

#Autism: A Cross-Sectional Study of the Quality of Diagnostic Information on TikTok

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Preface

This study marks the end of our three-year-long Bachelor of Psychology at the University of Stavanger. This educational course has been exciting and interesting for both of us, and it has opened our eyes to current and future challenges within the psychological field. This study is a product of a research question we deem to be more relevant than ever, with social media being a part of so many lives today. We have both witnessed the amount of misinformation about health-related topics online, which sparked our interest in conducting this study.

We would like to thank our advisor for this bachelor's thesis, psychologist Liss Gøril Anda-Ågotnes. Thank you for your inspirational and helpful guidance during this process. Thank you for your constructive criticism, motivation and advice. We appreciate your level of expertise and communication throughout this process. We would also like to thank you for your participation in this study, as a third-party rater. Your contributions have greatly improved this study. It has been a pleasure working on this bachelor's thesis with you, from start to finish.

Abstract

TikTok is one of the most popular social media applications worldwide. In this study, we aimed to investigate the quality of diagnostic information about Autism Spectrum Disorder (ASD) on TikTok. Although the amount of research on this topic is lacking, previous studies indicate that the quality of diagnostic information on TikTok is questionable. We conducted a cross-sectional content analysis, searching for the hashtag #Autism on TikTok and analyzing the 100 most liked videos. The videos were classified into three categories: misleading (M), personal experience (P) or useful (U). Results showed that 34% of the videos were misleading, 61% were personal experience, and 5% were useful. None of the videos were created or published by healthcare providers (HCPs). Lastly, there was a clear pattern in frequently highlighted ASD symptoms discussed on the application. Thus, it is important for clinicians and other HCPs to be aware of the dissemination of health misinformation on social media, as well as the potential impact this might have on clinical care.

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1.0 Introduction

1.1 Background

TikTok is one of the most used social media applications currently worldwide, with around 670 million downloads (Walbank, 2023). Among children and teenagers, the platforms' popularity surpasses that of other commonly used social media, such as Instagram, Snapchat and Facebook (De Leyn et al., 2022). We both have TikTok-accounts and consider us familiar with the application, as well as with the variety of content and information available. We have also found ourselves questioning the quality of the information we are presented with on the platform. Although the content may be entertaining and give insight to new information about all kinds of different topics, we have both found the content to be of questionable quality.

We both study psychology and take interest in topics regarding mental health, which may be the reason why our "feed" on TikTok often includes health-related topics from time to time. We noticed a pattern in what was "trending"; many of the videos about mental health were made by seemingly young individuals with no health-related background and a severe lack of sources to back up their claims. Autism Spectrum Disorder (ASD) is one of many disorders with popular hashtags on the platform, including #Autism, #AutismTok and #ActuallyAutistic. This sparked our interest in wanting to further scientifically investigate how the disorder is represented on TikTok.

We decided to look into the amount of research on diagnostic information about ASD on TikTok, which we found to be very limited. The lack of research inspired us to conduct a

study ourselves, seeing as ASD is such a relevant (and growing) topic on social media nowadays. TikTok reaches a wide variety of audiences, ranging from teenagers to adults, reaching all kinds of cultures, religions, and countries, making misinformation about the diagnosis more relevant than ever.

1.2 Clarification of Terms

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a manual used by psychiatrists, physicians and other health care professionals in the United States and other parts of the world to diagnose and classify mental disorders (American Psychiatric Association, n.d.). The diagnostic criteria for Autism Spectrum Disorder in this bachelor's thesis are based on the most recent edition of the manual, the DSM-5-TR, which was published in 2022 (APA, n.d.).

The International Classification of Diseases (ICD) is an international medical classification list that provides physicians, researchers and other health care professionals critical knowledge on human disease and death worldwide (World Health Organization, 2023). The ICD is published by World Health Organization (WHO) and is considered to be the global standard for diagnostic health information, with the most recent edition being the 11th revision, which came into effect in 2022 (WHO, 2023).

Autism spectrum disorder (ASD) according to DSM-5-TR, is a neurodevelopmental disorder defined by persistent challenges in social communication and interaction, as well as restrictive, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2022). These symptoms must be present in the early developmental period and

cause clinically significant functional impairments, as well as not being better explained by other disorders (APA, 2022).

TikTok is a social media application where users are able to produce, publish and watch an endless amount of short videos and live broadcasts (ByteDance Ltd., 2023). TikTok offers a personalized video feed based on the user's engagement with different types of content, easy-to-use tools for capturing daily moments, and a global community of creators (ByteDance Ltd., 2023).

1.3 Abbreviations

DSM: Diagnostic and Statistical Manual of Mental Disorders

ICD: International Classification of Diseases

ASD: Autism Spectrum Disorder

HCP(s): Healthcare Provider(s)

APA: American Psychiatric Association

1.4 Theoretical Background

1.4.1 TikTok and ASD

The social media application TikTok, released on iOS and Android in 2017, is a platform where the users can discover videos from around the world, watch a personalized video feed and create their own videos among millions of creators and a global community (ByteDance Ltd., 2023). The application allows users to post and watch videos lasting from a few seconds

to a couple of minutes. The videos can contain a wide range of topics ranging from comedy skits to more serious topics, such as politics and mental health-related issues.

TikTok uses a hashtag system where users can upload videos with different words associated with the content of the video. Users can also search for different hashtags to enter a stream of videos tagged with the same and/or similar words. For instance, if you search “mental health”, only videos containing this hashtag will show up. However, the video is not limited to one single hashtag, so it can also include other hashtags as well from a completely different topic. According to a study from 2021, #MentalHealth, #Anxiety, #ADHD, and #Autism are some of the most used health-related hashtags on videos on the application, all separately reaching billions of views (Zenone et al., 2021). This study also illustrates how common discussions of mental-health issues are on the application. TikTok also has a distinct algorithm. Based on the user’s preferences, interests, etc., the algorithm accumulates an entertaining, immersive personalized stream of videos tailored to fit the individuals interests (ByteDance Ltd., 2023).

