Journal of Autism and Developmental Disorders (2025) 55:1953–1958
https://doi.org/10.1007/s10803-023-06084-6

BRIEF REPORT

The Reach and Accuracy of Information on Autism on TikTok

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Accepted: 26 July 2023 / Published online: 6 August 2023

Abstract

Purpose: Although social media platforms have made information about autism more accessible to the general public, concerns have been raised about the unfiltered nature of the content they host. In the current study, we examined the reach and accuracy of videos providing informational content about autism on TikTok, a popular social media platform. **Methods**: We examined engagement indicators (including views and "likes") for the TikTok videos associated with the #Autism hashtag. Two coders independently fact-checked informational content of the most viewed videos from the #Autism hashtag videos and coded it as either accurate, inaccurate or 'overgeneralization' based on the consistency of the information in the videos with current knowledge on autism. **Results**: Videos associated with the "#Autism" hashtag accrued 11.5 billion views collectively. An examination of the top 133 videos providing informational content on autism, which totaled 198.7 million views and 25.2 million likes, showed that 27% of the videos were classified as accurate, while 41% were classified as inaccurate and 32% as overgeneralized. There were no significant differences in engagement between accurate and inaccurate/overgeneralized videos. Videos created by healthcare professionals were more likely to include accurate information. **Conclusion**: The informational content about autism made available on TikTok reaches a wide number of people. Most of the information provided, however, appears to be misaligned with current knowledge. It is important for healthcare providers and other professionals to be aware of the autism-related content being shared on TikTok so that they can better engage with the large community of TikTok users.

Keywords Autism · Social media · Public health · Policy · Stakeholder outcomes

Autism spectrum disorder (ASD; hereafter autism) is a highly heterogenous neurodevelopmental condition that impacts approximately 2% of the population (Maenner et al., 2023). Current research indicates that the internet is the most common source of information about autism for parents, with 93.9% having accessed the internet as a source in a 12-month period (Lindly et al., 2022). Although the internet has made information about autism readily accessible to the general public, concerns have been raised about the unfiltered nature of the content hosted by internet platforms, including social media (Chen & Wang, 2021). One of the most accessed social media is TikTok, a short-video format platform which had over one and a half billion active users in 2022 (Ruby, 2022). Although the platform is designed for entertainment, users frequently create and share videos intended to provide information, including on healthcare-related topics.

The "#Autism" hashtag was the ninth most viewed health-related hashtag on TikTok as of 2021 (Zenone et al., 2021). This points to the potential for TikTok and similar platforms to encourage public engagement, so that users can learn about life experiences, perspectives, and priorities voiced by diverse groups of stakeholders, including autistic self-advocates or family members. While this engagement can serve as an outlet for self-advocates and other stakeholders to advance important agendas (e.g., decreasing stigma), the unregulated nature of the informational content means that unchecked statements are widely distributed. This poses ethical dilemmas on the use of TikTok as a platform for learning and educating about autism. Indeed, lack

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of filtering (e.g., peer review) or fact-checking procedures means that inaccurate information about autism and other conditions may be widely shared, influencing the public understanding of autism and posing public health risks. For example, internet forums and social media platforms have been instrumental to the widespread dissemination of misleading information on the link between vaccines and autism, which undermined trust in life-saving vaccination programs and contributed to preventable infections and diseases in young children (Burki, 2019). In addition to blatant misinformation, TikTok and similar platforms can bias the general public's views on autism by providing more content on certain experiences, phenomena, populations or subgroups within the autism spectrum compared to others. For example, underrepresentation of content related to individuals requiring more intensive services and supports can lead to less awareness on their experience, which can affect advocacy efforts and service provision for those individuals and their families.

Although the literature on autism-related content on TikTok is limited, the platform has been the focus of several public health studies seeking to assess the quality and implications of information being shared regarding various conditions, including medical advice, condition portrayal, and the potential for misinformation spread (Zenone et al., 2021). Findings have documented misinformation for a variety of conditions and topics such as oral health education, hearing aid, genitourinary cancers, pediatric urology, and diabetes, with the potential to cause harm to the users (Fraticelli et al., 2021., Chen et al., 2022., Kong et al., 2021a, b; O'Sullivan et al., 2022; Xue et al., 2022). Another area of concern has been the role of TikTok as an informational resource regarding the Covid-19 pandemic (Ostrovsky & Chen, 2020), with data indicating 83.6 billion cumulative views under the #Covid19 hashtag as 2021 (Zenone et al., 2021). Given the sweeping engagement, there has been increasing debate on the risk for misinformation and potential for promotion of accurate health-related content on the platform (Basch et al., 2022., Li et al., 2021). In response to this, TikTok released a statement addressing the presence of misinformation in the sphere of public health, as well as implementing a process of fact-checking to reduce rates of misinformation (Keenan, 2022), including removal of medical misinformation about vaccines or abortion. However, to our knowledge, no effort to fact-check information related to autism has been undertaken by the platform, and no independent research on the accuracy of information has been conducted to date. A small but growing body of literature on content related to autism and other neurodevelopmental conditions on social media other than TikTok points to the importance of addressing this gap. For example, a study by Cortes Cavalcante et al. (2023) analyzed a sample of Brazilian-Portuguese YouTube videos on autism, finding that many of them were designed to educate viewers about specific aspects of autism but failed to provide reliable information. A recent study by Yeung et al. (2022) documented that 52% of content regarding ADHD on TikTok was misleading.

