# Weaving Autistic Voices on TikTok: Utilizing Co-Hashtag Networks for Netnography

Yihe Wang
ywan1125@ucsc.edu
University of California, Santa Cruz
Santa Cruz, CA, USA

Kathryn E. Ringland
kringlan@ucsc.edu
University of California, Santa Cruz
Santa Cruz, CA, USA

## ABSTRACT

While many autistic creators are active on TikTok, sharing content about autism and their daily lives, there is little research to capture the richness of these discourses. In this study, we propose to augment netnography with co-hashtag networks to gain a broader perspective of the online discourse among autistic people while depicting detailed contexts. We analyzed the use of hashtags in 3752 publicly available TikTok videos from 41 autistic creators and conducted an in-depth analysis of 55 of the scraped videos to explore the content and expression of autistic creators on TikTok. The results demonstrate the individuality and advocacy of autistic creators, highlighting their intersectional identities and engagement in various communities beyond the autism community. We emphasize technologies embracing diversity to prevent marginalization and empower children with autism diagnosis.

## CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in collaborative and social computing**.

## KEYWORDS

social media, autism, identity, netnography

## 1 INTRODUCTION AND RELATED WORK

Historically, technology research and design for autistic[1] populations has tended to focus on their functional limitations [32, 33] (i.e., medical model [23]). While these approaches can be helpful from a medical perspective, they neglect the needs beyond functionality, often to the detriment and harm of the autistic community they are

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[1]For consistency, we chose to utilize identity-first language (e.g., autistic individuals) in this paper. Studies have demonstrated that the autistic community, particularly in the United States where this study is based, prefers this language to advocate their identity [28].

attempting to help [32]. We argue that if we are concerned about the overall psychological well-being of the autistic population, we need to move beyond functional or neurodevelopmental standards or ideals, viewing disabilities through a social model [23]. Therefore, in this study, we aim to explore the broader life experiences of autistic individuals and identify potential research topics and design spaces around them.

A 2020 literature review showed that most technologies for use by disabled people are often created without the construction of knowledge with their target users [40], which perpetuates the "epistemic violence" from people in positions of power (e.g., neurotypical people) [40] and fails to rebalance power dynamics [32]. Therefore, the field of HCI has been promoting broader engagement of individuals with disabilities in the research process [34]. However, invasive, burdensome research methods, such as interviews, surveys, and in-lab experiments, can raise concerns, including "informant fatigue" [31] when frequently and repeatedly asked to share information, and "forced intimacy" [1] when asked to disclose deeply private matters.

Social media can serve as a source of information for supplements or pre-investigation to reduce unnecessary inquiries. However, a large body of social media study literature investigating autistic populations focused on caregivers' perspectives, including caregivers' help- and information-seeking behaviors on various social media sites (e.g., [5, 6, 9, 11]) and their considerations behind the disclosure of the stigmatized information related to their children [9]. When considering the use of social media by autistic people themselves, the academic conversation always revolves around their functional limitations, such as social interactions [38].

With a surge in popularity, TikTok, a short-video-based platform, now boasts over one billion users [2, 35] and gained particular traction among teenagers and young adults [36]. The platform has emerged as a notable venue for conversations surrounding mental health [3, 14], and its user-generated resources have improved mental health literacy [18, 24, 27]. This heated discussion also encompasses neurodivergence, which often refers to a number of identities such as autism, dyslexia, and Attention Deficit Hyperactivity Disorder (ADHD) [7]. A series of discussions investigates whether TikTok promotes the "pandemic" of ADHD in young people [17, 18] and the authenticity of the content [39]. This discussion around mental health also involves experimenting with a more humorous approach [30] to advocating, such as "Playful Advocacy" [15]. We believe that such massive engagement of neurodivergent people with TikTok, expressing themselves and sharing their lives, can provide valuable opportunities for researchers to probe into their thoughts and living experiences for shaping future technologies without further burdening these communities. However, there is a lack of clear methods for capturing this online content.

