

**TikTok as Algorithmically Mediated Biographical Illumination:
Autism, Self-Discovery, and Platformed Diagnosis on #autistok**

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BIOGRAPHICAL ILLUMINATION & PLATFORMED DIAGNOSIS (PRE-PRINT)**Abstract**

Scholarship in the sociology of medicine has tended to characterize diagnosis as disruptive to one's self-concept. This categorization, though, requires reconsideration in light of public conversations about mental health and community building around neurocognitive conditions, particularly among youth online. Drawing upon Tan's (2018) notion of "biographical illumination" (BI), which describes how medical frameworks can enrich personal biographies, we explored the shifting nature of BI through the case of TikTok. Combining quantitative and qualitative methods, we argue that TikTok serves as a space to discuss diagnosis and refine one's sense of self as a result of diagnosis. However, such personal transformation is inseparable from the app's affordances, or what we term "algorithmically mediated biographical illumination." BI shapes TikTok as a platform, and TikTok informs BI as a psychosocial process, leading to what we call "platformed diagnosis." These findings have broader critical applications for the study of algorithms, disability, and digital platforms.

Keywords: algorithms, autism, biopolitics, diagnosis, disability, identity, mental health, platform affordances, social media, TikTok

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Introduction

Over the course of 2021–2022, a slate of news articles appeared speculating about a link between surging usage of ByteDance-owned social media app TikTok and an uptick in mental health-related diagnoses among young US users since the start of the COVID-19 pandemic.¹ Some pieces instigated a moral panic by suggesting that those without neurocognitive conditions might suddenly develop symptoms or suspect a diagnosis based on viewing related videos due to the power of algorithmic suggestion (Caron, 2022). Other articles centered on young people discussing the unique multimodality of TikTok for consuming, circulating, and creating media about mental health and disability from a first-person perspective (Engel, 2022). Autism emerged as a particular focus, with youth on the spectrum speaking about the value of TikTok for self-advocacy and awareness (Tucker, 2021), and a few voicing their concern about the app “trivializing” autism by making the disability “trend” (Austen, 2022).² For its part, TikTok distanced itself from implication as a diagnostic tool and ByteDance representatives encouraged users to instead seek “professional medical advice” (Caron, 2022).

Theories of medicalization, selfhood, and biosociality (Conrad & Barker, 2010; Rabinow, 1996) offer important insights into how diagnosis and disability identity are collectively and individually negotiated offline and online through platforms like TikTok. Early scholarship in the sociology of health and illness characterized being diagnosed with conditions such as autism and attention-deficit/hyperactivity disorder (ADHD) as a “loss of self” (Charmaz, 1983a, 1991) or disruptive to one’s self-concept (i.e., “biographical disruption”) (Bury, 1982). In the era of modern biotechnology, other work has explored how knowledge of one’s genetics increasingly

¹ There is debate regarding classification of TikTok as “social media,” as opposed to an “entertainment platform,” owing to its emphasis on content creation (Newport, 2022).

² We use “autistic” and “on the (autism) spectrum” interchangeably, employing language preferred by community members.

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shapes the ways that people imagine themselves and their relations to others (Hacking, 1996).

The unclear genetic basis of autism, however, complicates such a forging of social relationships around the condition on a biological level (Singh, 2016).

More recently, Tan's (2018) ethnography of autistic individuals who learned of their diagnosis later in life found that explanations provided by medical frameworks enriched their personal biographies rather than destabilizing them, a phenomenon that Tan termed "biographical illumination." Tan's work, though, did not explore how new media might complicate one's identity as disabled (Bitman, 2022), nor how biographical illumination may occur among youth spending time on platforms (e.g., YouTube, Twitter) where mental health conversations are increasingly common (Rideout & Fox, 2018). We set out to explore the potentially mediated nature of biographical illumination through the case of individuals who discuss their personal relationships to autism diagnosis on TikTok as content creators and/or commenters. The US Centers for Disease Control estimates that roughly 2% of the adult population is autistic, generally on par with children (Dietz et al., 2020). Autistic people are highly heterogeneous, presenting with a range of social, communicative, cognitive, and intellectual differences. As a group, though, they are rarely considered experts on autism, with society lending more credence to parents and clinicians (Yergeau, 2018; Ymous et al., 2020). TikTok offers diverse youth on the spectrum a novel opportunity to generate multimedia commentary with a low barrier to entry.

