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Portuguese-language content about autism spectrum disorder on YouTube: a cross-sectional study

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ABSTRACT

Aim: This study evaluated the quality and reliability of information about autism spectrum disorder (ASD) available in Portuguese on YouTube, based on the growing demand for accessible information about ASD and the relevance of digital platforms as sources of health information. **Methods:** Using a cross-sectional observational study design, videos published in the last 5 years with more than 50,000 views were selected. The analysis consisted of two stages: characterization of the profile of the selected videos and assessment of information quality with the DISCERN Questionnaire. **Results:** A total of 48 videos, predominantly produced by healthcare providers and educators, were analyzed. The content of videos made by professionals was of higher quality and reliability compared to videos posted by laypersons and news reports. These findings highlight expertise in the field as a critical determinant of content quality, stressing the importance of relying on expert sources when disseminating information about ASD. The ICD-10 and DSM-V were rarely mentioned, especially in videos by non-professionals, which is indicative of challenges in

conveying diagnostic information. **Conclusions:** The findings of this study demonstrate the significant potential of YouTube as an educational tool to raise ASD awareness, but also highlight the need for a collaborative approach between content creators, healthcare providers, educators, and policymakers to ensure that the information made available is reliable, accurate, and of high quality. Therefore, we recommend the development of specific guidelines for content creators and the implementation of verification mechanisms for YouTube channels run by subject matter experts.

Keywords: Health Promotion; Austism Spectrum Disorder; Social Media.

INTRODUCTION

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by challenges in social communication, as well as repetitive and restricted behaviors.[1–4] The overall prevalence of ASD has increased in recent decades, which has intensified the search for information on diagnosis, treatment, and management of this condition, both by healthcare providers and by people with the disorder themselves and their family members.[5–7] In this context, the internet has emerged as a popular source of health information, especially for the lay (i.e., non-expert) public, as it offers immediate access to a wide variety of content.[8,9] As the second most popular social media platform worldwide, YouTube now plays a significant role in disseminating health information, including that related to ASD.[10]

Studies on the quality of information about ASD on other digital platforms, such as discussion forums and social networks such as Reddit[11] and Twitter,[11,12] have found significant variation in the accuracy and reliability of the content available, highlighting the need to evaluate the quality of health information made available in virtual environments. These studies provide an important counterpoint to the focus on YouTube, suggesting that the issue of quality of information regarding ASD is broad and affects multiple digital platforms, reiterating the importance of comprehensive strategies to ensure access to accurate, evidence-based information about ASD across the digital sphere.[10–13]

In this context, the growing prevalence of ASD and the search for reliable health information on digital platforms highlight the need to align research and public communication efforts with existing guidelines—in Brazil, these include the National

Health Promotion Policy[14]—and the Sustainable Development Goals (SDGs).[15] Health promotion, a core principle of both the Brazilian National Health Policy and the SDGs. By evaluating the quality and reliability of information about ASD available on YouTube, the present study aims to contribute to a more informed and aware society about the care needs associated with ASD, aligned with national and international efforts to improve health and education, reduce inequalities (SDG 10), and strengthen partnerships (SDG 17) through the effective use of digital platforms as tools to promote health and education.

The present study aims to bridge this gap by identifying and evaluating Portuguese-language videos about ASD on YouTube, with a particular focus on: (1) identifying the characteristics of videos about ASD available in Brazilian Portuguese on YouTube, including the type of content, number of views, likes, and dislikes; and (2) analyzing the content of these informational videos and assessing their reliability and overall quality.

MATERIALS AND METHODS

A quantitative, observational, cross-sectional design was used. The methodological approach consisted of two stages: I) characterization of the profile of the videos selected for analysis and II) quality assessment of the information conveyed in the selected videos.

As the number of videos posted on the YouTube platform exhibits exponential growth, a priori criteria were defined to select the most relevant videos and up-to-date content. YouTube is a widely used online platform that allows users globally to share and interact with video content, ranging from educational tutorials to health information[16,17]. It facilitates both the creation and dissemination of content, offering tools for community engagement such as comments, likes, and shares, which enhance the interactive experience and broaden the reach of the information[18]. Given its role as a major repository of user-generated content, YouTube not only serves as a platform for health education by professionals but also as a space for layperson engagement and content creation, which can vary widely in quality and accuracy[16,17,19]. This underscores the need for viewers to critically assess the reliability of health information encountered on the platform. The inclusion and

exclusion criteria, as well as details of the aforementioned methodological steps, are given below.