A study from 2021 shows a rise in social-media usage across the world during Covid-19; TikTok engagement went up by 180% after the pandemic outbreak in 2019 (Harwood, 2021). This study also shows a connection between mental health issues and social media, captured by the heavy reliance people formed to social media platforms, and TikTok in particular (Harwood, 2021). Seeing as social media is also shown to be an amplifier for misinformation about mental health-related issues (Nelson et al., 2020), we wanted to investigate how much of the information spread on TikTok is misleading and how much can be considered useful.

Social media is a part of many people's everyday lives and the different effects on individuals in the context of mental illness have been researched for many years (Aichner et al., 2021; Sloan & Quan-Haase, 2017). It can create new avenues for research across vast professional fields such as health sciences and psychology. However, social media often provides a narrow view of our social world as not all groups are represented equal, and parts of the world are absent from the internet. Even so, it has integrated itself into many areas of studies, including healthcare (Sloan & Quan-Haase, 2017). However, there is not a lot of research done specifically on TikTok in this context. Considering how the highly sophisticated algorithm operates, compared to, for instance Facebook and Instagram, we thought it was important to study this platform independently.

As mentioned above, we were concerned about the distribution of misinformation on the social media application, considering the potential dangers of distributing clinically incorrect information about mental disorders online. ASD is shown to be commonly discussed on TikTok (Harwood, 2021), and thus, the platform is a relevant arena for exploring the presented issue.

1.4.2 About ASD

Globally, the prevalence of ASD is around 1% of the population, however, the reported prevalence of ASD may be affected by misdiagnosis, as well as delayed diagnosis or underdiagnosis (APA, 2022). Worldwide, the male:female ratio appears to be 3:1, with concerns about under-recognition of ASD in women and girls (APA, 2022).

According to DSM-5-TR, ASD is a neurodevelopmental disorder defined by persistent challenges in social communication and interaction, as well as restrictive, repetitive patterns of behavior, interests, or activities (APA, 2022). Symptoms must be present in the early developmental period and cause clinically significant functional impairments, as well as not being better explained by other disorders (APA, 2022).

1.4.3 The Symptoms of ASD

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is used as an assessment-tool for ASD, by observing if needed criteria are present in the individual believed to have the diagnosis. The criteria consist of five groups: A, B, C, D, and E. Each group involves traits (symptoms) that must be present for the individual to be diagnosed. Group A is divided into three subgroups (A1, A2, and A3), and includes the persistent deficit in social communication and social interaction across multiple contexts (APA, 2022). They are manifested by all the following: currently or by history; A1: deficits in social-emotional reciprocity, A2: deficits in nonverbal communicative behaviors used for social interaction, and A3: deficits in developing, maintaining, and understanding relationships (APA, 2022).

Group B has four sub-groups (B1, B2, B3, B4), which entails the restricted, repetitive patterns of behavior, interests, or activities (APA, 2022). They are manifested by at least two of the following: currently or by history; B1: stereotyped or repetitive motor movements, use of objects, or speech, B2: insistence in sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior, B3: highly restricted, fixated interests that are abnormal in intensity or focus, and lastly, B4: hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (APA, 2022).

Group C entails that symptoms must be present in the early developmental period, although they may not fully manifest until social demands exceed limited capacities (APA, 2022). The symptoms may be “masked” by strategies that are learned and obtained in later life (APA, 2022). Group D entails that symptoms cause clinically significant impairment and difficulties in social or occupational areas, or other important areas of current functioning (APA, 2022). Lastly, Group E entails that these disturbances (A, B, C, and D symptoms) are not better explained by intellectual developmental disorder (intellectual disability) or global developmental delay (APA, 2022).

The essential features of ASD include persistent impairments in social communication and social interaction, and restricted, repetitive patterns of behavior, activities, or interests (APA, 2022). The symptoms must be present from early childhood and limit/impair everyday functioning, and the stage at which functional impairment becomes obvious varies according to different characteristics of the individual and their environment (APA, 2022). The core diagnostic features are evident in the developmental period, but compensation, intervention, and support may mask difficulties in some contexts (APA, 2022). The manifestation of the disorder also greatly varies depending on the severity of the condition, developmental level, chronological age, as well as gender; the word “spectrum” elevates this (APA, 2022).

Individuals with accompanying intellectual or language impairments, for instance, can greatly “mask” these deficits (APA, 2022). ASD also encompasses disorders previously referred to as infantile autism and childhood autism, as well as atypical autism, Kanner’s autism, high-functioning autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and lastly, Asperger’s disorder (APA, 2022).

1.4.4 ASD: DSM-5-TR and ICD-11

Diagnoses are most reliable when they are based on multiple sources of information; this includes clinician's observations and caregiver history, as well as self-report (APA, 2022). Standardized behavioral diagnostic instruments with good psychometric properties, including caregiver interviews and clinician observation, can also improve reliability of diagnosis over time and across clinicians (APA, 2022). However, the symptoms of ASD "(...) occur as dimensions without universally accepted cutoff scores for what would constitute a disorder." (APA, 2022, p. 63). Thus, ASD remains a clinical diagnosis, "(...) taking all information available into account, and is not solely dictated by the score on a particular questionnaire or observational measure." (APA, 2022, p. 63).

Individuals with ASD also have different features associated with the disorder, not specified in the DSM-TR-5; this can include intellectual and/or a language impairment, such as talking slowly (APA, 2022). This can also include motor deficits, such as an odd gait, clumsiness, and walking on tiptoes, and lastly, self-injury behaviors, such as biting the wrist, can also occur (APA, 2022).