Combining qualitative and quantitative methods, we found that while TikTok serves as a forum to discuss autism diagnosis and space to refine one's sense of self resulting from diagnosis, such personal transformation cannot be isolated from the politics, design, and culture of the app, or what we term "algorithmically mediated biographical illumination." Sociotechnical

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co-construction occurs, whereby biographical illumination shapes TikTok as a platform, and TikTok informs biographical illumination as a psychosocial process, leading to what we call “platformed diagnosis.” These findings have wider implications for the intersection of mental health, critical algorithm studies, and platform affordances. As a team of neurotypical and neurodivergent researchers, we are also invested in applying these findings to support the well-being of disabled youth. Before detailing our results, we review the role of TikTok’s algorithm in identity expression, legacies of autistic community building online, and the biopolitics of autism diagnosis.³

Literature Review

TikTok, Algorithmic Identity, and Self-Discovery

Social media users regularly make assumptions about how proprietary algorithms such as TikTok’s work, considering the opacity of their inner workings (DeVito et al., 2017; Klug et al., 2021). Regardless of how algorithms function, people’s perceptions of them affect how they act and see themselves (Taylor & Choi, 2022). TikTok in particular may signal a shift in social media platforms from engendering the “networked self” (or a selfhood shaped by dynamic online social networks; Papacharissi, 2011) to the “algorithmized self” (or a selfhood derived from reflexive engagement with versions of oneself, mediated by personalized algorithms; Bhandari & Bimo, 2022). Personalized algorithmic recommendations are highly visible within the TikTok mobile experience; the app’s “For You” launch page, colloquially known as “FYP,” features suggested videos from those whom the user does not already follow. The FYP may prompt self-

³ Though we have followed the traditional format of a research article as a form of access (e.g., signposting findings in the text), we also note that neurotypicality pervades many aspects of academia, including social scientific publishing norms (e.g., division of findings and discussion) (Yergeau, 2018).

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discovery and reflection for users about their algorithmic identity (Cheney-Lippold, 2011) as both viewers and creators (DeVito, 2022; Lee et al., 2022).

TikTok's lack of transparency regarding its generation of the algorithmized self can have specific effects on young people and members of marginalized groups (Karizat et al., 2021). Much of adolescent social life takes place on social media. TikTok fills developmental needs for identity experimentation, creative presentation, and self-discovery (Bossen & Kottasz, 2020). Those with socially marginalized identities (e.g., based on race, ethnicity, disability status, LGBTQ+ identity) may perceive their expressions of identity as technologically suppressed on digital platforms via algorithmic exclusion (Simpson & Semaan, 2021) and accordingly alter their self-presentations (Choi et al., 2022; DeVito, 2022). As such, algorithmic systems and the categories of meaning that they construct can have a disproportionate impact on how marginalized users manage their digital selves (Peterson-Salahuddin, in press; Simpson et al., 2022).

Disability Identity and Autistic Community Online

New media have long been vital in the development of autistic people's individual and collective identities (Pinchevski & Peters, 2016), even though autism may be more or less part of their overall self-concept (Davis, 2013). As an identity category, autism is amorphous because its boundaries and definitions have shifted over time relative to evolving diagnostic tools like the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*; for example, the removal of "Asperger's Disorder" as a standalone diagnosis in the *DSM-5* (Silberman, 2015).⁴ Autism can be thought of as a "neuroidentity," or an identification based on having a brain that differs from that which is considered neurotypical (Bagatell, 2007). Empirical research has shown that

⁴ Another dimension of autism diagnosis being discussed on TikTok is the fraught legacy of Hans Asperger (Eloise, 2020).

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developing a positive autistic identity is related to higher self-esteem and improved mental health among adolescents and adults on the spectrum (e.g., Cooper et al., 2017).

Digital platforms enable autistic people to generate counternarratives (Guberman, in press) that challenge dehumanizing, deficit-based framings of autism (Yergeau, 2018). The historical importance of social networking (e.g., listservs) for autistic people is connected to certain affordances (i.e., where social and technical potentialities meet; Davis, 2020) (Page et al., 2022). For instance, autistic adolescents report that social media privacy settings relieve public pressure to conceal or “mask” stigmatized markers of being on the spectrum (Jedrzejewska & Dewey, 2022). Social media offers interpersonal connections that may be harder to forge offline (Gillespie-Smith et al., 2021), though platforms also pose safety risks (Alper, 2023; Rocheleau & Chiasson, 2022). The proliferation of online autism communities and modes of expression (e.g., autism-related hashtags) (Egner, 2022) points to a need for platform-specific studies that attend to age-related differences (Koteyko et al., 2022), such as with TikTok.

