalized clinical care, promote social integration, and support and oversee mental health care within the primary care network.25

However, despite these intentions, the ASD population faces additional obstacles in accessing healthcare and interacting with professionals in the field, which not only increases stress but can also discourage or even prevent timely access to medical care. Often, these individuals seek help late, presenting with severe problems and high levels of distress, making it difficult for them to communicate and process information. Moreover, many try to hide their autistic traits to avoid social stigma, which can make them appear to lack typical characteristics of autism.²⁶

Failing to recognize and appropriately address an individual with ASD can result in a range of adverse impacts for the individual and the service in question. A negative patient experience can discourage future help-seeking or lead to delays until the person's health deteriorates significantly.²⁷ As the number of diagnoses increases, there is also greater interest in the social representations of autism and the need for representation. After all, it is through representation in society, especially in the media and entertainment, that this topic is exposed to a larger audience. In recent years, we have observed how entertainment culture, with its series, films, and soap operas, has increasingly addressed this topic.28

Conclusion

Social media platforms serve as significant sources of social interaction and public expressions. Through analyzing the expressions of the Brazilian population in tweets about autism, we identified a general reference to the limited progress in public policies and legislation aimed at the inclusion of individuals with ASD, with persistent challenges, particularly in education. There is a clear need for improvements in the enforcement of laws and support for schools. Additionally, the public sector must take responsibility for developing and implementing informative initiatives about ASD, using the dissemination of information and ongoing public servant training as strategies to combat prejudice and stereotypes.

This analysis underscores the necessity for a more comprehensive and effective approach that not only involves developing and implementing more efficient policies but also calls for additional research to identify gaps and develop interventions. Furthermore, the continuous training of education professionals and the dissemination of information about ASD are crucial for combating prejudice and stereotypes, thus promoting a more inclusive and supportive culture.

Study limitations

This research presents limitations primarily due to its reliance on Twitter data. The tool used to extract the dataset is limited to 10,000 tweets per search term and only allows the import of tweets posted within a seven-day period. This constraint resulted in a limited scope of publications and restricted the available period for data collection.

Authors' Contributions

Gama JLG: Conception and design of the study; Collection of data; Analysis and interpretation of data; Statistical analysis; Writing of the manuscript; Critical revision of the manuscript;

Lima HC: Conception and design of the study; Data collection; Data analysis and interpretation; Writing of the

Oliveira A: Conception and design of the study; Data collection; Data analysis and interpretation; Writing of the manuscript;

Pereira ND: Study conception and design; Data collection; Data analysis and interpretation; Statistical analysis; Critical revision of the manuscript;

Harmuch C: Conception and design; Data collection; Data analysis and interpretation; Statistical analysis; Writing of the manuscript; Critical revision of the manuscript.

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