ICD-11 is used as a functioning assessment and decision tool developed and updated by the World Health Organization used at the global standard for recording health information and causes of death (WHO, 2023). In contradiction to DSM-5-TR, ICD-11 also records, analyzes, interprets and compares mortality and morbidity data collected in different countries at different times (WHO, 2023). It also ensures a semantic interoperability and reusability of recorded data for cases beyond mere health statistics, which includes decision support, resource allocation, guidelines and more (WHO, 2023).

Unlike DSM-5-TR, ICD-11 has a list with diagnostic requirements who are *all* required to be met by the individual being assessed for ASD (World Health Organization (WHO), 2019/2021). However, both manuals have similar symptomatic structure. The requirements are first listed, then explained by several examples illustrating how the symptoms may look (World Health Organization (WHO), 2019/2021). The two can be used complimentary, but we chose to base this study on the symptoms of ASD in DSM-5-TR. Although controversial (Wakefield, 2016), we chose DSM-5-TR due to the precise way the manual assesses ASD.

1.4.5 Psychological Theory

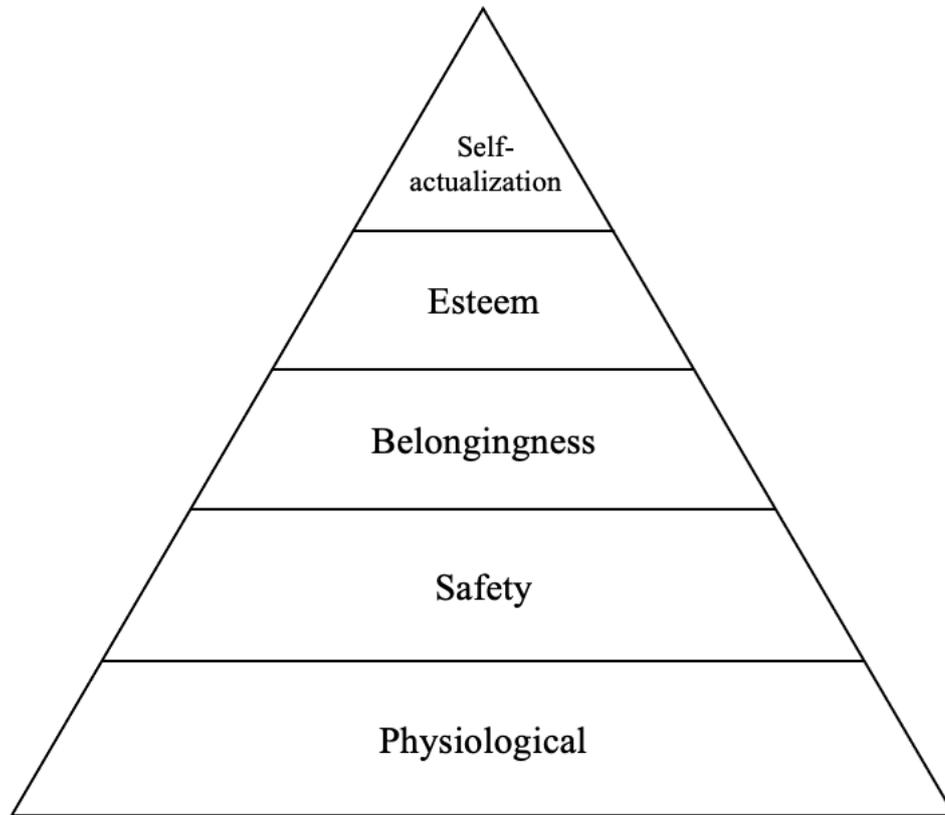
So, why have mental disorders, such as ASD, become such a common topic on social media? We theorize that a possible reason for this could be the general need to *belong*. Abraham Maslow proposed a hierarchic theory of motivation, where self-actualization is the ultimate goal (Larsen et al., 2017). This theory is often referred to as *Maslow's Hierarchy of Needs* (Figure 1) and consists of five levels; basic needs are on the bottom and are more pressing than higher level needs (Larsen et al., 2017). The physiological needs at the base of the pyramid are crucial for human survival, followed by safety needs, such as security and health (Larsen et al., 2017). Social media, such as TikTok, may make health-related information more accessible to the general public. The general understanding of the pyramid is that the needs at the base need to be satisfied before proceeding to higher needs. The third level is belongingness needs, which include interpersonal needs, such as belonging and acceptance in social groups (Larsen et al., 2017). Social media can create a unique community for people with similar health-related experiences, making it possible to communicate, share information and assist each other (Harwood, 2021). The fourth level is called esteem needs, and entails

cognitive and aesthetic needs, such as creativity, respect and self-esteem (Larsen et al., 2017). On TikTok, creators can publish videos using different tools, such as music, filters and trends (ByteDance Ltd., 2023), making the process of disseminating health-related information creative and entertaining, regardless of the quality of said information. Relating to the content published on social media platforms may provide personal validation for users struggling with mental health issues. Once all these needs are fulfilled, Maslow argued that one would desire to reach self-actualization; the realization of one's full potential (Larsen et al., 2017).

Based on the motives in this theory, the third and fourth level in the pyramid might explain why people seek out social connection and belongingness on social media, whether they have a diagnosis or not. But what if the content within these communities cause more harm than good?

Figure 1.

Maslow's Hierarchy of Needs



Note. This figure demonstrates the theory of Maslow's hierarchy of needs categorized into five levels; physiological needs at the bottom, followed by safety needs, belongingness needs, esteem needs, and lastly, self-actualization.

1.5 Aim with Thesis

Based on the presented information, the general aim for this bachelor's thesis is to investigate the quality of diagnostic information by sampling videos from TikTok and classifying them into three categories, depending on whether the information is useful, misleading, or personal experience.

