

# TikTok and YouTube Shorts by Autistic Individuals for Increasing Autism Awareness

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**Abstract.** *Introduction:* Autistic individuals, parents, organizations, and healthcare systems worldwide are actively sharing content aimed at increasing awareness about autism. This study aims at analyzing the type of contents presented in TikTok and YouTube Shorts videos under the hashtag #actuallyautistic and their potential to increase autism awareness. *Methods:* A sample of 60 videos were downloaded and analyzed (n=30 from TikTok and n=30 from YouTube Shorts). Video contents were analyzed using both thematic analysis and the AFINN sentiment analysis tool. The understandability and actionability of the videos were assessed with The Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT A/V). *Results:* The contents of these videos covered five main themes: Stigmatization; Sensory difficulties; Masking; Stimming; and Communication difficulties. No statistically significant differences were found on sentiment expressed on videos from both channels. TikTok videos received significantly more views, comments, and likes than videos on YouTube Shorts. The PEMAT A/V tool showed that there is a high level of understandability, but little reference to actionability. *Discussion:* Autistic people videos content spread valid and reliable information in hopes of normalizing difficulties and provide hope and comfort to others in similar situations. *Conclusions:* Social media videos posted by autistic individuals provide accurate portrayals about autism but lack information on actionability. These shared personal stories can help increase public literacy about autism, dispel autism stigmas and emphasize individuality.

**Keywords.** Autism; Social Media; Health Literacy; Health Education

## 1. Introduction

The rise in the number of autistic individuals has sparked increased interest from researchers, the healthcare system, and society at large [1,2]. Notably, social media has witnessed a surge in autism-related searches over the past decade, becoming one of the top-searched topics on these platforms [1,3]. Despite the increased interest in autism, more than half of autistic individuals feel socially isolated, with many expressing concerns about encountering negative behaviors that hindered their ability to leave the house [3]. Research shows that autistic individuals, parents, organizations, and

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healthcare systems worldwide are actively sharing content on various aspects of autism, including general characteristics, personal experiences, or everyday life, all aimed at fostering understanding and knowledge about autism [1,4-6]. However, content discussing the negatives of interventions aimed at autistic individuals or containing recommendations for harmful therapies is also posted on these channels [1,6]. Social media platforms hold the potential to redefine how autism is portrayed, and videos posted on these channels can be seen as a valuable instrument for health education [7]. Quality content created by autistic individuals provides firsthand insights based on their expertise, interests, opinions, and challenges, can play a significant role in broadening the conversation around autism, distancing it from traditional media's influence, and potentially increasing awareness and acceptance of autism [1,3-4, 6].

Despite the increasing research on autism representation in social media, not much is known about the contents and potentially value of TikTok and YouTube Shorts videos made by autistic individuals. The objective of this study is to analyze the type of contents presented in popular videos on TikTok and YouTube Shorts under the hashtag #actuallyautistic and their potential to increase autism awareness.

## **2. Methods**

A sample of the 60 most popular videos tagged with the hashtag #actuallyautistic were identified (n=30 from TikTok, and n=30 from YouTube Shorts). This hashtag was selected as being commonly used by social media users to identify themselves as autistic. The popular videos on TikTok refer to the videos that appear under the 'Top' category when doing a search, and on YouTube Shorts, to the videos that appear when you sort the search results by view count. The first author contacted the authors of these videos, informed them about the study, and offered them the opportunity to withdraw their content. After their agreement, the videos and their metadata were downloaded, and blurred with Adobe Premier. Both audio and text displayed on video were transcribed by the first author and verified by the second one. A mixed methods approach was used to analyze the data. The content in these videos was analyzed using both reflexive thematic analysis, and AFINN sentiment analysis tool [8], which assigns scores ranging from -5 to +5, with higher scores indicating more positive sentiment and lower scores indicating more negative sentiment [8]. SPSS version 28.0.1.0 was used to summarize metadata and sentiment analysis. The quality of the videos was assessed with The Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT A/V) [9], a tool that evaluates the understandability and actionability of patient education materials. The processing of the data of this study was approved by The Norwegian Agency for Shared Services in Education and Research (SIKT, Ref. 381338).

