Welcome to AnxietyTok: An Empirical Review of Peer Support for Individuals Living With Mental Illness on Social Networking Site TikTok

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The mobile app TikTok is different from any other platform before it, thanks to its highly sophisticated algorithm that shows users a custom feed of videos tailored to their interests and identities. The site is especially popular with young people and encourages a high level of creativity and engagement among users, which provides a space for communities to form and thrive. One of these is the mental illness community, where users tell personal stories, share accomplishments, and tell jokes about getting treated for and living with mental illness. I chose to focus specifically on videos made by people that identified as having a mental illness themselves. In this observational study, I sort TikTok videos into four categories -- informational, anecdotal, humor, and accomplishment sharing, and the resulting comments under those videos into six categories -- praise, questions, strategy sharing, experience sharing, criticism, and agreement with the creator. The proliferation of the mental illness community on TikTok allows users to feel empowered by sharing their stories and start dialogues to raise awareness and celebrate one another's victories.

Introduction

TikTok is a free mobile app where users create, share, and watch three-minute-or-less looping video clips. The TikTok app as we know it launched in 2017, and is especially popular with young people -- 60 percent of TikTok users are between the ages of 16 and 24. TikTok videos are high-energy, diverse and empower self-expression (1). Bresnick characterizes TikTok as a virtual playground and states that the differentiating feature of TikTok against other social platforms is the level of creativity it allows for (2).

The unique value proposition of TikTok lies in its algorithm; the primary way users encounter content is through a catered “For You” page (“FYP”), which shows the user the videos that they are most likely to enjoy based on artificial intelligence. Users naturally give feedback to the algorithm in the form of “Likes” and a “Not interested” button. Although TikTok users are able to follow other users, the people someone follows are much less likely to be someone they know in real life, unlike platforms like Facebook and Instagram. This makes TikTok more of an entertainment platform than a social network (3). The FYP also mixes viral videos with videos that have little to no views, which allows new creators to get started with an audience (4), which is the primary differentiator between TikTok and other video creation platforms such as YouTube.

The TikTok algorithm also allows users to informally join communities within their experience on the app. ByteDance, the company that owns TikTok, has been notoriously secretive about how their algorithms work so well. Over time, as the algorithm learns what a user likes, they show the user more and more videos about that topic. This allows communities to form based on interests -- for instance, the witchcraft community, the gender nonbinary community, and the frog lover community. The strength of the TikTok algorithm allows users to explore their own interests and identities. For some people, one of these interests is mental health, specifically their own struggles with mental health. TikTok has become the home of thousands of videos and comments of people sharing their experiences with mental illness and offering praise and support to others, creating an environment of peer support. My objective is to examine the interactions among TikTok users in the comments sections of videos, find common themes within them, and evaluate the extent to which peer support may be helping the community members' mental health.

Literature Review

There has been previous research into the effects of social media peer support in the context of mental illness. However, TikTok as a platform has been the subject of limited research. Because of the vast differences between TikTok and other social media sites, I thought it was important to study this platform independently.

TikTok versus other media

Primarily algorithm-based: A style writer in the
New York Times wrote, “Imagine a version of Facebook that was able to fill your feed before you’d friended a single person. That’s TikTok.” The first thing a user sees when they open TikTok is their “For You Page,” (“FYP”), an endless feed of videos that the TikTok algorithm thinks the user will like based on previous videos they have watched and interacted with. This is a stark contrast to other social media apps that are primarily focused on showing users content created by their friends and family (5). The importance of this in a peer support context is that users both have: one, more anonymity because the things they post may not be seen by their friends and family, and two, the ability to join communities like the mental illness community outside of their immediate circles.