Netnography [20] was introduced as a relatively naturalistic method [19] that is rooted in computer-mediated communication [21], which involves observing and analyzing spontaneous data from online platforms [8], such as social media [21], with much less intrusion into the lives of research subjects [21]. It has been used by researchers who work with marginalized communities (e.g., [15, 16]). To leverage the benefits of computer-mediated communication, we propose a further methodology that uses co-hashtag networks to scaffold researchers in conducting netnography. Hashtag, a typical and widely used social media feature for indexing keywords, has now been expanded to ubiquitous use, such as movement and protest [10]. With a co-hashtag network (i.e., a graphical representation of the co-occurrence patterns of hashtags used in posts), researchers are able to gain a broader perspective of online discourses while following specific contexts and depicting details. The intention of this work is not to improve upon existing methods of constructing hashtag networks but rather to introduce a novel approach that captures online discourse by combining qualitative and quantitative data.

Our work is designed to contribute twofold: (1) We aim to highlight the broader life of autistic people beyond their autistic identities. (2) We seek to address the limitations of current techniques that fail to capture the richness of the online social media space. Our study challenges this issue by proposing an augmented methodology with greater descriptive power.

The rest of this paper is organized as follows. First, we outline our method, which covers iterative data collection, co-hashtag network construction, and in-depth analysis of critical videos. Next, we present the main themes identified, which demonstrate the individualities of autism, their advocacy initiatives, and how they express themselves through TikTok trends. Finally, we discuss the implications of our findings and identify potential avenues for future research.

## 2 METHOD

Our research utilized an iterative process of data collection and analysis, with the study divided into three phases. Given that the data used was publicly accessible during our investigation in November 2022, the study does not require IRB approval at our university in the United States.

### 2.1 Iterative Data Collection

We identified 42 autistic creators by using general autism-related keywords such as "autism", "autistic", and "actuallyautistic" as inputs, sorting the results by "all time" and "most liked," and manually confirming their video content talks about their own autistic experiences and their profile bios contained autistic. We used a scraper[2] to collect their most recent 100 videos, including the video URL, hashtags, and post text. If the number of videos the creators uploaded did not reach a hundred, we collected all their videos. Our scraper also collected whether creators self-reported themselves under 18 to the TikTok platform. The result shows that most of them (N=41) indicated they were above 18, suggesting that only one creator in our study may be underage, whose data was later excluded.

## 2.2 Co-Hashtag Network for Contextual Understanding

We built co-hashtag networks to gain a more comprehensive understanding of discussed topics among the creators. We logged the hashtags attached to each video, their frequency (the nodes and their weights), and the joint use of hashtags and their frequency (the edges and their weights). Finally, we used Gephi[3] to visualize the co-hashtag network using a force-directed layout. This layout method helped us identify clusters (i.e., nodes that are densely connected) and familiarize us with the context of the hashtags (see Figure 1).

### 2.3 Focused Analysis of TikTok Videos

Using the co-hashtag network, we iteratively labeled each hashtag and identified 7 main topics (intersectionality[4], comorbidity[5], advocacy, interest & passion, social interaction, self-love, and current affairs) and applied a critical case sampling approach [25] to select 55 videos from these topics. This technique involves selecting a limited number of the most representative cases in order to obtain the maximum amount of information. We conducted an inductive thematic analysis of the selected videos and summarized the themes that construct the finding session.

## 3 RESULTS

### 3.1 Illustrating Individuality in Autism

*3.1.1 Diversity of autistic experience.* Comorbidity is an important topic among autistic creators, with various related hashtags, as shown in Fig. 1, colored in green, interconnected with other aspects of people's lives. These include but are not limited to dysautonomia, chronic pain, Obsessive-Compulsive Disorder (OCD), anxiety, eating disorders, Irritable Bowel Syndrome (IBS), and Postural orthostatic tachycardia syndrome (POTS). It should be noted that the situation faced by each autistic creator differs. They also share personal experiences, including traumatic upbringing, consequential mental health issues (#mentalhealth was mentioned 102 times) as well as different levels of masking abilities[6] they have developed (#masking was mentioned 103 times).

*3.1.2 Lives beyond autism.* The diverse identities of our creators extend beyond their medical conditions and demonstrate the individuality of each person, highlighting that while autism is part of their lives, it does not encompass the entirety of their being. One creator even posted a Q&A reclaiming themselves by saying, *"I am annoying, not because of the autism, though. Mind you. I am just a bitch."* , prioritizing their own individuality over their diagnosis.