Autism and the Biopolitics of Diagnosis

Though the online social sphere has facilitated new forms of connection, it has also engendered debate about membership in “the autism community” (Parsloe & Holton, 2018). The biopolitical nature of autism diagnosis is one topic of contention (Eyal et al., 2010). Autism diagnostic criteria has historically favored cisgender White boys and men, and excluded those who are BIPOC, women/girls, and gender minority (Jack, 2014).⁵ Health inequalities exist at the intersections of race, ethnicity, class, and geography in accessing diagnostic services (Liu et al., 2023). US adults who grew up prior to the 1990s—an era marked by passage of the Americans with Disabilities Act, introduction of the Individuals with Disabilities Education Act, and

⁵ The abbreviation BIPOC (Black, Indigenous, People of Color) originates in Canada and speaks to racial hierarchies in this context, though it has gained traction in the US and elsewhere.

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updated publication of the *DSM-IV*—tend to receive diagnoses later in life, if at all (Lai & Baron-Cohen, 2015). Among children, parents may choose to conceal diagnosis, whereby a child learns of being autistic at an older age (Smith et al, 2018). The value of a clinical diagnosis is an additionally controversial topic; some autistic people assert that self-diagnoses (i.e., personal determinations about being on the spectrum) are as valid as external evaluations and may provide additional benefits. Self-diagnosis can be the end point or a first step in obtaining an official clinical diagnosis (Sarrett, 2016).

Biographical illumination is an alternative approach to prevailing diagnosis discourse (Tan, 2018). It is a sense-making process whereby individuals review their life history in light of a suspected or confirmed diagnosis and, as a result, undergo a transformation of self-concept. Biographical illumination inverts the negative characterization of diagnosis by reconstructing one's life story to understand the root of individual challenges (Huang et al., in press). Through biographical illumination, autistic identity exists not completely outside medical frameworks but is loosely structured by them. Interestingly, the language of illumination is evident in popular discussions of TikTok and neurodivergent diagnoses (e.g., “After years of thinking something’s not quite right, finding a [diagnostic] label can feel transformative—even if it’s a TikTok video that finally illuminates the possibility”) (Krouse, 2022). Considering the role that social media algorithms play in self-construction, the novel affordances of TikTok for autistic community building, and the heated discussions surrounding autism diagnosis, we posed the following research question: How do autistic TikTok creators express their relationship to autism diagnosis through their video content, and how do commenters discuss autism diagnoses in response to the videos of autistic TikTokers?

Methods

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We received IRB approval from [anonymized] to conduct this work, after which a new TikTok account was created to view posts. Data collection was approached initially through an exploratory lens by conducting TikTok searches for common autism hashtags (e.g., #actuallyautistic) and those specific to TikTok (e.g., #autistok) on other social media platforms. Through these means, we discovered an English-language Instagram account that reposted “actually autistic” (i.e., created by autistic instead of non-autistic people) TikTok posts discussing autism-related topics. Owing to the difficulty of studying TikTok in a methodologically straightforward manner (Kanthawala et al., 2022),⁶ we created a TikTok data set based on the Instagram corpus for several reasons: the account’s representative diversity (i.e., a significant portion of posts from LGBTQ+ and BIPOC autistic creators appearing to be under the age of 30); a large follower count (nearly 100K as of early 2023); and an active comments section. A member of our team contacted the Instagram account owner through direct message to better understand their selection criteria. They were unresponsive, however, and as such, we refrain from publishing their username.

We used a Python scraper to pull data (e.g., captions, URLs) from 1093 Instagram posts, dating from September 2020 to June 2022. As their captions included the TikTok poster’s username, we reconstructed a data corpus in Summer and Fall 2022 to locate the originals. We eliminated those that were duplicates, deleted by TikTok users, or not TikTok posts (e.g., from Instagram), leaving 639 posts. Following recommended methodologies for studying visual social media (Highfield & Leaver, 2016), we used a combination of paid and freely available automated tools and manual data entry to collect relevant qualitative and quantitative information. We exported all videos and up to 100 comments on each post. With respect to

⁶ In 2023, TikTok announced the development of a Research API, which may eliminate some methodological barriers but also add new challenges.

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ethical online research conduct, all data were stored on a private institutional Google Drive account. To maintain anonymity, we do not include identifiable information, instead referring to specific videos by their designated number in our dataset. We quote directly, though, from comments and captions, and employ preferred identity labels (e.g., pronouns) indicated in user profiles.⁷

To address our research question, we set inclusion and exclusion criteria for content reflecting personal relationships to autism as a diagnosis. For comments and the original post (i.e., video, profile description, hashtags, caption, video description, on-screen text), material was included if the following was referenced: 1) explicit diagnosis (e.g., “undiagnosed,” “self dx”), 2) official diagnosis (e.g., “referral,” “eval,” “doctor”), or 3) self-diagnosis (e.g., “realization,” “signs”). Comments were excluded if they consisted of a non-autistic person talking about another’s autism diagnosis (e.g., a relative). We worked through the data by combining quantitative descriptive analysis (e.g., number of comments generated by posts) alongside qualitative reflexive thematic analysis (Braun & Clarke, 2022), which allowed for patterns of meaning to emerge from the data set while recognizing researchers’ active roles in knowledge production.