Against this background, social media end-users and stakeholders, including autistic individuals, have raised concerns about the potential for misinformation on autism to be spread on TikTok and other platforms (Bakombo et al., 2023; Camp, 2023; Goddard and Cook, 2022). However, to our knowledge, there are not yet any studies reviewing the nature, accuracy, and reach of autism-related content on TikTok. To address these gaps in the literature, the current study was designed to examine the quantity and quality of autism-related information on TikTok. Specifically, study aims were to (1) document the reach (number of views and 'likes') of videos providing informational content on autism under the "#Autism" hashtag and (2) document the degree of accuracy of the information on autism in the most viewed videos under the "#Autism" hashtag.

Method

Procedure

As the first step, to document the reach of informational content on autism posted on TikTok, a new TikTok account was created, thereby preventing algorithm bias associated with previously used accounts. The TikTok mobile phone application was then queried for "#Autism" hashtag on July 29th, 2022. The hashtag query search results are displayed based on the engagement ('likes', views) a video receives, with the most popular videos appearing at the top of the search (Fig. 1). The first set of exclusion criteria were non-English videos, videos not related to autism, or duplicate videos. These initial parameters yielded 365 eligible videos.

As the second step, within this sample, an additional set of inclusion/exclusion criteria were applied in order to select videos designed to provide information on autism, i.e., "informational videos". Informational videos were operationally defined as videos advancing claims on autism in general, including what causes it and how autism should be diagnosed or treated. This category was defined as mutually exclusive with "personal experience" videos, i.e., videos designed to share personal experiences (for example, an autistic individual reporting about her sensory supports, or a caregiver narrating her experience taking her child to the hair salon), which do not include statements related to autism in general (e.g., what causes it, how it should be diagnosed). The applied criteria resulted in 133 videos being identified as informational.

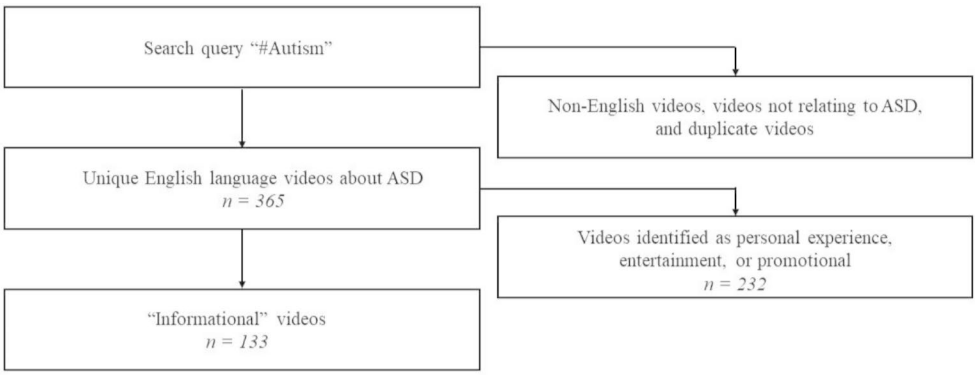

Fig. 1 Inclusion/exclusion criteria flow chart

Fact-checking and Reliability

Two coders independently fact-checked the videos and coded the informational videos as either accurate, inaccurate, or 'overgeneralization' based on their consistency with existing scientific knowledge related to causes, presentation, diagnostic criteria, evidence-based interventions, and other relevant areas of research. For example, statements like "you can determine if you are autistic using this simple three question test" would be classified as inaccurate, while the statement "many autistic children can benefit from using alternative and augmentative communication" would be classified as accurate. The code 'overgeneralization' (OG) was used for statements that overgeneralize the experience of some individuals on the spectrum to the entire population (e.g., "autistic children hate to play with sand", or "autistic adults never want to socialize"). Coders fact-checked statements made in the videos to assign one of the three codes for each video through an examination of the scientific literature under the supervision of a senior clinician and the study senior author (a researcher), who both each have approximately 20 years of experience in the field. Intercoder reliability was established via percentage agreement which indicated that the two coders agreed on 80.1% of codes. After independent coding, discrepancies were resolved by a secondary consensus review led by the study senior author acting as the third coder. Each discrepancy was examined through a thorough examination of the relevant scientific literature, with the senior author making the final decision on accuracy. A conservative approach was adopted, whereby only statements that were unequivocally misaligned with current knowledge were classified as "inaccurate". For example, the "inaccurate" code would be applied for a statement like "medical marijuana can cure autism" but not for "medical marijuana has the potential to be beneficial for some individuals on the autism spectrum". Similarly, the "overgeneralization" code would be applied for a statement like "children on the autism spectrum don't want to be hugged", but not for "some children on the autism spectrum don't want to be hugged".