Considering how common the discussion about mental health is on TikTok, especially ASD, we wanted to further assess what type of information is being distributed. In 2019 there were a total of 4.7 billion views on videos tagged with “#Autism” (Zenone et al., 2021). In comparison, at the time of the query there were 20.1 billion views. One study shows that TikTok operates as an arena for online communities consisting of younger people with mental health issues (Harwood, 2021), using the platform to assist and communicate with each other. This study illustrates the importance of further researching social media platforms distributing mental health content. With this study, we wanted to investigate the potential amount of misinformation being distributed by HCPs and non-HCPs.

A cross-sectional study of social media content shows that over half of the information found on TikTok was misleading, containing incorrect statements on Attention Deficit/Hyperactive Disorder, also known as ADHD (Yeung et al., 2022). This study inspired us to see if we would encounter similar results by researching ASD on the platform ourselves, which to our knowledge, has not been done before.

1.6 Research Question

In this study we aimed to investigate the quality of diagnostic information about ASD on the social media application TikTok, by categorizing our collected data into three groups: misleading, useful, or personal experience. Additionally, we wanted to investigate the amount of content published by HCPs, as well as explore any patterns related to frequently highlighted symptoms of ASD on the platform.

2.0 Method

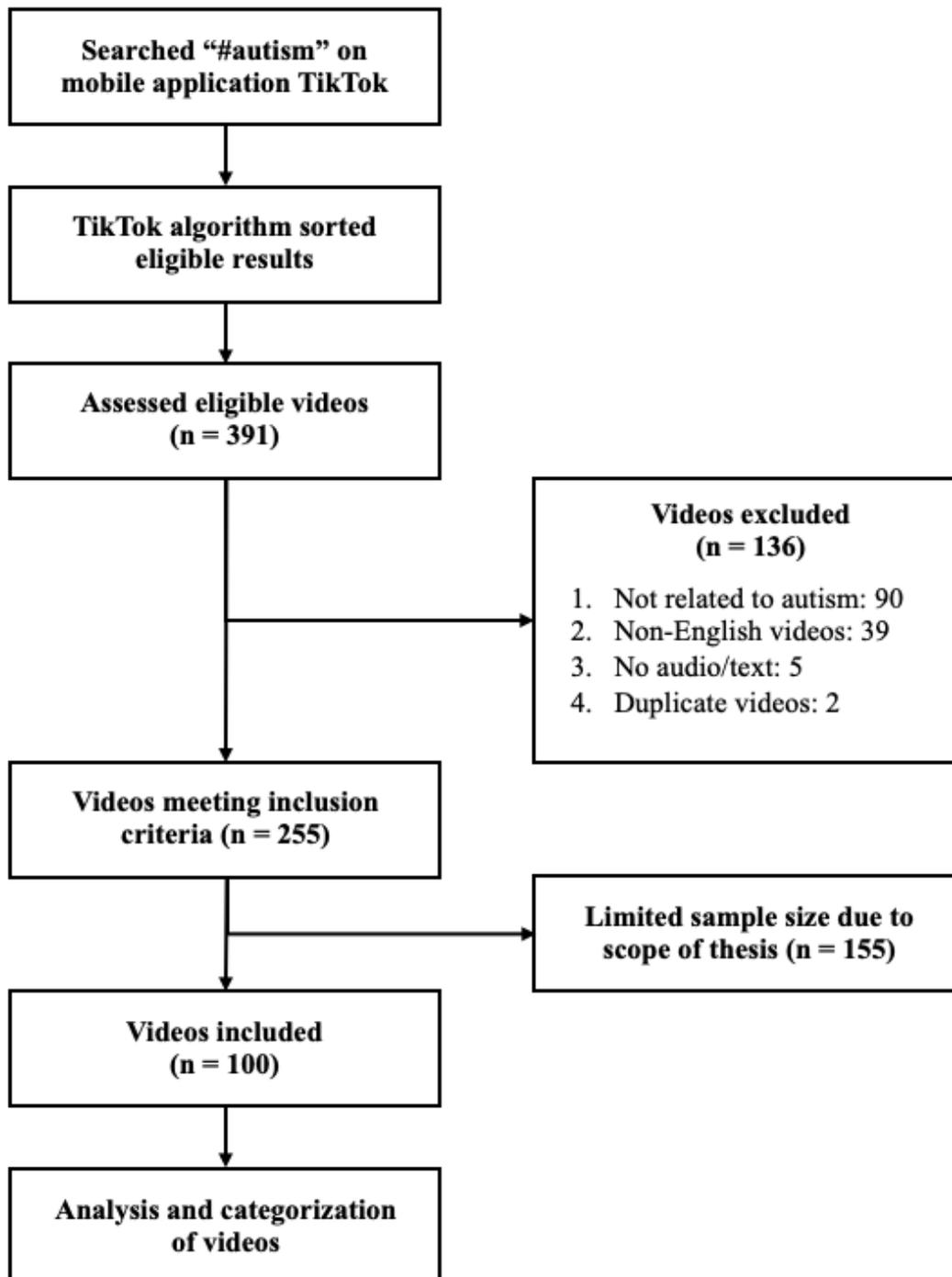
2.1 Approach

The methods used in this study are based on previous studies similar to ours, largely inspired by the works of Anthony Yeung, Enoch Ng, and Elia Abi-Jaoude and their research on the diagnostic quality of ADHD on TikTok (Yeung et al., 2022). We created a new account on TikTok in an attempt to avoid algorithmic data bias affecting our search results on the application. Due to TikTok's recommendation algorithm, the user's previously watched and liked videos affect future recommended videos as a result of the application's "targeted catering" approach (Zhang & Liu, 2021). On February 2nd, 2023, we searched for the popular hashtag #Autism on the mobile phone application (Figure 2). The inclusion criteria were that the video content had to include any aspect of ASD; e.g., description of or awareness about symptoms, diagnosis or management. The exclusion criteria were videos that were non-English, videos with no audio or text, duplicate videos or videos that were not related to ASD in any way (such as pet videos and dance "trends").