With respect to researcher positionality, our project centered autistic meaning making (Rauchberg, 2022a), in line with recent ethical shifts in autism research (Pellicano & Stears, 2011) and work with disabled populations in human-computer interaction (Ymous et al., 2020). Members of our team have varying relationships to autism diagnosis; one identifies as autistic,

⁷ For good measure, we tested out our direct quotations and did not find TikTok search to lead to re-identification in almost every case. For the one exception, the TikToker posting the video has nearly 800,000 followers as of May 2023 and is a public figure who identifies as autistic, so we believe that re-identification in our paper would not cause considerable harm. We have also chosen not to edit typos in quoted comments unless they obstructed the poster’s intended meaning.

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and two others as neurodivergent. In addition to domain expertise in social media, lived experiences of disability were assets. As an example of reflexivity, team members discussed their own diagnoses of neurological difference as part of data analysis. We employed grounded theory (Glaser & Strauss, 1967) and an iterative approach to coding (Strauss & Corbin, 1998). Using inductive and deductive analyses (Charmaz, 1983b), we collectively generated themes and grouped them under categories while reflecting on the concept of biographical illumination to find commonalities as well as divergences in our data set.

Findings

Eighty-nine TikTok posts (~14% of posts) met inclusion criteria, in addition to 847 user comments (~4% of comments). Posts were dated from March 2020 to April 2022, and received an average of 12,231 likes and 154 comments. Videos were uploaded by 69 unique users and comments posted by 833 unique users. The average poster follower count was approximately 170K (range = 131–2.6M). Five-hundred and twenty-nine comments were associated with posts in the dataset (from 62 unique videos) and 318 were associated with posts not in the dataset (from 161 unique videos), illustrating the widespread nature of diagnosis discourse on autistic TikTok. A total of 432 unique hashtags were added to original posts, the most frequent being #actuallyautistic ($n = 42$), #autism ($n = 34$), and #autisttok ($n = 33$). Overall, the biographical illumination provided by diagnosis of which Tan (2018) writes is present in the data (what we call “the explanatory self”), but so too are identifications with autism without an official diagnosis (“the liminal self”) and relationships to autism diagnosis that are inseparable from the very platform through which they are articulated (“the mediated self”).

The Explanatory Self

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Though autism provided partial explanations for the past and present biographies of autistic TikTokers, the need to explain themselves to others following diagnosis disrupted the full integration of these individuals' conditions into their selfhood.

Reflection and Introspection in Response to Diagnosis

Autistic TikTokers conveyed a range of emotional and affective reactions to diagnosis. Some were more positive, including relief (e.g., “I was diagnosed in January. Legit, the most relieving day in my life. ♡”), gratitude (e.g., “When I was told I was autistic I was terrified- now I see it as the greatest gift in the whole world ♡”), and clarity (e.g., “At 18 finding out I’m diagnosed autistic, feeling awkward but better because now i know why I feel like an alien”). For others, sentiments were mixed, encompassing confusion (e.g., “I was diagnosed at 33. I’m now 34. Life makes soooo much more sense now, and less at the same time.....”) and grief (e.g., “I just got diagnosed at 21 it’s relieving but also overwhelming. I feel like all the bad things in my life could have been different if I knew”).

Emotions were bound up with the life stage at which TikTokers received their diagnosis. They used temporal identity signifiers of diagnosis status in their profile descriptions, hashtags, usernames, and comments (e.g., #latediagnosedautistic; “pre-diagnosed”). Commentors regularly shared the age at which their diagnosis occurred (e.g., “I’m really lucky I was diagnosed at 10”), while several referred to the instability of diagnosis over their lifetime (e.g., “I got diagnosed when I was like 12 but the diagnosis was lost because I got bumped around from group homes to foster homes so often.”). The “masking” of autistic traits, especially among girls, also delayed diagnosis. In Video 629, for example, a Latina autistic woman lip syncs to audio saying “Oops! I accidentally created a false reality,” with superimposed text reading, “When you hide your autism so well that you don’t get diagnosed until your mid 20’s.”