**Dominated by Generation Z:** 60 percent of TikTok users are from Generation Z, which is profoundly different from any American generation before it. Gen Z is highly personal online and loves exploring their identities, which makes TikTok a great way for them to express their different identities through the different video genres they interact with. Compared to Millennials, Generation Z would rather create content than consume it because they see sharing on social media as a confidence booster rather than a source of insecurity (1). TikTok is a democratic platform that anyone can find success on and build a following based on the algorithm’s inclusion of new videos on everyone’s FYP (4).

**Engagement among users:** TikTok has the highest engagement rates (5% for large creators, 18% for small creators) among its peers, Instagram (1% large, 4% small) and YouTube (<1% large, 2% small) (5). Users are encouraged by the app to respond and add to one another’s content using the “Stitch” and “Duet” features. Challenges and viral “sounds” that users can copy into their own videos sweep through the app’s different communities quickly (6). This high level of engagement and conversation facilitates peer-to-peer support in ways that other platforms could never accomplish.

**Previous Studies**

Peer-to-peer support for mental illness is widely regarded as beneficial to improving patients’ mental health. Mead, Hilton and Curtis noted that mental health patients historically “have become victims of social and cultural ostracism and consequently have developed a sense of self that reinforces the “patient” identity.” Many people have found embracing this identity to be empowering, especially when they are able to use their personal experience to help others. The authors describe peer support as a movement towards autonomy and community building by encouraging each other to live their most authentic lives and be proud of their accomplishments (7). The purpose of this empirical review is to examine the extent to which peer support groups have formed on TikTok.

Houston, Cooper and Ford conducted a study on formalized Internet support groups for depression and found that people that utilized the support group heavily (for more than 5 hours in 2 weeks) were more likely to experience a resolution of their depression than people that utilized the support group less or not at all. This study was extremely formalized and conducted nearly twenty years ago on adults with a median age of 40 years (8), which is far different from the young adults today that are using TikTok informally to share their experiences. Nevertheless, it serves as a good comparison point to see how the Internet culture around mental illness has evolved.

The idea of peer-to-peer support being completely beneficial was challenged by a randomized controlled trial by Kaplan, Salzer, Solomon, Brusilovskiy, and Cousounis. In the study, participants with a schizophrenia spectrum or affective disorder either received a mental health-related email subscription, participated in an online bulletin board, or did nothing. After 4 and 12 months, participants that participated more in the peer-to-peer support networks reported higher levels of psychological distress than those participating less or not at all. The authors suspected that this could have been a backwards correlation -- people experiencing greater levels of distress were more likely to seek help, but seeking help did not cause people to experience greater levels of distress (9). This study raises a good question as to whether TikTok peer to peer support could actually make people more distressed.

Naslund, Grande, Aschbrenner, and Elwyn examined peer-to-peer support networks on YouTube serving individuals with severe mental illnesses, specifically bipolar disorder, schizophrenia, and schizoaffective disorder. They categorized comments on videos about mental illness into four categories: minimizing isolation and providing hope; support through peer reciprocity; coping with day-to-day challenges; and sharing health care experiences. Their major findings were that people regularly shared private health information in the comment sections of YouTube videos, which demonstrates the extent to which people felt safe in online communities and that the benefit of sharing their experiences and helping others outweighed the risk of being judged or ridiculed themselves (10). The format of that study heavily influenced this one, as it was a good balance of qualitative and quantitative analysis and was
completely observational so as to avoid interference with the participants.

Most recently, Herrick, Hallward, and Duncan examined the eating disorder recovery community on TikTok and found five themes: awareness, inpatient treatment stories, eating in recovery, transformations, and humor. The authors gave examples from each category of different trends and sound clips that users were employing to make their videos, like “Storytimes” where creators shared anecdotes, and “Let’s confuse people who…” videos where creators shared familiar items and photos associated with their eating disorder. To highlight the creativity aspect of TikTok, the authors also compared video creation to clinical dramatherapy, which is highly regarded, because of the way that creators personified their eating disorders and acted out scenarios (11). This is a great piece of research into eating disorders specifically, and provided a good understanding of what subject-matter experts look for in peer-to-peer support networks.