The process of video selection was conducted by a single researcher to ensure uniformity and to mitigate the influence of algorithmic variations according to a protocol proposed by Furtado et. al.[20]. This search took place in April 2021 through the YouTube. The search terms employed were 'autism spectrum disorder' and 'Autism' in Portuguese. To further minimize the impact of YouTube's recommendation algorithms and ensure the retrieval of a broad range of videos, several preparatory steps were undertaken by the examiner prior to the search[20]:

1. The examiner disconnected the YouTube personal account;
2. Adblock software was installed to avoid advertisements;
3. The examiner searched in the anonymous mode.

Included in the analysis set were YouTube videos whose titles addressed the topic “TEA” (Portuguese for “ASD”), published in the last 5 years (i.e., from the year 2019 onwards), with more than 50,000 views, a duration equal to or greater than 4 minutes, and that fell into one of the following content types: personal videos on the topic of ASD; professional videos on the topic of ASD; or news videos that presented content related to ASD. Recordings of live streams, debates, podcasts, interviews, round tables, and discussions in general were excluded during the screening stage.

To ensure the traceability of our findings, the videos selected for analysis were saved to a YouTube playlist: [https://youtube.com/playlist?list=PL5Urh0aswciQCgz9Utgu8YwW7LkcfHbF4&si=t94up3IXXJaqa8oj].

After selection, the first stage of analysis consisted of a content analysis seeking to characterize the profile of the selected videos according to a prior study.[21] To do so, we first identified the YouTube channel which posted the video, the length of the video, and the date of publication. These data were tabulated in a Google Forms spreadsheet, which is available at the following link: [https://docs.google.com/forms/d/e/1FAIpQLSc6TXM3xzbQ9EEZPklZRny25lRlouW90EzLOC98dHZNk9MYPA/viewform].

In addition to these platform-related data, during the first stage of analysis we also identified whether the video was presented by layperson(s) or healthcare provider(s) and whether the video consisted of news or reportage content. The

gender of the presenter responsible for the video, and whether the content consisted of a personal or professional opinion, were also recorded. Finally, audience engagement with the video was evaluated by tallying the number of views and “likes” and the normalized number of interactions based on the monthly engagement rate

As we sought to identify whether the selected videos contribute to better communication of and clarification regarding the diagnostic criteria for ASD, in addition to contextual and engagement data, the content of the videos was then evaluated with the aim of identifying whether the presenter used or at least referred to the ICD-10 and DSM-V descriptors. For this purpose, every video was watched in full. Finally, we checked whether the presenter listed or referred to the DSM-V diagnostic criteria for ASD.

If a video mentioned the ICD-10 at all, it was considered to be of “good quality” in relation to diagnostic criteria. If at least three of the five DSM-V criteria were mentioned, the quality of the video was considered “good”; if only two criteria were mentioned, quality was considered “fair”; and if it one or none of the criteria was mentioned, quality was deemed “poor”.

The second stage consisted of applying the DISCERN questionnaire, a content quality assessment instrument, to the information contained in the videos selected during the screening stage.[22,23] The DISCERN instrument was originally developed to evaluate written information provided to consumers about health and treatment options, and is divided into three classes of items: I) reliability of the publication, analyzed through the first eight questions; II) quality of information, analyzed through the seven subsequent items; and III) one final item that gives an overall quality rating.[22] Furthermore, each question comes with instructions and recommendations to guide the evaluator in analyzing and classifying the content. This instrument was validated for Brazilian Portuguese by Logullo et al.[23] The quality of the information in each video was assessed on a Likert-type scale from one to five, in accordance with the norm of the DISCERN questionnaire, in which one is a total lack of quality and five denotes total compliance with the item being evaluated.[24]

At the end of the second stage, mean scores were tabulated and, for crossings between categorical variables, contingency tables were created to apply the chi-square test of independence. This test indicated significant statistical

associations between some descriptive characteristics of the videos and the quality or reliability of the information provided.

This study was exempted from submission to the Research Ethics Committee as it involves the use of publicly accessible data, in accordance with Resolution 466 of 2012 of the National Health Council (CNS) and the Brazilian General Data Protection Law (LGPD). The data used in this research were obtained from YouTube, a platform that provides publicly available information, thereby ensuring compliance with ethical standards and regulations.