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Childhood—which may not have been too far in the past for teen and young adult TikTok users—was a particular focus of retrospection. Diagnosis, they relayed, led to a reassessment of their youth as an undiagnosed person (e.g., “I was so oblivious to how much I had actually been bullied throughout my life until I got diagnosed.”). For instance, in Video 383, a White autistic person lip-syncs to audio spoken between two characters (whom she plays) with on-screen text reading “me as a kid not understanding why I felt so different and alone. me now finally diagnosed with autism and realizing I’m not alone at all.” Autistic TikTok users also mapped existing traits and preferences onto autism due to their diagnosis (e.g., “Something interesting I’ve noticed after being diagnosed with autism later in life is that what I thought were pet peeves are actually sensory issues”).

Reactions to Diagnosis Disclosure

Having a diagnosis may have legitimized autistic TikTokers ways of being in the world, but they also detailed contending with discrimination. Many complained about having their diagnosis questioned by neurotypical people, particularly those closest to them (e.g., “My bestfriend told me I didn’t seem like I had it the day after I got diagnosed and showed him proof.”). Sometimes these remarks veered into microaggressions and ableism (e.g., “I just got Dx and ppl have consistently told me sorry like it’s a bad thing when really it was a relief”; “When I got diagnosed, nothing changed. I thought I would use it in job applications. That was a big huge mistake 😞”). TikTokers also pointed to support from some but not others following diagnosis. In Video 669, a White autistic woman roleplays characters’ responses to her diagnosis. Her friends and family offer acceptance, while mental health professionals, strangers, and educational service providers demonstrate a lack of understanding. Varying reactions to diagnosis often did not align with TikTokers’ own views, leading them to discuss this discrepancy on the app.

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The Liminal Self

For TikTok users who did not have an autism diagnosis, yet expressed some kinship with the experiences of autistic individuals, the liminal status of their relationships to diagnosis led to more tenuous articulations of the self.

Barriers to Official Diagnosis

Many TikTokers discussed barriers in obtaining an official diagnosis. This included material barriers to medical care (e.g., “I’ve tried getting a diagnosis, but there is nobody in my small town that diagnoses adults.”). Negative experiences with healthcare providers placed roadblocks on a path towards diagnosis (e.g., “My doctor took one look at me and said ‘you’re not autistic’. Wouldn’t even talk about an eval when i brought it up.”).⁸ Young TikTokers also expressed annoyance and anger towards ostensibly neurotypical caregivers who they perceived as gatekeepers of diagnostic services (e.g., “my parents refuse to get me diagnosed even though [two] previous therapist say I am on the spectrum”). Besides these material and interpersonal obstacles, TikTokers also discussed systemic biases related to gender, race, and culture (“The diagnosis for Autism was literally built around cis white males, if you ain’t, they’ll ignore ya”; “diagnosis and accommodations when ur white but a ‘problem child’ when black 😞”).

Debates over Self-Diagnosis

Discussion of these individual and institutional barriers provided insight into why some TikTokers turned to self-diagnosis. They drew connections between marginalization and self-diagnosis (e.g., “hey, do you believe self diagnosis is valid? I cant get diagnosed cuz I’m poor and trans.”). Users found support among those asserting the validity of self-diagnosis (e.g., “somebody who’s self diagnosed doesn’t make your professional diagnosis less legitimate.”) and

⁸ Poor interactions with clinicians were not universal (e.g., “I have an autistic therapist who helped me realize I was autistic. It has been the best experience.”).

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the instrumental role of self-diagnosis as a diagnostic precursor (e.g., “I get so much shit about being self diagnosed when it’s literally just the phase in my life before professional diagnosis”). Some expressed a preference for self-diagnosis over formal routes for reasons including fear of discrimination (e.g., “If I get a dx I’ll never be able to be a foster parent”) and psychological impacts (e.g., “An assessment for me I know will just bring more trauma. I’m very happy being a self dx autistic. 😊”). Others conveyed ambivalence towards outcomes of the diagnostic process (e.g., “For me a formal diagnosis wouldn’t change anything”). Stigma surrounding self-diagnosis was also discussed, be it internalized by TikTokers (“I’m also on the spectrum but [...] I don’t like it when people self diagnose themselves any disorder/illness”) or generated by them (“Your self diagnosis is not valid”). Some also stated personal preferences for official diagnosis due to worries about misdiagnosis (e.g., “I’m afraid to self diagnose cause what if I’m wrong :(”).