Method

Ethics

The general consensus about the ethical permissibility of using social media data in public health research is that public social media posts may be used in research without the creator’s consent (12). On TikTok, users have three privacy settings: viewable to everyone on the Internet, viewable to their mutual followers (“friends”) only, and viewable only to themselves. In line with similar studies, I only examined completely public posts and public comments on those posts. I also de-identified all comments and video links in all results reported in this article.

Data

In May 2021, I used the TikTok web browser to search hashtags of abbreviations of common mental illnesses. Hashtags included:

- #depression
- #anxiety
- #ptsd
- #psychwardstories
- #npd
- #bpd
- #bipolar
- #recovery
- #hpd
- #dissociativeidentity

Videos were selected based on: one, whether they were actually about mental illness to exclude spam, two, whether they were a first-person account of the user’s own experience with mental illness, as this was the scope of the research, and three, whether the videos had at least 100 comments, to ensure there was a great deal of discussion and replies to the video that the algorithm and I could analyze. Any video that was created by a business (including therapists, doctors and other mental health professionals) or other institution, or was not in English were also eliminated. Twenty-eight videos that best fit these criteria were chosen by rotating through the above list, pulling the first video shown by the algorithm for each hashtag, and evaluating whether it met the criteria.”

I then evaluated whether the pool of videos I had chosen was distributed across several different mental illnesses, genders, racial identities and perceived ages of the creators in the videos. Then, I sought out videos from missing groups.

To categorize the age, race, and gender of the creator, I used the creator’s self-identification if they provided it, and made an estimate based on their appearance if they did not. For perceived age: I chose 50% that were created by young adults, 25% that were created by older adults, and 25% that were created by teenagers. For racial identities: 72% appeared to be created by white- or white-passing people, 11% by Black people, 4% by Latinx people, 13% by Asian people. For gender: 61% appeared to be created by women, 18% by men and 21% by nonbinary people. I then exported the first 10 comments, as shown to me by the TikTok algorithm (which is not chronological), from each video, to analyze a total of n=280 comments and categorize them.

Procedure

This study employs online ethnography. By definition, ethnography is completely observational, so participants were not engaged at all in the comment sections. After reviewing each of the videos I chose and their first 10 comments, I created video categories based on the primary purpose of the video and comment themes based on the primary message of the comment.

Results

The search on TikTok for videos about first-hand accounts of mental illness yielded hundreds of thousands of videos. After screening for videos that met the criteria I listed in the Data section of this report, I chose 28 videos, all from different creators, to analyze closely.

The videos had an average of 649,000 views each. The overwhelming majority of videos under mental
health-related hashtags were created by female and non-binary people, possibly because of the additional stigma associated with mental illness in males (13). Most videos were also created by young people; the narrators in 21 of the 28 videos selected appeared to be under the age of twenty-five. Most first-person videos with mental illness hashtags were created by white people; this may be due to the increased stigma around mental health in BIPOC communities.

Black and Hispanic Americans use mental health services at about one-half of the rate that white Americans do, and Asian Americans at about one-third of the rate (14), despite reporting similar (within 4%) rates of “severe psychological distress” (15).

Video Categories

This study determined four categories that videos could fall into, based on the primary purpose of the video: Informational, Anecdotal, Accomplishment Sharing, Humor.

Informational

Informational videos were videos explaining the science or psychology behind a specific mental illness-related behavior or phenomenon. One creator says:

“Stuff I didn’t realize was ADHD related, part three. Delayed sleep phase syndrome. It’s a circadian rhythm sleep disorder where your internal body clock is delayed by 2+ hours than what’s considered ‘socially acceptable.’”

The comments in informational videos usually consisted of experience sharing -- commenters wrote in response:

“Yeah I’ve been sleeping every other day for almost a year and just got diagnosed with ADHD a couple weeks ago.”