Characterization of Videos

To characterize the videos, the following information was extracted from each video. First, we classified user type by examining whether the creators of the videos identified themselves as (1) health care practitioners/professionals in the field (HCPs), (2) individuals who identified themselves as autistic creators (AC), or (3) non-AC and non-HCP creators. User types were ascertained by information provided by the creators of the videos (e.g., a creator stating that they are autistic in a video) or from their TikTok account "bios". Additionally, to characterize the reach of each video we extracted engagement variables, including the amount of 'likes' and views each video received. Engagement variables were recorded on October 20th of 2022.

Analytic Plan

We first obtained descriptive data related to reach and engagement variables (views and 'likes') as well as characteristics of those who created the videos and accuracy of the informational content. We then examined whether accuracy of the videos was associated with differences in engagement variables (i.e., more views or 'likes' depending on the accuracy of the information in the videos) and whether it differed depending on the type of creator (health care professional, autistic creator, or 'other'). Non-parametric analyses were used as data were not normally distributed. A p-value of less than 0.05 was considered significant for all analyses. All statistical analyses were performed using SPSS v28.

Results

Reach and Video Characteristics at Baseline

Our findings related to the reach of autism-related content on TikTok revealed that at the time of data collection the "#Autism" hashtag had accrued 11.5 billion views. The sample of videos classified as "informational" (n = 133) in

this study totaled 198,695,946 views and 25,192,402 likes. There was an average of 1,493,955 (range: 2351-15,300,000) views and 189,417 (range: 636–3,000,000) likes per video. One hundred and twenty-six videos were uploaded by non-HCPs, including ninety-five by ACs, while seven videos were uploaded by creators identifying as HCPs. There was one creator who identified as both a HCP and an AC. The remaining thirty-one videos were uploaded by creators who did not identify themselves as ACs or HCPs.

Video Characteristics by Accuracy

Of the 133 analyzed videos, 55 (41%) were classified as inaccurate, 42 (32%) were classified as 'overgeneralization' and 36 (27%) were classified as accurate. Videos classified as being inaccurate or OG totaled 144,584,203 views and 16,724,125 likes with a mean of 1,490,558 views and 172,413 likes. The videos classified as being accurate totaled 54,111,743 views and 8,468,277 likes with a mean of 1,503,103 views and 235,229 likes. There were no significant differences in mean views and likes for accurate versus inaccurate/OG videos (views, $U = 1665.5$, $p = .684$; likes, $U = 1618.0$, $p = .517$). A Chi-square test of independence revealed that accuracy of videos differed by creator type ($\chi 2$ (2, $n = 133$) $= 10.54$, $p = .005$). Pairwise comparisons showed that videos created by HCPs were more likely to be accurate compared to both those uploaded by creators categorized as ACs and 'other' (non ACs and Non-HCP) (adjusted p-values [Bonferroni] < 0.05 and < 0.005, respectively). There was no difference in accuracy for videos created by ACs and 'other' creators ($p = .20$). Results are illustrated in Fig. 2.

Discussion

The current study examined the reach and accuracy of information on autism available through the TikTok platform. We found that 'informational' videos designed to educate the audience about aspects of autism culminated nearly 200 million views, and that most of the information provided (73%) was inaccurate or overgeneralized. Inaccurate or overgeneralized information was 'liked' and viewed as frequently as accurate information. These findings are aligned with research on social media content related to other conditions and healthcare topics (Fraticelli et al., 2021., Chen et al., 2022., Xue et al., 2022., Kong et al., 2021a, b).