Negotiating Diagnostic Boundaries

Such talk of misdiagnosis comprised part of a larger discussion on TikTok around similarities and differences between autism and other conditions. Comments on “actually autistic” videos were filled with those who saw parallels between being on the spectrum and other disabilities, especially ADHD (e.g., “can people with ADHD relate to people with autism? I relate to a lot of your content but I was never diagnosed with autism so I’m just wondering.”). Some TikTokers with ADHD questioned whether they had the wrong diagnosis or qualified for an additional diagnosis based on the relatability of autistic TikTok creators’ content (e.g., “I’m diagnosed ADHD but I experience this so much, it’s so powerful, could this be ADHD too? Or maybe I’m misdiagnosed 😊”). Other TikTokers preached caution around collapsing diagnostic categories. In Video 177, a Latine autistic person speaks directly to the camera from inside their

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car with the caption of “are ADHD and Autism really that similar? or do you just have both?”—a duality reflected in the blended #audhd hashtag used by a handful of creators in the dataset.

The Mediated Self

Thus far, we have focused on how TikTokers personally discussed autism diagnosis. We now turn to how the technical, communicative, and social affordances of the platform (Bucher & Helmond, 2017; Zulli & Zulli, 2022) played a role in constructing autistic agency and selfhood. While content illuminating the liminal self and the explanatory self was focused on experiences that occurred outside the platform, other content explored how personal relationships to autism diagnosis were facilitated by the Internet and specifically TikTok.

Education and Learning about Diagnosis on TikTok

TikTokers provided and sought out information about autism diagnosis, as well as posed questions about diagnosis to generate conversation. Creators solicited feedback from and engaged in dialogue with the autistic TikTok community regarding diagnosis. In Video 355, for example, a Latine autistic person tells their viewers (via on-screen text), “I want to hear from others, have you disclosed your diagnosis in the past? how and what happened?” TikTokers also used video comments sections to seek advice about obtaining a diagnosis (e.g., “If you can’t afford an official diagnosis (like me) do you know of any online resources that could maybe lend a hand in self diagnosis?”).

Besides encouraging dialogue, autistic TikTokers produced educational outreach material about diagnosis. In Video 120, as a reply to a comment left on another video by a user claiming their autism was “reversed,” a Latine autistic person dances while on-screen text reads, “Autism doesn’t go away. It is possible you had a misdiagnosis.” Other videos chronicled the diagnosis process. Video 397 depicts a White autistic woman explaining her journey to being diagnosed

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with autism through captions and acting out the steps. Commenters also offered resources for peers considering diagnosis (e.g., “I, an afab [assigned female at birth] non-binary person, just got diagnosed at 26. The book *Divergent Mind* has been so incredible and eye opening.”)

Several users discussed the instructional impact of this information. Some claimed to have considered getting diagnosed in response to autistic experiences shared on TikTok (e.g., “Idk if this makes you feel better, but I just found your channel and it’s giving me the confidence to seek out an autism diagnosis :) 🤔🤔🤔”). Others, having received a diagnosis, pointed to the videos of autistic TikTokers as helpful in navigating the process (e.g., “I love your videos so much! I’ve recently been diagnosed with ASD after 17 years of masking and being dismissed, and they are so informative! ❤️ Fab! ❤️”). Creators and commenters also reflected on how other social media platforms predating TikTok had played a similar role (e.g., “thank you tumblr and Pinterest for educating me bc my psychs did NOTHING.”)

Role of TikTok in Relationship to Diagnosis

Though TikTok shares the expressive potential of other communication technologies (e.g., emoji), the app’s design and architecture present unique opportunities as well as potential drawbacks. Commenters regularly speculated about whether TikTok’s personalized recommendation algorithm can diagnose a person as autistic (e.g., “I feel like the algorithm just diagnosed me”). This elicited feelings of anxiety for some, as if the app and its data collection practices had transgressed users’ personal psychological space (e.g., “🤖 when you realize this came on your fyp too accurately and you might be undiagnosed 😬”). Some framed the app as one of several social influences in their self-discovery (e.g., “I legit found out through tiktok and by my sister I was autistic”).

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The stylistic cultures of communication, expression, and play on TikTok were integral to how creators and commenters conveyed their personal relationships to autism diagnosis. For instance, a White autistic woman in Video 360 voiced how she felt before and after her diagnosis, playing upbeat music and using colorful lighting filters with the caption, “Let’s vibe with our diagnoses! 😊❤️.” Humor and sarcasm were also employed. Besides role playing, some creators personified “my undiagnosed autism” as a character when acting out scenarios in videos, such as in Video 522, for which the on-screen text reads, “Relative: ‘Don’t do that it makes you look autistic.’ My undiagnosed autism: ‘So uh... who’s going to tell her?’” Lastly, the comments section on several TikTok videos afforded comradery and commiseration among those at various points in the autism diagnosis process, akin to a “waiting room,” though one likely warmer and more supportive than in their physical lives (e.g., “i have a follow up appointment to double check i’m autistic on the 6th of feb... wish me luck!”).