RESULTS

The increasing use of virtual environments as sources of health information has led the field of education and health promotion into uncharted territory, particularly when it comes to such complex topics as ASD. Within this context, content analysis of Portuguese-language videos about ASD available on YouTube emerged as an opportunity to understand how knowledge about this condition is being shared and consumed by the general public. We found significant issues regarding the quality, reliability, and characteristics of content made available to the public.

Overall, we analyzed 48 videos posted on the YouTube platform: 5 produced by laypersons, 2 news reports, and 41 videos by professionals, as described in Table 1. Videos by professionals made up the majority of the sample, suggesting a trend for health and education experts to share information about ASD on YouTube. These videos had substantial reach and engagement, with an average of 244,683.8 views each; nevertheless, videos by laypersons recorded the highest average number of views (313,197.6 each). This suggests a high demand for informative content about ASD on the YouTube platform.

Table 1: Sample characterization

	Laypersons (n= 5)		News reports (n= 2)		Professionals (N=41)	
	Mean	SD	Mean	SD	Mean	SD
Views	313197.6	368832.0	99273.0	28524.7	244683.8	235898.8
Likes	14740.0	14906.0	2150.0	1060.7	16909.8	15513.6
Overall Quality	2.6	0.5	2.5	0.7	3.1	0.9
View Rate	24176.0	33552.3	1887.4	517.9	9652.8	10662.4
Like Rate	1089973.5	1395025.9	41092.2	20756.5	680798.2	740840.5
DISCERN score	28.6	5.3	28.0	9.9	40.2	10.5

Assessment of reliability and quality assessment, as measured by the DISCERN score, showed that videos by professionals had higher quality and reliability (average score: 40.2) compared to videos by laypersons (average score 28.6), and news reports (average score: 28.0), as shown in Table 2.

Table 2: Assessment of reliability and quality assessment, as measured by the DISCERN score

		Laypersons (n= 5)		News reports (n= 2)		Professionals (N=41)	
DISCERN score		Mean 28.6	SD 5.3	Mean 28.0	SD 9.9	Mean 40.2	SD 10.5
		N	%	N	%	N	%
DISCERN Section 1	Good Reliability	0	0.0	0	0.0	13	31.7
	Questionable Reliability	1	20.0	1	50.0	14	34.1
	Poor Reliability	2	40.0	1	50.0	1	2.4
	Fair Reliability	2	40.0	0	0.0	13	31.7
DISCERN Section 2	Questionable Quality	0	0.0	0	0.0	7	17.1
	Poor Quality	5	100.0	2	100.0	33	80.5
	Fair Quality	0	0.0	0	0.0	1	2.4
DISCERN Section 3	Overall Assessment: Good	0	0.0	0	0.0	14	34.1
	Overall Assessment: Questionable	2	40.0	1	50.0	11	26.8
	Overall Assessment: Poor	0	0.0	0	0.0	1	2.4
	Overall Assessment: Fair	3	60.0	1	50.0	15	36.6
Qualitative Score	Good	0	0.0	0	0.0	7	17.1
	Moderate	0	0.0	0	0.0	13	31.7
	Very poor	2	40.0	1	50.0	2	4.9
	Poor	3	60.0	1	50.0	19	46.3

Quality analysis in relation to diagnostic manuals revealed few mentions of either the ICD or DSM criteria in lay and news videos, while a much larger portion of videos done by professionals addressed these diagnostic aspects, with 56.1% of these mentioning the DSM (A), as shown in Table 3.

Table 3: Quality analysis in relation to ICD or DSM criteria

		Laypersons (n= 5)		News reports (n= 2)		Professionals (n=41)	
		N	%	N	%	N	%
Mentions ICD	No	5	100.0	2	100.0	37	90.2
	Yes	0	0.0	0	0.0	4	9.8
Mentions ASD	No	2	40.0	0	0.0	3	7.3
	Yes	3	60.0	2	100.0	38	92.7
Mentions DSM (A)	No	4	80.0	2	100.0	18	43.9
	Yes	1	20.0	0	0.0	23	56.1
Mentions DSM (B)	No	5	100.0	2	100.0	26	63.4
	Yes	0	0.0	0	0.0	15	36.6
Mentions DSM (C)	No	5	100.0	2	100.0	34	82.9
	Yes	0	0.0	0	0.0	7	17.1
Mentions DSM (D)	No	5	100.0	2	100.0	31	75.6
	Yes	0	0.0	0	0.0	10	24.4
Mentions DSM (E)	No	5	100.0	2	100.0	35	85.4
	Yes	0	0.0	0	0.0	6	14.6

Content creator expertise was significantly associated with a higher quality assessment ($p=0.03$), and mention of the ICD-10 was strongly associated with “good” quality of information ($p<0.001$), as detailed in Table 4.