Given the reach of TikTok autism content, it is important that stakeholders in the autistic community (including autistic individuals, family members, and professionals interfacing with autism) are aware of the unfiltered nature of information about autism happening on TikTok and other social media. Misinformation about autism, including overgeneralization and oversimplification, has the potential to pose barriers to trust, communication and shared decision-making between professionals and autistic individuals and their families. This can be counteracted or mitigated by an increased awareness of autism-related content spread through TikTok. For example, professionals providing diagnostic or intervention services might benefit from familiarizing themselves with "trending topics" that are widely shared on TikTok, such as the promotion of untested products, or the adoption of an antagonistic stance against diagnostic or intervention protocols, so that constructive conversations about needs and supports for each individual can be established. The disconnect between information produced by scientific research and content shared on TikTok also points to the need for broadening research dissemination efforts

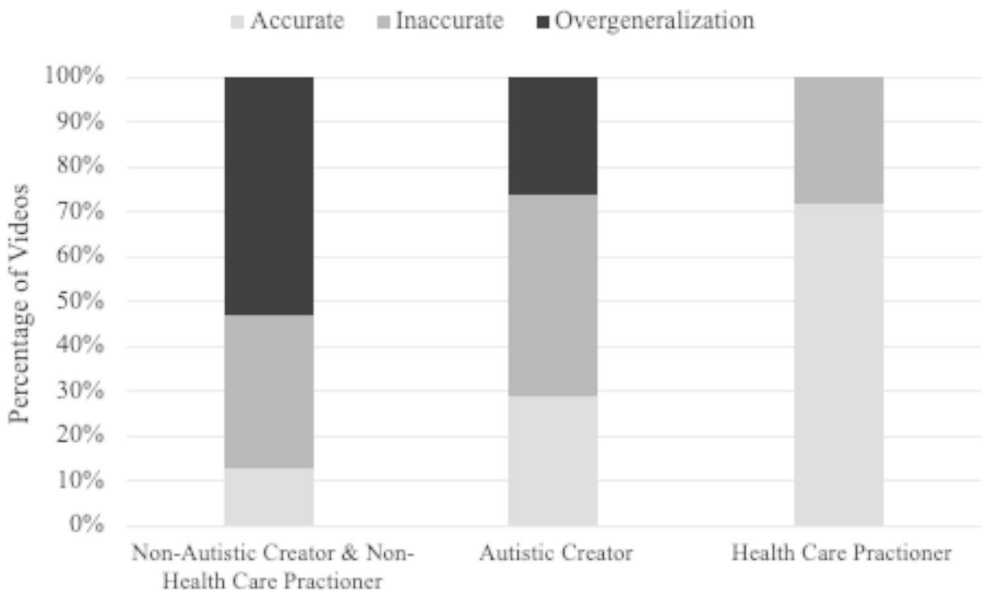

Fig. 2 Accuracy of Tik Tok videos by creator type

so that reliable and fact-checked information can reach a broader audience.

It should be noted that while this study focused on the sample of 133 informational videos (i.e., videos designed to 'educate' the audience about autism), these videos accounted for "only" a total of 198,695,946 views out of the reported 11.5 billion views in the hashtag – i.e., 1.7% of total views. The majority of popular videos associated with the "#Autism" hashtag was coded as "personal experience". These videos anecdotally document the lives of autistic people and their families, without the claim of disseminating knowledge on autism as a condition in general, pointing to the unprecedented opportunity offered by TikTok to create a content space where autistic individuals and family members can share their personal experiences with many people. These videos should be analyzed in future research to examine their public health impact, including the potential to reduce stigma and inform professionals and practitioners about lived experiences.

One of the limitations of this study was that engagement statistics and videos were only documented at a single timepoint. The dynamic nature of social media is such that since the collection of the data for this study, there are undoubtedly new videos created and potential changes in the engagement statistics of the examined videos. Future research examining time trends of autism-related content and engagement on TikTok has the potential to offer important insights. Furthermore, view counts as recorded by TikTok are not a measure of unique views – i.e., one user viewing a video twice would be recorded as two views. Additionally, the limited scope of this preliminary study precluded a comprehensive thematic analysis of the content of the videos. Future research should examine themes emerging from TikTok videos to generate insight on discourse on autism in social media platforms. Finally, although we strove for objectivity, fact-checking is not an exact science, especially in the context of an area in which evidence is constantly evolving. Therefore, additional independent research and more sophisticated fact-checking processes are needed to corroborate the data presented here. Nevertheless, the notion that a substantial amount of misinformation on autism exists on TikTok is consistent with research findings related to other platforms (Cortes Cavalcante et al., 2023) and other conditions (Yeung et al., 2022).

Despite the limitations listed above, our findings provide novel insight on the reach and accuracy of autism-related content disseminated through TikTok, a platform where fact-checked information and misleading information might coexist with similar perceived levels of authority. Engagement of the research community with content generated by TikTok and similar platforms is critical to facilitate communication with individuals and families impacted by autism, and to gain perspective on how autism and the scientific and clinical community engaged with autism is perceived and experienced by the large community of TikTok users.

Funding The authors did not receive support from any organization for the submitted work. All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

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