## **3. Results**

From the thematic analysis of video content posted by autistic individuals, five main themes emerged: Stigmatization; Sensory difficulties; Masking; Stimming; and Communication difficulties. Several videos address autistic stigmatization, while the approach differs between YouTube Shorts and TikTok. YouTube Shorts often feature videos based on personal stories, while TikTok videos often contain elements of sarcasm (i.e., 'Autism is not real' or 'You don't look autistic'). Sensory difficulties were a prevalent

theme on TikTok, with users openly sharing overwhelming experiences at the hairdresser due to sensory challenges, including issues with the hairdryer, water, and bright lights. They also employ TikTok to connect with other autistic individuals to discuss handling visits to the hairdresser. The theme of masking is also common in social media videos. Videos addressing masking had less text than others but effectively conveyed what masking entails. One notable aspect of these masking-related videos is that their titles tended to be more implicit than explicit in conveying the theme. For instance, titles like 'You Know, Like a Lier' and 'I hide it so well that no one can see it's really me' do not directly mention masking. However, they subtly hint at how masking is perceived by others, often involving elements of deception or concealing one's true self. In terms of stimming, referring to self-stimulatory behaviors involving repetitive movements or sounds (i.e., hand-flapping, spinning, repeating phrases, etc.), a YouTube Shorts video showcases various stimulating toys. The video briefly demonstrates usage, featuring sparkling orbs, teddy bears, and toys with cracking sounds, with accompanying text descriptions. Multiple videos address difficulties with communication. In one TikTok video, it starts with the statement, 'Literally, just try to communicate as an autistic person,' followed with another person who responds, 'Why are you so argumentative?' The individual who uploaded the video expresses their frustration through body language, crossing their arms, and exhibiting heavy breathing after the comment.

The sentiment expressed in the text and audios from TikTok and YouTube Shorts was compared using AFINN scores and the Mann-Whitney U test. The sentiment analysis scores for written text were 0 (SD=2,10) for TikTok videos and 0,54 (SD=2,08) for YouTube; and 2,86 (SD=7,02) and 2,69 (SD=4,19) for audio respectively. The U statistic was 367 for sentiment expressed in text ( $p=0,413$ ); and 107,5 for audio ( $p=0,430$ ). Regarding the metadata of these videos, their average duration was similar (TikTok=19,5 seconds vs. YouTube Shorts=17,4 seconds,  $p=0,67$ ). Statistically significant differences were found between channels' videos in the average number of views, comments, and likes (see Table 1). The PEMAT A/V tool showed that there is a high level of understandability among videos from both channels (90,09% for TikTok videos, and 90,24% for YouTube Shorts videos,  $p=0,08$ ). However, 59 among the 60 videos did not score on actionability, therefore providing little or no information to users on what they could do.

**Table 1.** Comparison of AFINN scores and metadata (TikTok vs. YouTube Shorts)

	<b>TikTok (n=30)</b>	<b>YouTube Shorts (n=30)</b>	<b>p-value</b>
<b>AFINN score text</b> Mean (SD)	0,00 (2,102)	0,54 (2,083)	0,413
<b>AFINN score audio</b> Mean (SD)	2,86 (7,015)	2,69 (4,191)	0,430
<b>Views</b> Mean (SD)	2868199,97 (3844448,22)	2142,50 (2354,29)	<0.001
<b>Comments</b> Mean (SD)	3681,55 (3515,75)	14,30 (29,45)	<0.001
<b>Likes/thumbs up</b> Mean (SD)	438084,93 (599055,03)	112,70 (151,81)	<0.001