The search results revealed 391 videos, and we applied the inclusion criteria to the videos in descending order by like count. Of these 391 videos, 255 met the inclusion criteria. However, due to the scope of this bachelor's thesis, we decided to reduce the sample size to 100, as this has been deemed an acceptable sample size in previous content analysis studies (Basch et al., 2022; Yeung et al., 2022; Zheng et al., 2021).

Figure 2.

Flow Chart of Method of Video Inclusion & Exclusion.



Note. This figure demonstrates the method used in this study as a flow chart, including the inclusion and exclusion of videos, as well as the final sample size.

2.2 Sample

We analyzed the top 100 most popular videos of all time with the hashtag #Autism by number of likes. We then classified the videos into three categories: misleading, useful, or personal experience. These categories are a part of a categorical classification scale used to assess the content quality of videos on social media (Sood et al., 2011). We also investigated how many of the top 100 most popular videos were uploaded by HCPs by analyzing the content creators' profile biographies, as well as investigating which symptoms were more highlighted than others.

2.3 Classification Method: The Sood et al. Scale

Both psychology students independently viewed, assessed, and analyzed each of the 100 videos using the categorical classification scale. In cases where disagreement between the psychology students arose, the final rating was decided independently by psychologist Liss Gøril Anda-Ågotnes, PhD. Videos were classified as misleading (M) if they contained information lacking scientific evidence or scientifically incorrect statements, such as unsubstantiated claims about ASD in general or ASD symptoms. Videos were classified as useful (U) if they contained scientifically correct information about any aspect of ASD, such as symptoms, etiology, or epidemiology. If the video additionally contained any scientifically incorrect statements, it was classified as misleading. Videos were classified as personal experience (P) if they described or illustrated users' own anecdotal/personal experience with ASD. If the video additionally contained any scientifically incorrect statements, it was classified as misleading. Calculation of the kappa statistic was performed to assess inter-rater reliability between the two raters classifying the videos.

2.4 Investigating Frequently Highlighted Symptoms

In addition to classifying the videos using the Sood et al. Scale, we also wanted to investigate which symptoms of ASD were most highlighted in the top 100 videos. This was done using the Bar Charts feature in IBM SPSS Statistics, where the bars represented all ten symptoms of ASD as shown in Figure 3. Symptoms included A1, A2, A3, B1, B2, B3, B4, C, D and E in DSM-5-TR (APA, 2022). Symptom E could only be registered if specifically stated in the video, as there was no way of knowing whether it was present or not unless stated so.

2.5 Content Made by HCPs versus. Non-HCPS

Lastly, we wanted to assess whether the videos were published by HCPs or non-HCPs. This process included analyzing the content creators' profiles to investigate if their biographies included any sign of healthcare-related education, profession, or experience.

2.6 Methods: Data Collection and Analyses

Data collection was performed using Microsoft Excel Spreadsheet Software 16.69.1, Flow chart and pyramid was made using Microsoft PowerPoint 16.70, and all statistical analyses were performed using IBM SPSS Statistics 28.0.1.1 (14).

3.0 Results

3.1 Video characteristics

The 100 videos included in this study had a total of 71.6 million views. None of the videos were uploaded by HCPs, i.e., licensed therapists, psychologists, physicians, or nurses. None of the videos in our sample were uploaded by corporations, health organizations, for non-profit and profit entities.

3.2 Video characteristics by classification

Description of video characteristics by classification are described in Table 1. Of the 100 videos, 34% were classified as misleading, 61% were classified as personal experience and 5% percent were classified as useful. Agreement between the raters was 97% with a kappa statistic of 0.941 ($P < 0.001$).

There was a total average of 7 166 000 views (range: 1 600 000 - 32 600 000), 1 171 974 likes (range: 437 300 - 7 800 000), 15 344 shares (range: 419 – 187 300), and 110 411 comments (range: 0 - 46 937). The average video length was 40 seconds (range: 5 – 248).

Table 1.*Video Characteristics by Classification.*

	Misleading (n = 34)	Personal experience (n = 61)	Useful (n = 5)
Mean Views (SD, range)	5488235 (3767063, 1600000-18000000)	7740984 (5600339, 2000000-32600000)	11560000 (6310151, 3400000-19100000)
Mean Likes (SD, range)	1047053 (1014767, 440600-6005000)	1235315 (1096472, 437300- 7800000)	1248680 (798844, 489800-2300000)
Mean Shares (SD, range)	20250 (36008, 1396- 187300)	12819 (19550, 419- 124500)	12786 (12016, 2137- 31400)
Mean Comments (SD, range)	11700 (12942, 2501- 61018)	10673 (10505, 0- 46937)	11056 (11859, 2612- 31651)

Note. This table demonstrates the mean views, likes, shares and comments for the 100 videos included in this study, classified into the three Sood et al. Scale categories: misleading, personal experience and useful. SD = Standard Deviation.

3.3 Results: The Sood et al. Scale

Of the 34 misleading videos, 15 videos (44%) contained misinformation about symptoms, such as misattributing certain poses and behaviors as being specific to only ASD. This includes sitting down with a bad posture and sleeping on one's left side. 13 videos (38%) contained misinformation about the disorder in general, e.g., stating that autistic people cannot go to bed with pants on and do not know how to say "thank you". Three videos (9%) stereotyped the disorder, such as comparing ASD to being a "sigma male" or a "gifted kid", implying there is only one way to have the disorder. Two videos (6%) contained scientifically incorrect statements about the epidemiology of ASD, such as life expectancy and genetics. One video (3%) contained incorrect information about the screening/assessment of ASD, claiming that only pictures of frogs are used in this process.

Of the five useful videos, four videos (80%) were created and published by parents attempting to educate viewers about their children's ASD diagnosis. One video (20%) was created and published by an adult describing their own symptoms of ASD.

All 61 (100%) of the personal experience videos described or illustrated individuals' own personal experience with ASD and the symptoms of ASD, as well as how the diagnosis affected them personally and the people around them.