“Yessss and when I fall asleep at a ‘normal’ time I wake up at 3am TOTALLY ALERT but fall back asleep & wake at 7am groggy”

For non-mentally ill people viewing the video, the experiences shared in the comment sections may reinforce their understanding of what it is like to live with that mental illness symptom. For people who have experienced this symptom, hearing that it is “real” and not just them can be incredibly relieving. A potential danger with informational videos is that unfamiliar or young people may receive false information from an “informational” post created by an amateur as opposed to a medical professional.

Anecdotal

Anecdotal videos describe a single, specific experience that someone had living with mental illness. One creator wrote on TikTok:

“In one manic episode I spent $1000 on lingerie using a stolen card, painted my walls black in the middle of the night because the walls were too loud, seduced a 27 year old man into buying me Juul pods, and convinced myself I could play guitar and made an entire album thinking it was genuinely good.”

The comments in anecdotal videos were typically either sharing their own, similar or different experience related to the one described, or agreeing with the creator that the anecdote adequately represented what it is like to live with mental illness. To this video, commenters responded:

“thank you for not romanticizing it.”

“I’m so tired of people being like “I dyed my hair” like ok?? Cool?? mania is scary as hell”

“I drove to my grandmas house 12 hours away in SC by myself in the middle of the night and didn’t pack anything but i did stop to buy a gecko on the way.”

The benefit of anecdotes is that they are non-aggregated and come from real people that are telling their own stories. The drawback of anecdotes is that people might be fabricating or exaggerating them in order to get more “views” or “likes” on TikTok.

Accomplishment Sharing

Accomplishment sharing videos are videos whose primary purpose is to share a milestone with their peers on TikTok. This demonstrates how supportive
the TikTok community is -- that people feel a desire to share their wins.

“Addiction took over my life. I lost hope. I packed up to go to rehab in 2019. Sobriety date: August 28, 2019. 313 days clean.”

The comments to accomplishment sharing videos are extremely positive and supportive, most of them congratulating the creator.

“What the heck!!! I’m so happy for you!!!!”
“Congratulations!! remember, Just For Today.”
“Girl you’re a hero! just wanted u to know that <3”

One thing I noticed was that people tended not to share their own experiences in the comment sections of accomplishment sharing videos, maybe to avoid stealing the spotlight or recognition from the person sharing their (often very serious) story.

Humor

The humorous videos about mental health were often treated like inside jokes -- the punch lines being only things that people who have struggled with mental illness can understand. One humorous video is of a creator standing alone and staring at the screen, with text typed over her that says:

“I should get a tattoo of a cutting board so you know…”

Contrary to one’s instinct, the response to these videos was overwhelmingly positive, probably because this video was only shown to those within the mental health community (thanks to TikTok’s algorithm). Peers responded in the comments:

“Girl wait this is a good idea lmfaooo.”
“Bro it’s funny to us because we’ve been through it.”
“This joke is so funny I’m definitely gonna tell it to my therapist.”

Humorous videos tended to be the shortest - some were even just a joke written on the screen while a person danced or glared into the camera in the background. All of these are methods of storytelling that creators use to portray different emotions or vibes, whether they are kidding or not and who their intended audience is. Much of this is completely effortless to the Gen Z creators making these videos; because they have grown up creating content, they do not fully understand how creative they are really being.

Comment Categories

After reading the first 10 comments on each video, they were categorized into six groups: Praise, Agreement, Criticism, Experience sharing, Question, Strategy sharing.

Comment Sentiment

I also categorized all n=280 comments more broadly into “Positive” or “Negative” sentiment, based on whether the words were supportive or critical of the video creator. The overwhelming majority, 95% of the comments, were positive, with the remaining 5% being negative.