Our findings also provide strong support for further examining the intersectionality of neurodivergent groups with other forms of

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[2]The scraper we used is Apify. For more detailed information, please refer to Apify.com.

[3]Gephi is an open-source graph visualization platform. For detailed information, please refer to https://gephi.org/.
[4]Intersectionality recognizes the complex ways in which multiple social identities and systems of oppression (e.g., race, gender, sexuality, and socioeconomic status) intersect and interact to develop inclusive solutions.
[5]Autism comorbidity refers to the co-occurrence of additional conditions or disorders alongside autism [4].
[6]Masking is the suppression of natural autistic behaviors and the adoption of alternative behaviors, often due to societal stigma surrounding autism [26].
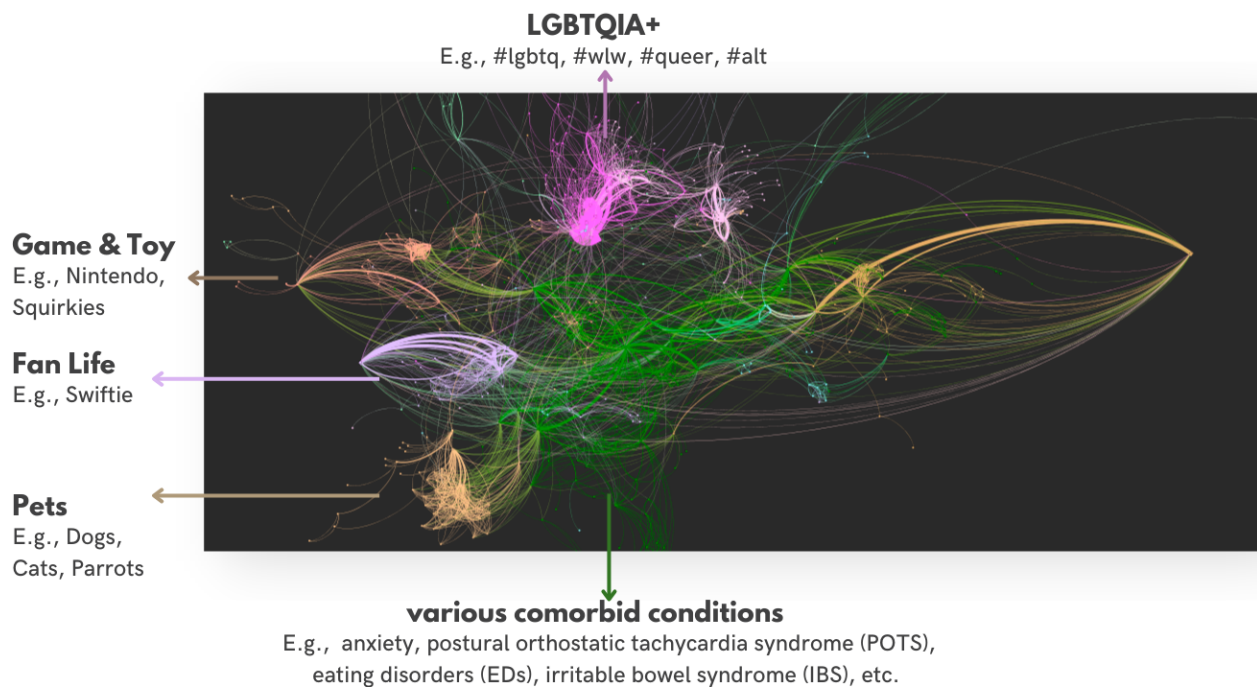
**Figure 1: Co-hashtag network generated through iterative analysis of hashtags used by creators with autism on TikTok, showing each node representing a hashtag and labeled by researchers during the iterative process, with colors distinguishing different label categories and connections between nodes representing their frequency of co-occurrence.**

marginalization [22, 32], including race (e.g., *#autizzy*[7] and *#autisticlatina*) and feminism (e.g., *#autisticwomen* was used 142 times). We also found that our creators showed a diverse range of sexual and gender identities[8], with eight identifying as LGBTQIA+. They used terms such as *#lgbtq*, *#wlw*[9], and *#queer* in their profile bios and videos to promote their content to the larger LGBTQIA+ community.