Finally, none (0%) of the videos recommended viewers to seek out medical, psychiatric, or psychological assessment, nor do their own research before self-diagnosing with ASD based on presented signs and symptoms. Table 2 provides additional examples of misleading, personal experience and useful videos that were included in this study.

Table 2.

Examples of Misleading, Useful and Personal Experience Videos.

Examples of misleading videos

Video stating that individuals who “take things apart to see how they work” have ASD.

Video stating that sleeping on your left side with “dinosaur hands” are signs of ASD.

Video describing ASD as not knowing how attractive you are.

Video stating that autistic people are smarter or stronger than non-autistic people.

Video stating that grabbing your neck and touching your jewelry when stressed means you have ASD.

Examples of useful videos

Video of an individual educating the viewers about their child’s ASD symptoms, such as unusual sensory needs, including spinning in circles continuously throughout the day.

Video describing ASD symptoms that may be present in toddlers in the early developmental period, such as little to no eye contact and intense meltdowns.

Video showing ASD signs/symptoms in early childhood, such as repetitive motor movements (hand flapping) and deficits on social-emotional reciprocity.

Video showing a day in the life of a child diagnosed with ASD, educating the viewers about the diagnosis using scientifically correct information.

Video of an individual describing their own ASD symptoms using scientifically correct information.

Examples of personal experience videos

Video of an individual describing their own personal experience of ASD symptoms, such as different types of stimming or adherence to routines.

Video of an individual, often a parent, educating the viewers about their child’s ASD symptoms, such as extreme distress at small changes.

Video showing an individual experiencing ASD symptoms, such as hyporeactivity to sensory input or excessive touching of objects.

Video of an individual describing a day in their life with diagnosed ASD and the challenges they face doing regular tasks.

Video of an individual displaying deficits in nonverbal and verbal communication, such as using speech tablets to communicate with other people.

Note. This table demonstrates 15 examples of misleading (5), useful (5) and personal experience (5) videos.

3.4 Videos by Healthcare Providers or Non-Healthcare Providers

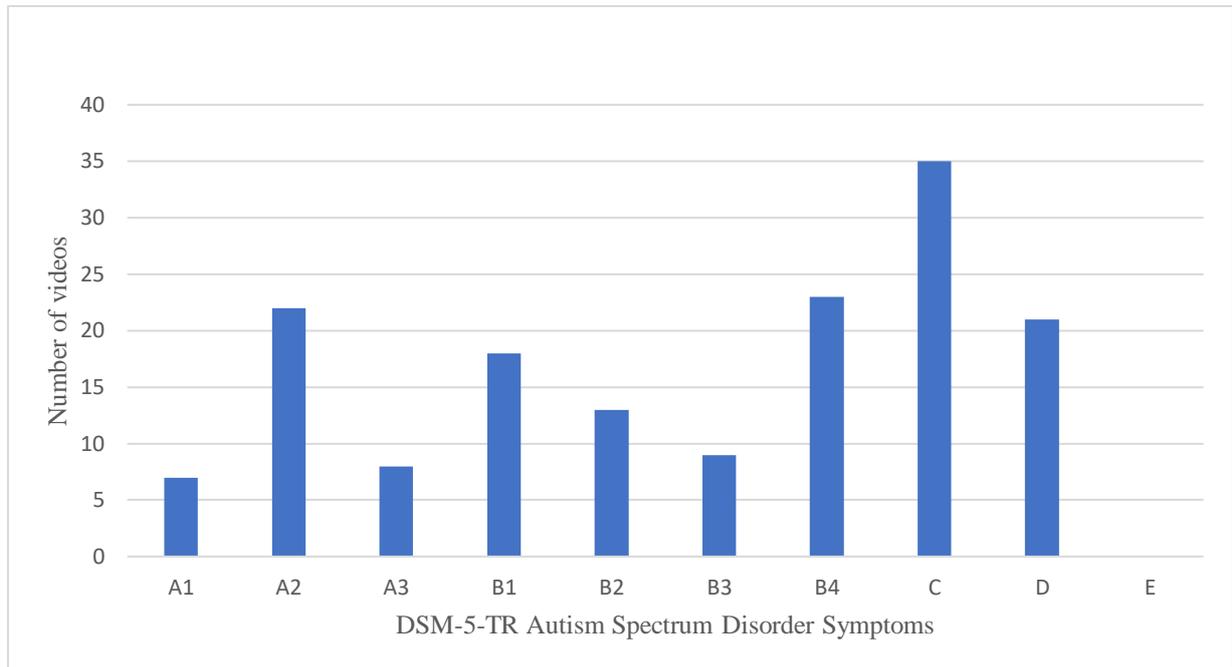
None of the top 100 videos analyzed under the hashtag #Autism were created or published by HCPs, according to our assessment.

3.5 Frequently Highlighted Symptoms in Analyzed Videos

Among the top 100 videos analyzed, we found that the three most highlighted DSM-5-TR symptoms of ASD were A2, B4 and C, as illustrated in Figure 3. Of the videos meeting the A-criteria, seven videos (7%) met criterion A1, 22 videos (22%) met criterion A2, and eight videos (8%) met criterion A3. Of the videos meeting the B-criteria, 18 videos (18%) met criterion B1, 13 videos (13%) met criterion B2, nine videos (9%) met criterion B3, and 23 videos (23%) met criterion B4. Of the remaining criteria, 35 videos (35%) met criterion C, 21 videos (21%) met criterion D, and none (0%) of the videos met criterion E.

Figure 3.

Frequently Highlighted Symptoms in Analyzed Videos.



Note. This figure demonstrates the distributions of ASD symptoms across all 100 videos included in this study. The bars represent the ASD symptoms occurrence in number of videos.