Table 4: Associations betweens variables evalatued

	Date	Specialized	Gender	ICD Mention	ASD Mention	DSM Mention	Experience	Approach	Overall Quality	Views Rate	Likes Rate	Qualitative Score	DISCERN
Specialized	0,352												
Gender	0,526	0,343											
ICD Mention	0,352	0,356	1,000										
ASD Mention	0,352	1,000	0,714	1,000									
DSM Mention	0,431	0,358	1,000	0,602	0,345								
Experience	0,352	1,000	0,689	0,815	0,398	0,245							
Approach	0,446	0,843	0,517	0,173	0,422	0,446	0,049						
Overall Quality	0,591	0,302	0,002	0,002	0,109	0,033	0,792	0,212					
Views Rate	0,243	0,432	0,432	0,432	0,432	0,432	0,432	0,423	0,405				
Likes Rate	0,087	0,472	0,465	0,352	0,648	0,352	0,352	0,400	0,618	0,243			
Qualitative Score	0,377	0,033*	0,001	0,087	0,001	0,098	0,024	0,147	0,000	0,414	0,411		
DISCERN	0,341	0,407	0,255	0,077	0,038	0,224	0,143	0,238	0,000	0,289	0,303	0,000	
Profile	0,313	0,108	0,345	0,689	0,069	0,110	0,000	0,008	0,874	0,423	0,313	0,062	0,010*

These results highlight the predominance and importance of professional content about ASD on YouTube and demonstrate that subject matter expertise by content creators is a critical determinant of the quality of the created content. They also highlight the need for greater accuracy when discussing diagnostic aspects and inclusion of information based on up-to-date scientific evidence, especially in videos produced by laypersons and news reports.

DISCUSSION

The present study investigated the quality, reliability, and characteristics of Portuguese-language videos about ASD available on the YouTube platform. The results revealed a predominance of content produced by professionals (healthcare providers and educators), which obtained higher quality and reliability scores compared to videos by laypersons and news reports. However, even among videos by professionals, the heterogeneity in quality and diagnostic content suggests a need for more rigorous criteria in the production and curation of educational content about ASD on networks and social media.

The significant association found between content creator expertise and higher quality scores reinforces the importance of relying on expert sources when disseminating information about ASD. This finding is consistent with the existing literature, which suggests that information provided by experts and healthcare professionals is generally more accurate, reliable, and in line with best practices and current scientific evidence.[9,25–28] Such expertise not only ensures accuracy of content, but also reflects an understanding of the complexities associated with ASD, promoting a more comprehensive awareness of the condition among the general public.

When discussing the importance of expertise in the dissemination of information about ASD, one important aspect to be considered is how it is defined and perceived by the public. Expertise, in this context, is not merely the demonstration of technical and scientific knowledge about ASD; it also involves the ability to communicate that knowledge to a lay audience in a way that is accessible, engaging, and trustworthy. One way for content creators to convey their expertise is by presenting their credentials, such as academic titles, affiliations with teaching and

research institutions, or participation in relevant research in the field. These markers of subject matter expertise can increase audience trust in the content presented.[28–30]

However, the notable presence of lay-produced videos with high view counts highlights a supplementary facet of disseminating information about ASD: the public's search for lived experience and personal narratives. This interest demonstrates an essential human dimension in understanding ASD, whereby personal stories and lived experience with the condition resonate deeply with individuals and families facing similar challenges.[31–33] This phenomenon highlights the importance of balancing technical-scientific knowledge with the authenticity and empathy of human-interest stories if one is to effectively engage the public. Therefore, while expertise should provide the foundation for content accuracy and reliability, the inclusion of personal experiences can broaden its appeal and impact, facilitating a connection with audiences and promoting a holistic understanding of ASD.