Our results demonstrate that the influence of maker culture [29] and "Play Advocacy" [15] extends beyond traditional domains (e.g., gameplay) and encompasses various forms of playful activities, such as fashion, makeup, artwork, and fan engagement. This has allowed them to learn from and connect with others who share similar interests, and engage with larger communities. In addition, fandom is another popular topic. Eight of our creators call themselves Swiftie[10], with *#taylorswift* mentioned 33 times along with other related hashtags such as *#taylorswiftmidnights*[11].

## 3.2 Creating Videos for Autism Advocacy

*3.2.1 Autism awareness: late diagnosis and childhood trauma.* Autistic creators are raising awareness about the negative impact of late diagnosis, with *#autismawareness* (used 420 times) and *#latediagnosedautistic* (used 323 times). One shared their personal experience

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[7]The term autizzy is considered a Black exclusive term that refers to a black autistic person.
[8]LGBTQIA+ an initialism that stands for lesbian, gay, bisexual, transgender, queer, intersex, and asexual
[9]Acronym of women-loving woman or women-loving women or similar phrases.
[10]Swiftie is slang for a fan of American singer, songwriter, and actress Taylor Swift.
[11]Midnights is an album by Taylor Swift, released on October 21, 2022.

of being late-diagnosed, describing feelings of distrust and powerlessness, saying *"She (the creator's mother) just didn't think I had it (autism). I was, again, 16, I can't drive myself to doctor's appointment."* Similarly, another expressed hopelessness by saying, *"When you're a kid, you don't see that (the end of the problems caused by autism and undiagnosis), or at least I didn't."* These creators emphasize the importance of early diagnosis in empowering children, informing parents about their needs, and rationalizing so-called "abnormal" behaviors. As one creator said, *"If I had known as a child, maybe my behaviors were explained, I had more accommodations, more resources, maybe I wouldn't have felt as broken growing up, and I would've had a happier, more stable childhood."* They also advocate for self-diagnosis to be recognized as a valid diagnosis, with *#selfdiagnosisisvalid* (used 14 times). Recent work in CSCW and HCI echoes this proposition and advocates self-diagnosis as a valid pathway to participation and research [37, 41].

*3.2.2 Call for acceptance: ableists should reflect.* With 212 videos tagged with *#autismacceptance*, creators are using TikTok to raise awareness about conscious and unconscious ableism [1, 12] (*#ableism* was mentioned 53 times) and its negative impact. Hashtags such as *#ableismisntcute*, *#ableistsuck*, *#ableistassnonsense*, and *#fuckableism* demonstrate the frustration and anger of creators facing discrimination and dehumanization. One called out to the public, *"Before commenting [...] 'you're making me so scared that I might be autistic,' stop and ask yourself, 'is this ableist?'"* They hope to raise awareness about the importance of empathy and understanding when interacting with autistic individuals.

### 3.2.3 Enhance accessibility: respecting diverse needs.
With 35 videos attached to *#accessibility*, creators share their struggles and experiences in navigating the world built with significant systemic barriers against them. Also, there are other used hashtags such as *#support*, *#disabilitysupport*, and *#specialneeds*. For example, one expresses their difficulty finding food at college that is both tasty and will not trigger their body's negative reactions[12]. Another performed the reactions of others upon learning of their autism diagnosis as if they were saying, *"I'd rather erase your identity than accommodate your needs."* This highlights the harsh reality that, on some occasions, people are not willing to accommodate the needs of individuals with invisible disabilities.

## 3.3 Leveraging TikTok Trend to Voice Themselves

### 3.3.1 Borrowing lines to reveal the heart.
One way that our creators express themselves is by borrowing lines or lyrics from popular songs or memes and incorporating them into their videos to express their emotions and ideas in a creative and engaging way. For instance, one played the song *Mastermind* by Taylor Swift while displaying the text *"Autistics, how are you doing after listening to Mastermind? That song is so us. My inner child is dying over here."* They try to use these background audios to stimulate the audience's emotions and communicate advocacy.