4.0 Discussion

4.1 Video Classification Results

4.1.1 Misleading, Useful and Personal Experience: Summarized Results

Approximately one-third of the analyzed videos (34%) were categorized as misleading. Over half of the videos (61%) were categorized as personal experience. Lastly, only 5% of the analyzed videos were categorized as useful. None of the videos were uploaded by HCPs. Our quantitative content analysis about videos using the hashtag #Autism shows an average of 7.1 million views per video with 1.1 million comments. The videos were also shared on average 15,300 times. As mentioned, 34% of the videos were categorized as misleading, meaning that a substantial amount of misinformation may be reaching millions of people worldwide.

4.1.2 Comparison of Results

Compared to the TikTok/ADHD-study we based our methods on, our Sood et al. Scale results are relatively similar. Approximately 1/3rd of the analyzed videos in this study were classified as misleading, while approximately half of the videos in the TikTok/ADHD-study were classified as misleading (Yeung et al., 2022). We theorize that the cause of the slightly smaller number of misleading videos in our study, is that most of the videos fit into the personal experience category. We included videos in this category as long as they did not contain any scientifically incorrect statements based on DSM-5-TR, as well as published studies and textbooks.

4.1.3 Misleading Versus Useful

Due to the dominating number of misleading videos compared to useful videos in our results, we argue that the content on TikTok is not scientifically comprehensive enough to be considered educational material regarding ASD. The alarming 34% of misleading videos compared to the 5% of useful videos illustrate the clear uneven distribution of good scientific information when discussing ASD on the application. The fact that none of these videos were uploaded by HCPs strongly affirms this. A professional HCP would most likely refrain from describing ASD as, for instance, having “dinosaur hands”.

4.2 Content Creators – HCPs

After analyzing all 100 content creators’ profiles, we could not identify a single HCP.

Profiles on the social media application TikTok are fairly short and concise, consisting of an icon (profile picture), a username, following-, followers- and likes count, and a small section where users can write a short biography. HCPs often include their title(s) if they are publishing educational content. However, we found that none of the videos in this study were published by creators with such titles in their biographies. Some of the creators may still be HCPs but choose not to include this information on their profiles, however, this may indicate that they do not have a health-care related purpose on the platform. There is no actual way of knowing whether the content creators are HCPs or non-HCPs. Participation and direct communication with the creators may be necessary in future research to establish the relationship between videos published by HCPs and videos published by non-HCPs.

4.3 DSM-5-TR Autism Spectrum Disorder Symptoms – Bar Chart Results

We also wanted to investigate how common the different ASD symptoms are on TikTok in accordance with DSM-5-TR. On social media, some ASD symptoms are more “acknowledged” than others. Therefore, we wanted to investigate if there was a pattern present in the videos on TikTok regarding which symptoms are most highlighted in each video. Among the 100 videos analyzed, we found that the three most highlighted DSM-5-TR symptoms of ASD were A2, B4 and C, as illustrated in Figure 3.

The A-group involves the social communications deficits manifesting with ASD. Symptom A2 entails the failure of responding to social interactions, for instance, reduced sharing of interests, emotions, or a failure to initiate or respond to social interactions (APA, 2022). This symptom can be generalized to fit a broad aspect of everyday life, and therefore may be more interesting to viewers. We all experience periods in life where such traits may be more prominent than usual, not necessarily meaning that we have a diagnosis.

B4 entails abnormal reactivity to certain sensory input, or an unusual interest in sensory aspects; for instance, an indifference to pain or temperature change, or specific textures or sound (APA, 2022). We argue that this symptom includes relatable issues that can be applicable to the general population. Hating loud noises is not an exclusive trait to people with ASD, as such sensory input may be uncomfortable to most people. Similarly, being fascinated with lights or movements may be something many people can relate to, e.g., fireworks, light shows, and such. Videos stating that “you *have* ASD, if X and Y”, may create

a false representation of the disorder, when X and Y may be normal behaviors not exclusive to ASD.

The high statistics for criterion C could possibly be explained by the usage of children as tools for educational intentions on the social media platform. According to criterion C, the symptoms of ASD must be present in the early developmental period (APA, 2022). One could argue that the high prevalence of this symptom is simply due to individuals wanting to spread awareness about how ASD may present itself in children. Educational health-related content is both relevant and common on TikTok, and children are often portrayed in videos for educational purposes. For instance, four out of five useful videos in this study included children and described their experience with ASD. This was also the case for many of the personal experience videos.

Interestingly, almost none of the videos contained information about either B1, B2, nor B3, all appearing in under 20% of the 100 videos analyzed. Criteria A1 and A3 both scored under 10%. The B3-criterion was only present in 9% of the videos. We argue that this may be due to these symptoms not being “as relatable” to the general public.

None (0%) of the videos met criterion E, which states that the disturbances are not better explained by other disorders (APA, 2022). Unless explicitly stated so, there was no way of detecting the presence of criterion E. We argue that this causes the videos to appear more relatable; some of the ASD symptoms (behaviors, thoughts, etc.) may be applicable to the general public, and not necessarily be proof of ASD or other disorders.

The difference in common and less common symptoms serves a few afterthoughts. With there only being a few symptoms dominantly present, this may create a false image of the prevalence of ASD in the population, considering one has to fulfill 8 out of 10 symptoms to receive the diagnosis, according to DSM (APA, 2022). *None* of the videos mention this fact, which is a major factor as to whether or not one will be diagnosed. In many of the videos, it appears as if having only 3-4 symptoms is sufficient and qualifies for the diagnosis. This pattern in frequently highlighted symptoms may be an issue on other social media platforms as well. This may serve as a point for future research to investigate.

4.4 The Intent of the Videos

Although this study aimed to investigate the quality of diagnostic information about ASD on TikTok, educating and disseminating diagnostic and medical information may not be the intent of all videos published on the application about ASD. During our analysis process, we encountered several videos created with humorous and relatable intent, including memes and “TikTok trends”.