Table 1

<table>
<thead>
<tr>
<th>Category</th>
<th>Agreement</th>
<th>Criticism</th>
<th>Experience Sharing</th>
<th>Praise</th>
<th>Question</th>
<th>Strategy Sharing</th>
<th>Total Comments</th>
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<td>Anecdotal</td>
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<td>Informational</td>
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<td>Total All Videos</td>
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Praise

Comments of praise, most commonly found on Accomplishment Sharing videos, often included a congratulations or a compliment directly to the creator of the video.

“Congrats on your journey.”
“BIG CONGRATS ON GETTING THROUGH IT <3.”
“literally...i'm so sorry you have to deal with this, must be so frustrating sometimes... keep your head up girl.”

These comments would be the most likely to be extremely helpful for the creator. They can serve as a tangible reminder in the form of permanent comments reminding them of their strength and that other humans are out there that care about them and their accomplishments.

Agreement

Comments of agreement are comments that express agreement with the video creator’s words or actions. They do not necessarily share their own experience, which is what differentiates them from Experience Sharing comments.

“This!!!!”
“yeah true.”
“way more people have ptsd from non military related events (not trying to invalidate those who have it from that) it’s wild how that even became the “standard” for people with ptsd.”

Agreement comments have the ability to help the creator by “backing them up” in a sense and showing other commenters and video viewers that there are other people that agree and are on the creator’s side.

Criticism

Critical comments were far less common than any of the other comment types. Only 13 of the 280 comments I catalogued (less than 5%) were critical of the video creator.

“Am I the only one who can’t stand this dude? Idk. Just somethin about how confident he is in being a narcissist irks my nerves.”
“how about you make good choices in the beginning.”
“im not too sure why you would want to live like this but it must be pretty lonley heaving too change around loved ones.” [sic]

These comments would most likely not be helpful to a video creator. They may discourage the video creator from sharing their story again, or even prompt them to turn off the comments to avoid being criticized. This also has a negative impact on the entire community, as someone considering sharing their story with a video or comment may read a critical comment and decide against doing so.

Experience Sharing

Experience Sharing was the most common comment type -- about 49% of the top comments on the videos studied consisted of a person telling their own, related story connected to something the creator said in the video.

“I was diagnosed with cPTSD ~7-8 years ago. I was the only person in my online communities and my local community with cPTSD. I was invalidated.”
“I've had to describe mania to my mother once and I said it's like getting stabbed by a knife a bunch of times and finding it funny.”
“same, i'm completely behind on everything. everything makes me cry. my brain now can't comprehend anger correctly and I view it as other people leaving.”

These comments are the most likely to create community on the app. Some of them had long threads of responses below them, with other TikTok users replying to their comments and sharing more stories or offering advice or support.

Question

Sometimes, viewers had questions after watching a creator’s video, especially with illnesses that are less common like Dissociative Identity Disorder. Some questions that commenters left on TikTok videos include:

“I do have a question, what do u think about DID portrayals in media, like jane from doom patro.l”
“How do people call you on day to day basis (because they can't always know who is in “charge”??)
“why is the hospital forcing people to eat though,, forcing recovery will just lead to hard relapses.”

It was not always the video creator that answered these questions. Sometimes, other viewers stepped in to offer their perspective, creating a dialogue around mental illness.
Strategy Sharing

The last category of comments found was Strategy Sharing -- where creators and commenters provided advice to one another.

“For those self-diagnosing... it’s important to note many people have histrionic personality traits but that does not mean someone has HPD.”

“Check the OCPD subreddit, it’s very useful.”

Similar to informational videos, there is a danger with strategy sharing comments that the ideas given may be not helpful, contradictory to clinical practices, or even dangerous. The number of strategy sharing comments was relatively small, only representing about 3% of total comments I studied.

Discussion

The overwhelming majority of top comments consisted of either experience sharing, praise or agreement with the creator. Comments on mental illness related videos are overwhelmingly positive, which is ironic given how seriously the topic is usually taken. Sometimes, people even get emotional in the comments and express how genuinely happy they are to have found others that think like them or exhibit the same behaviors as them, especially when they may not know anyone in their real life with a similar mental health condition.