#### 4. Discussion

Our findings indicate that autistic individuals share contents on TikTok and YouTube Shorts dealing with stigmatization; sensory difficulties; masking; stimming; and communication difficulties. Despite similarities in sentiment, lengths, and understandability, TikTok videos currently have higher engagement, including more views, comments and likes. However, videos from both channels lack information on actionability or practical advice. Results from this study align with previous research

indicating a prevalent theme of stigmatization [10]. The posts seek to debunk misconceptions and stereotypes, emphasizing that autistic individuals are diverse [11]. The sample of videos analyzed also exhibits honesty, openness, and the sharing of personal experiences, particularly in addressing sensory difficulties. Frustrating experiences related to sensory overload, including loud noises were also reported in previous research [12]. This type of video contents can normalize these difficulties while providing accurate information and help autistic individuals discover tools for emotional regulation [13]. Findings also show that some autistic women share insights into masking and its practical implications in daily life, consistent with previous research [14]. When such content becomes popular on these platforms, it offers diverse perspectives on masking, enhancing understanding of its complexity and the challenges it poses for autistic individuals [14]. Moreover, it can encourage them to reduce masking, fostering a more tolerant environment. Online communication provides stress-free environments for autistic individuals to improve their communication skills [12]. Furthermore, social media posts encourage audience engagement, inviting individuals to share their own experiences, seek support, and offer comfort and assistance in the comments section. This sense of community fosters acceptance and provides valuable support for autistic individuals [15]. Being part of such a community could potentially enhance their quality of life and offer hope, motivation, and shared learning experiences [11]. While autism is a commonly portrayed topic in TV, movies, and other media [2], traditional education programs often offer limited information about autism. Social media, especially among younger generations, can have power to shape opinions [3,11] by providing opportunities for more authentic portrayals of autism. By gaining insights directly from autistic individuals, it can contribute to increasing awareness and fostering a more inclusive and accepting society [11]. Our findings indicate that social media videos about autism, made by autistic individuals, could be valuable resources for increasing autism awareness, helping people understand the spectrum, varying degrees of intelligence and comprehension, and the significance of considering high and low-functioning individuals [1]. However, it would be desirable for these videos to improve actionability by providing clear steps for parents on how to support their autistic children, suggesting coping mechanisms for managing sensory overload, or explaining how to access services.

The advantages of autism-related content on TikTok and YouTube Short as educational contents could be twofold. Firstly, these videos enhance public' ability to detect early signs of autism [16]. Secondly, personal stories shared on these platforms can provide valuable insights into living as autistic individual, which can be beneficial in conversations with parents. Collaboration between parents and educational institutions is vital for ensuring autistic individuals receive the support they need [11]. However, social media platforms do not guarantee safe environments [4,17,18]. Both TikTok and YouTube Shorts allow anonymous comments, including sentiments such as not wanting autistic children, believing autistic people are not smart, or suggesting that society is better off without them [11], potentially leading to negative reactions that harm the self-esteem and confidence of autistic individuals. Since autism is a diagnosis with the most videos published on social media [1,3], this leads to a dual representation where balanced portrayals coexist with stigmatizing connotations [12].

This study has several limitations, and the findings cannot be generalized to the broader autistic population or to autistic individuals on social media platforms. We focused solely on TikTok and YouTube Shorts, specifically on videos including the hashtag #actuallyautistic, and only posted in English. This limited scope may not provide

a holistic representation of autism on social media. Additionally, we analyzed a small sample, and the autistic identity is based on users' self-identification.

## 5. Conclusions

Social media videos posted by individuals self-identified as autistic seem to provide accurate portrayals about autism. These videos shed light on autism traits like sensory challenges, masking, tuning, and communication, and also address marginalization and offer an alternative to face-to-face communication. While TikTok videos have more engagement, YouTube Short's clear presentation style remains valuable. Although these shared personal stories mostly lack information on practical applicability, they can help increase public literacy about autism, dispel autism stigmas and emphasize individuality.

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