Social media applications, such as TikTok, Tumblr and Twitter, create arenas for online community building for marginalized groups, for instance, people with mental illnesses (Brusilovskiy et al., 2016). Abraham Maslow argued that humans possess a strong need to belong in groups and be accepted by others (Larsen et al., 2017). Acceptance in the form of participation in online communities may fulfill this need for social belonging, helping individuals on their journey to self-actualization. However, once normal behaviours and thoughts are portrayed as exclusively being symptoms online, seemingly healthy individuals

may seek out diagnoses and communities based on different diagnoses, such as the hashtag #Autism on TikTok.

Within these online communities, users often share their experiences with their diagnosis and discuss strategies for coping (Brusilovskiy et al., 2016). These tendencies were present in many of the videos categorized as misleading, where creators would use memes, dark humor and trends in their videos about ASD, possibly in an attempt to “bond” with the viewers. Although not created with harmful intent, such videos may contribute to overgeneralizations, harmful stereotypes, unsubstantiated claims and misinformation about ASD in general.

4.5 TikTok Algorithms

We created a new TikTok-account on the application in an attempt to avoid algorithmic data bias affecting our search results. Due to TikTok’s recommendation algorithm, the user’s previously watched and liked videos affect future recommended videos (Zhang & Liu, 2021). We were unsure as to which extent this would affect our search results. Of the 391 videos assessed for eligibility, 39 videos were non-English. Among these 39 videos, there were a small number of Norwegian videos, which may indicate that despite creating a new account on the application, some algorithmic data bias may have occurred. However, these Norwegian videos were among the bottom 391 videos due to their small number of likes, and therefore, not included in this study.

Additionally, TikTok’s proprietary search algorithm results may have limited the possibility of including all eligible videos in this study, such as deleted or removed videos (Yeung et al., 2022). At the very end of this study, we decided to go through each of the 100 videos once

more to assess whether or not they had been deleted during our research process. Indeed, one of the videos was no longer available, and many of the videos had “switched places” in the like count order. This indicates that the top 100 videos under the hashtag #Autism on TikTok are constantly changing, due to factors such as deletion, like count, engagement, and so on. Future research should take this into account, especially in cases of non-cross-sectional studies.

4.6 Strengths and Limitations

The inter-rater agreement in this study was high (97%) with a kappa statistic of 0.941 ($P < 0.001$). Psychologist Liss Gøril Anda-Ågotnes, PhD, decided the final rating in three cases (3%) due to disagreement between raters. It is important to note that we (the raters) are both Norwegian students, close in age and well acquainted, which may contribute to some conformation bias, such as paying closer attention to information confirming already existing beliefs. Other personal biases that may have occurred in this study are perception and overconfidence bias. However, the classification of videos (M/P/U) was performed separately, and the results are similar to other studies concluding that videos on TikTok with health-related information are of questionable quality (Kong et al., 2021; Yeung et al., 2022).

In addition to biases, our conceptualization of what we consider to be misleading, useful and personal experience is from the perspective of being psychology students. We are not HCPs, patients or professionals, all of whom could have a different perception of the three categories. For instance, deeming a personal experience video as misleading due to new research in the field of ASD.

As stated, we have based our methods on previous, similar studies. Most of these studies have used a *web scraper* using TypeScript programming language to extract video metadata automatically (Yeung et al., 2022; A. Zheluk et al., 2022; A. A. Zheluk et al., 2022), however, we executed this process manually on all 100 videos. This was done by analyzing the videos on the application one by one, while simultaneously documenting the date and number of likes, views, shares and comments manually in Microsoft Excel. Despite the fact that we went over the numbers multiple times, we might have missed some numbers as we did not use a web scraper.

While analyzing the videos, we encountered several cases where the content in the videos met more than one of the three criteria (M/P/U). There were many cases of videos being eligible for both the useful criterion and the personal experience criterion, such as videos showing a parent spreading awareness about their child's ASD diagnosis in an educational matter, as well as videos describing an individual's own experience with substantiated ASD symptoms. In other cases, videos could have been classified as both misleading and personal experience, often including an individual describing their own personal ASD symptoms, with the symptoms lacking scientific evidence.

If we were to repeat this study, we would modify the scale to include several classifications at once, such as categorizing videos as either useful or misleading first, then assess whether or not the video could be categorized as personal experience. Future research should take this into account when using the Sood et al. Scale.

4.7 Clinical call to action

The results showed a higher engagement in terms of views and comments on the videos classified as personal experience. This may suggest that the users on TikTok find the videos showcasing relatable content more interesting and/or entertaining. These videos also often included emotional music, trends, comedy and other forms of entertainment. Therefore, we argue that these videos are more likely to reach out to more users, compared to videos listing scientifically correct information about ASD symptoms. For useful videos to be more visible on social media platforms in the future, we argue that clinicians and other HCPs could benefit from participating in trends and other popular entertainment tools on social media to reach a wider audience. Simply “stating the facts” may not accumulate the same amount of engagement as personal experiences and trends would.

This study does not consider cultural-, gender-, and age differences. We have chosen to focus our attention and research on the general quality of diagnostic information on TikTok, regardless of the content creators’ differences and traits. Future research could look at the difference in content quality on TikTok uploaded by, e.g., men versus women, or teenagers versus adults. It would also be interesting for future research to look at the connection between the Covid-19 pandemic and the rise of ASD’s relevance and popularity on social media platforms.

5.0 Conclusion

This study found that 34% of the top 100 videos on TikTok under the hashtag #Autism were misleading, containing misinformation or information lacking scientific evidence about ASD. None of the videos were created or published by HCPs. Only 5% of the videos in this study were found to be useful. Lastly, this study found a clear pattern in popular ASD symptoms (A2, B4, and C) discussed on the application, suggesting that some symptoms are more relevant on social media than others. It is important for clinicians and other HCPs to be aware of the dissemination of misleading content about ASD on social media platforms.

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