Discussion

In our mixed-methods study of how personal relationships to autism diagnosis manifest on and through TikTok, we find that existing medical frameworks can illuminate the self (i.e., the explanatory self), yet they may also generate instability in one’s life story (i.e., the liminal self). Moreover, this inward focus is impossible to fully separate from the Internet as socially networked and algorithmically shaped (i.e., the mediated self). TikTok is a space for those with diagnosis, without diagnosis, and for what we term “platformed diagnosis,” which has significant implications for how computer-mediated communication informs mental health and well-being, especially among young people. These findings generate several areas for reflection, including the nature of biographical illumination as algorithmic; how medical diagnosis and diagnostic

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expertise are mediated by digital and social media platforms; and the sociotechnical construction of neurodivergence among youth online.

Biographical Illumination as Algorithmic

Our findings illustrate the utility and limits of biographical illumination as a concept for describing how personal biography and social relationships can be enriched by diagnosis. We find that social media engenders biographical illumination on a communal scale, rather than solely on the level of the individual, as Tan (2018) conceptualized. Our study builds upon work in algorithmic identity, marginality, and data surveillance (Peterson-Salahuddin, in press; Simpson & Semaan, 2021) by demonstrating how self-concept around diagnosis is developed in a circular manner on TikTok. This can be seen in users' peripheral access to online autistic communities through seemingly personalized algorithmic recommendations. The TikTok "For You" page reflects an algorithmic identity to the individual user constructed from their trace data. Algorithmically mediated biographical illumination thus highlights how algorithms can be sense-making tools for identity work, but ones with questionable predictive power (i.e., the FYP "outing" a person as autistic, or alternatively suggesting that they might be). Though algorithmic identity may not always be aligned with how one views themselves, our work illustrates that TikTok has nevertheless played an active role in users finding "#actuallyautistic" community.

The converging and overlapping conceptualizations of self that we identify highlight the algorithmic nature of biographical illumination. In terms of the explanatory self, concordant with Tan's findings, autistic TikTokers expressed that having an autism diagnosis added new dimensions to their sense of self. However, the benefits of illumination were tempered by stigmatizing reactions from others. Tan's study involved adults aged 22–65 who had obtained an official diagnosis from a medical provider. Their selfhood was less liminal than those without

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such “biocertification” (Samuels, 2014), whereas our sample included those identifying with autism who did not have a firm diagnosis. Our study also included far younger individuals, whose identities are already fluid online (Davis, 2012). And with respect to the mediated self, mass media played some role in biographical illumination among those that Tan studied; for example, becoming more aware of autism through books and magazines. However, none of those respondents discussed digital platforms as dynamic sites for information gathering, social connection, and emotional support. Algorithmically mediated biographical illumination describes how the personal explanations that medical frameworks potentially provide are increasingly mediated by algorithms.

Platformed Diagnosis

Our study additionally demonstrates how TikTok is part of an assemblage of formal and informal diagnostic technologies with which young people interact, including the *DSM-5* and “Are You Autistic?” online quizzes that comprise the “autism industrial complex” (Broderick, 2022; McGuire, 2016). Though concerns have been raised regarding medical misinformation about mental health circulating on TikTok (e.g., Yeung et al., 2022), autistic creators also help move information about diagnosis outside the realm of the biomedical. Through video testimony, narrative accounts, and visual documentation, they actively engage in what Fullagar and colleagues (2017) term “therapeutic publics.” This study sheds light on the sociotechnical construction of therapeutic publics by revealing a complex relationship between medical gatekeepers, autistic individuals, and social media algorithms in defining what it means to be autistic. Borrowing from work in science and technology studies on the political implications of artificial intelligence (AI) diagnostic tools (Semel, 2022), as well as the medicalization of

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everyday life (Zola, 1972), we term this phenomenon “platformed diagnosis,” as the platform and diagnosis are mutually constitutive.

Platformed diagnosis, however, raises bioethical questions and concerns over AI ethics. TikTokers who did not seek diagnosis may be targeted for algorithmic pseudo-diagnosis. Users might perceive the platform to be an epistemic authority on diagnosis, or what Avella (in press) describes as “designating a diagnostic gaze to a charismatic algorithm.” TikTok’s algorithmic recommendations are subject to users’ cognitive biases that FYP suggestions are more meaningful than they are, akin to “personalized” predictions of a horoscope (i.e., the “Barnum effect”). Popular press articles, for instance, offer advice for “what to do if you suspect the algo’s got you figured out” as neurodivergent (Krouse, 2022). In addition, algorithmic surveillance (e.g., suggested advertisements) can have a material impact on real-world health decisions (Gaeta, 2023), including pursuing a formal diagnosis. In addition to social media algorithms, AI is bound up with diagnosis in other ethically questionable ways (Nagy, in press). Algorithmic autism screening, for instance—pitched as a lower cost, low resource, and more “accessible” option—may exacerbate racial and ethnic discrimination in healthcare (Keyes, 2020).