### 3.3.2 Interacting with their audience by asking questions.
Our autistic creators actively engage with their audience by asking questions, building a community of individuals with shared experiences and knowledge. They use their platform to spark discussions and reflections on important topics. Some creators seek to connect with their audience by asking questions, for example, starting with *"Does anyone else..."* to find people with similar experiences, or by asking *"Tell me if you know..."* to share knowledge on certain topics. Asking questions is also a way to draw attention and promote reflection. One creator who has POTS and uses a cane posted a video, questioning, *"what do I do when the building is on fire?"* The creator starts a conversation and brings public attention to the need for accessibility.

### 3.3.3 Storytelling by acting.
Our autistic creators explain their sensory experiences by anthropomorphizing their inner monologues and acting them out through multi-role playing. By embodying this technique, they are able to convey the intensity and complexity of their experiences in a relatable and understandable way. For example, one demonstrates the conversation between themselves and their sensory overload,

Sensory overload: *"Oh, have you noticed how itchy your legs are, though?"*

The creator: *"I didn't, but now I'm hyper-aware of it, so thank you."*

Sensory overload: *"No worries. All good, all good, all good. What we're talking about is itchy. The tag on the back of your shirt must be a pain."*

The creator: *"Look, don't make me..."*

Sensory overload: *"Oh, come off it. It's just a bit of fun."*

Similarly, our creators reproduce their interactions with others. For instance, one plays their parents, worried that he/she would party like crazy in college, and this is edited together with the creator's puzzled expression and the on-screen script, *"Me who gets sensory overload from the sound of lightbulbs."* These videos demonstrate occasions when they have to resign themselves to others' misunderstandings or misconceptions.

## 4 DISCUSSION AND CONCLUSION

Our study explores the lives of autistic people from a broader perspective by employing a mixed approach. Unlike traditional research methods, which typically focus on a single context, by combining qualitative and quantitative data collection and analysis, we capture the richness created by autistic creators. The results showed us the lives and identities that extend beyond autism and highlighted the voices of adult autistic individuals who have been underrepresented in academic research [33], showcasing their intersectional identities [22, 32] (e.g., race, gender, and socioeconomic status) and engagement in not only the autism community but also various others. Additionally, the results demonstrate the playfulness needs of autistic adults, including makeup, fandoms, and games. Through our study, we catch a glimpse of the complexity of the lives of autistic people. In the context of human-computer interaction, our findings underscore the importance of technologies that should help individuals embrace their diversity (e.g., individuality in autism) rather than imposing a "standard" ability. Mainstream ideals and pursuits of society in terms of externalizes, neurological development, culture, and thought can lead to marginalization (e.g., the exclusion and disregard of diverse needs) and questioning (for example, from conscious or unconscious ableism) of individuals who do not conform.

The remembrances of autistic adults about their childhood also emphasize the importance of empowering children in the diagnosis process to promote the mental well-being of autistic individuals. Also, previous studies point out that an increasing number of teenagers are turning to TikTok for self-diagnosis for ADHD [17, 18]. Although there are concerns about the accuracy of such content (one paper found that half of its limited sample was "misleading" [39]), the proliferation of the information points to a lack of capacity in the real world to accommodate diverse needs and the difficulties in getting trust and proper care without a diagnosis. Therefore, we propose that future technologies can find ways to help, firstly, make parents and children aware of their needs and provide them with the necessary resources to navigate the diagnosis process. Secondly, provide children with age-appropriate information to help them initiate self-diagnosis and involve them in decision-making processes. Thirdly, establish trustful and efficient communication between the child and parents regarding the diagnosis, such as creating an open and non-judgmental environment for children to share their thoughts and feelings. Additionally, providing parents with support and guidance on how to communicate with their child about the diagnosis.

The study demonstrates the potential of hashtag networks in aiding qualitative researchers to gain broader perspectives of online discourse. Further research could explore more hashtag analysis

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[12]Autistic individuals may experience great discomfort when eating certain foods due to their sensory sensitivity [13].

methods to achieve a deeper understanding. We also acknowledge the limitations of our work-in-progress and the potential for incomplete representation. To enhance the reliability of the results, the subsequent investigation will expand the sample size to include a broader range of creators and videos for in-depth analysis.

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