Additionally, language and content presentation play significant roles in the perception of expertise. Using clear, precise, yet accessible language can help establish a content creator as a trusted source of information.[8,25,26] This is especially important in complex topics such as ASD, in which medical jargon and abstract concepts can be difficult to understand and assimilate for the general public. The ability to simplify explanations without losing accuracy is therefore an essential aspect of perceived expertise.

In our analysis of videos about ASD on YouTube, the scarcity of mentions of gold-standard diagnostic classifications—namely, the ICD and DSM—stood out, especially in content produced by non-professional sources. This gap in the presentation of diagnostic information is remarkable, and raises questions about viewers' ability to understand these diagnostic criteria and the complexity of ASD.[34,35] Diagnostic accuracy is extremely important in the correct identification of ASD and plays a crucial role in the development of individualized, personalized treatment plans. The literature supports the importance of diagnostic clarity and accuracy, stressing that a detailed understanding of the diagnostic criteria and characteristics of ASD is essential for adopting appropriate management approaches and effectively supporting individuals and families who are navigating this diagnosis.[34–37]

The findings of the present study highlight the importance of strategic approaches in health education and in public policymaking. There is a critical need to improve the quality of information about ASD in the digital space, not only to support affected individuals and their families but also to educate the general public.

One example that can be used to demonstrate these strategies is the "TEACCH Autism Program" initiative, developed by the University of North Carolina, which not only offers direct services but is also dedicated to training professionals and disseminating evidence-based information about ASD.[38] This initiative demonstrates how well-structured programs can contribute significantly to ASD health literacy while providing replicable models for education and community engagement.

Likewise, the collaboration between the U.S. National Institute of Mental Health (NIMH) and digital platforms to launch mental health information campaigns exemplifies how partnerships between public agencies and social media platforms can amplify the reach of reliable, evidence-based information.[39] Such initiatives can serve as a model to address the challenge of improving the quality of information about ASD available on YouTube and other digital platforms.

Finally, policies that encourage the verification and certification of health-related channels on YouTube, analogous to the verification process applied to health professionals on other social networks such as LinkedIn, can help increase the visibility of trusted information sources. This would not only make it easier for users to access high-quality content but would also promote greater responsibility among content creators about ASD. The deliberate, strategic incorporation of YouTube and other digital media platforms into public health policies can not only improve health literacy related to ASD, but also contribute to a more informed, inclusive, and empathetic society.

This study has several limitations that must be considered. Our analysis was restricted to Portuguese-language videos, which may restrict the generalization of our findings to other languages and cultural contexts. Furthermore, the assessment of quality and reliability was based on specific instruments, such as the DISCERN questionnaire and the mention of the ICD and DSM documents. While these are validated and provide a robust framework for evaluating medical information, they may not capture all relevant dimensions of ASD content. Notably, the educational

and pedagogical aspects of autism, which can be prominent in videos created by education professionals, may not necessarily reference these medical documents yet still offer quality content within the field of teaching and education. This highlights a potential limitation in the scope of our evaluation criteria, suggesting the need for broader assessment metrics that encompass diverse perspectives on ASD. Future research could explore the effectiveness of interventions targeting content creators on the YouTube platform to improve the quality of information about ASD. Additionally, further studies might investigate the perspectives of content consumers on these platforms regarding the usefulness and impact of these videos on their understanding and management of ASD, incorporating a wider range of content quality indicators.

CONCLUSIONS

This study on the quality, reliability, and adequacy of information regarding ASD available in Portuguese on the YouTube platform identified a predominance of content produced by healthcare professionals and educators, as well as variability in the quality and reliability of the information presented. Given these findings, we recommend that content creators seeking to develop material about ASD rely on evidence-based guidelines and prioritize the accuracy and accessibility of information. Healthcare providers and educators should consider the YouTube platform as a viable channel for disseminating reliable information, collaborating closely with content creators to produce and verify educational materials. Furthermore, public policymakers should be encouraged to develop and promote policies that support the production and dissemination of high-quality content about ASD on social media, encouraging the development of clear guidelines for content producers and the implementation of verification systems for experts' channels.

We conclude that, despite the significant potential of YouTube as an educational tool to raise ASD awareness, a collaborative approach between content creators, healthcare providers, educators, and policymakers is needed to ensure that the information made available is reliable, accurate, and of high quality. Adopting these measures would improve ASD-related health literacy and contribute to a more informed, inclusive, and empathetic society.

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