Sociotechnical Construction of Neurodivergence Online

Finally, our findings suggest that neuroidentity is being socially and technically constituted through TikTok in multifaceted ways, reflecting the complex cultures of authenticity on the platform (Barta & Andalbi, 2021) and among disabled people online (Bitman, 2022). Self-diagnosis may be more validated in the TikTok autism community than in groups formed around other diagnostic categories. Though autism was our primary focus, clinical research suggests common co-occurrence with ADHD (Lai et al., 2019). Culturally, autism rights activist Sinclair (2005) has described those who are not autistic but have similar social and communicative

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differences in an extended familial sense, or as autism “cousins.” Outside of these overlaps, neurodivergent conditions also gain associations by virtue of TikTok suggesting autism videos to those watching ones about ADHD and vice versa (Krouse, 2022), and as such, creating an algorithmic interpretation of neurodiversity.⁹

The platform vernaculars (Gibbs et al., 2015) of TikTok allow for creative and diverse articulations of autistic culture, particularly among youth. Neurodiversity-affirming content creation is a form of crip technoscience (Hamraie & Fritsch, 2019) enabling new agentic styles of self-expression and relationality beyond cure. Through the lens of crip theory, which examines sites of resistance and reclamation at the supposed margins of identity (McRuer, 2006; Kafer, 2013), the goofy and silly vernacular of TikTok lends itself to a queering of diagnosis by making it playful and performative. Emoji also serve as paratextual discourse around the emotional complexity of diagnosis and as an access technology for autistic people by indicating tone. The front facing smartphone camera view of most TikTok videos affords more “intimate reconfigurations” (Suchman, 2007; Xiao et al., 2020) of autism discourse and self-advocacy online. The visibility of historically marginalized BIPOC and LGBTQ+ autistic creators on TikTok may also lead users from these groups to better locate appropriate resources, though continued work is needed to explore this empirically.

Conclusion

With respect to study limitations, we cannot determine the curation strategy employed by the owner of the sourced Instagram account without being in contact. Given prior evidence of the suppression of disabled creators’ content on TikTok via “shadowbanning” (Rauchberg, 2022b), algorithmic bias may have indirectly influenced data exclusion. It was also challenging to

⁹ Ironically, though TikTok might be used as an ADHD self-diagnosis tool, the platform’s design can interact with the condition in potentially negative ways (e.g., capitalizing on distractibility).

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manually cross-reference posts on the Instagram account with their TikTok counterparts. We may have erroneously removed posts that we were unable to locate on TikTok due to changed usernames. Though the sample was large and diverse, it does not reflect all perspectives and preferences of autistic people, including autistic TikTokers who communicate through augmentative and alternative communication (AAC) methods and tools. Almost all videos reposted by the Instagram account were made by speaking rather than non-speaking/minimally speaking individuals on the spectrum, who are largely rendered invisible in autism research yet comprise roughly 25–35% of the autistic population (Norrelgen et al., 2015). Our sample may also reflect the COVID-19 pandemic as an inflection point in seeking explanations about neurodivergence from TikTok (i.e., increased social media usage, more stress, isolation from in-person social support networks).

Despite these constraints, our work points to future theoretical, methodological, and applied directions. We offer platformed diagnosis and algorithmically mediated biographical illumination as useful frameworks for understanding algorithmically shaped online communities' engagement in mediated self-discovery and reflection about one's past, present, and future relationship to stigmatized, marginalized, and medicalized identities. Our method was novel in that we employed a repost account on one social media platform (Instagram) as a tool for analyzing content originally posted to another posing access challenges for researchers (TikTok).¹⁰ This study additionally highlights the need for continued applied work on how the multiplicity of neuroidentity plays out with respect to intersectionality online (Botha & Gillespie-Lynch, 2022), especially considering the popularity of TikTok among BIPOC youth (Pew Research Center, 2022). It also adds to a small but growing body of work on TikTok and youth

¹⁰ The ethics of studying accounts dedicated to reposting (e.g., Twitter's @AITA_online, a repost account for Reddit's "Am I the Asshole" subreddit) merits further study.

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mental health. Most mental health content on the app has supportive and validating comments (Basch et al., 2022), and as such, might attract young people seeking sensitive, judgment-free community and information around diagnosis. In close, this study serves to separate the cultural hype from the material help that young disabled TikTokers provide one another beyond the purview of clinical authorities and diagnostic gatekeepers.

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