TikTok users also shared the similarities and differences they encountered during treatment.

“Thanks for explaining my life in 60 seconds when I couldn’t do it for years!” one person commented on a creator’s video about living with C-PTSD. “Pfffff my staff yelled at me for falling asleep after having panic attack after panic attack the night before,” someone described their experience in inpatient treatment.

Comments expressing praise for the creator’s effort in persevering through their mental health struggles have the ability to make a big difference in the creator’s life. Previous research has shown that praise for effort is linked with an increase in motivation for difficult tasks, including living with a mental illness (16).

Sometimes commenters sought and gave practical advice to peers -- “What’s the first step for addicts like myself to become sober?” People in the comment sections rushed to answer questions and provide support, especially for people that seemed new or unfamiliar with mental illness or mental health treatment. Someone suggested to a creator that had just been diagnosed with a personality disorder -- “Check the OCPD subreddit, it’s very helpful.”

I also found negative comments interesting - the ones I categorized as “Criticism.” The videos most criticized were videos about addiction and videos about personality disorders. Specifically, there were lots of negative comments on a video where the creator was dancing and smiling with her children while facts about her came across the screen -- that she went to rehab twice for alcoholism, got married young, relapsed when she had twins, and lost custody of her children twice before becoming 3 years sober and regaining custody. Commenters criticized her for ‘making poor choices’ and sarcastically asked why she would put this content on TikTok. Another video that gained a lot of negative attention was a video of a man with Narcissistic Personality Disorder responding to a video made by another creator whose loved one has NPD. Some commenters said they ‘couldn’t stand this man’ and called him a ‘micromanipulator.’ Other commenters defended his video and told the creator that they appreciated him coming forward and informing people about what it is like to have NPD.

One of the most widely-shared mental illness topics on TikTok is #PsychWardStories, where creators share their experiences with inpatient mental health treatment. The hashtag has 164 million views of the videos tagged with it (17). The phenomenon of “Psych Ward TikTok” was documented by Refinery29, and the article included interviews with two of the young women that posted mental illness TikTok videos. One creator, Mia, said, “The main purpose of my videos is to make people feel less alone with what they’re going through, and to bring some light and laughter to the situation.” Another creator, Siobhan, explained that she makes videos because she is “trying to make humor out of a situation that was really hard,” and TikTok is one way that she copes with the day-to-day struggles of mental illness (18). These interviews are relevant because they reveal the reasons why people tell what is seemingly the entire world about their mental health struggles.

Overall, a sense of community is facilitated for people with mental illnesses on TikTok, because the algorithm only shows mental health content to people that react positively to mental health content and want to see more of it. The more that users like and comment on the videos, the more often they see mental illness-related videos, and the closer to the mental health community they feel.

Conclusion

Creators that make TikTok videos about their
experience with mental illness are improving their own lives and the lives of others by receiving and giving praise for accomplishments, reducing stigma, and starting dialogue about mental health challenges. TikTok, with its uniquely young audience, has the ability to facilitate a new generation of people that are proud of their stories and experiences around mental health. The difference between the mental illness community on TikTok and other forms of peer support lies in the difference in values between Generation Z and its predecessors. The thoughtful algorithm allows communities to form and amplifies previously marginalized voices in a way that is accessible to anyone with Internet access. Talking about mental illness on TikTok and in other ways has the opportunity for our generation to create a positive culture of support for those struggling.

TikTok is still a relatively new app and platform and is beginning to gain traction with older users. As more people in different demographics join the platform, and if TikTok begins including more paid advertising on users’ feeds or changes its algorithm, the social environment will likely change.

Future research could investigate the direct impact of posting videos to TikTok about one’s mental illness. More interviews with the creators and commenters in the mental illness TikTok community could reveal whether the seemingly positive effects of praise and experience sharing are actually benefiting people’s mental states.

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REFERENCES
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