SUMMARY

Adolescent and young adult mental health is becoming more of an issue, while social media platforms are becoming more popular as a way to exchange medical information online. Evidence suggests that the internet is a predominant, if not the primary, source of health-related information for adolescents. It provides access to sources of knowledge regarding preventative care and healthcare, in addition to serving as a tool as an online support network.

In recent years, TikTok has grown to become one of the most popular of these sites. Adolescents and young adults use the site to share personal experiences via popular video formats, short storytelling, and educational content development. There is a need to understand TikTok users who are having mental health issues. Their manner, attitudes, knowledge, and engagement in the TikTok mental health community are all important factors in determining how to design for these people and how to reinforce the positive aspects of the TikTok mental health community. In light of this, we address the following research topic in this paper:

- **RQ:** *How is a mental health community on TikTok considered a platform for support and information, and how may design further strengthen the positive aspects and mitigate the negative aspects of the community?*

We follow a digital ethnographic approach as a way to consider and make use of digital technologies to take part in and observe the mental health community on TikTok. Rather than bringing the members to us, we investigate their communication by analyzing the community and environment. We start by interviewing two certified psychologists, one of whom creates his own content about mental health on TikTok. Following this, we look to Etienne Wenger's theory and framework on communities of practice and tailor his framework to fit a digital approach. In doing this, we perform a deductive thematic analysis to look at the comment sections of 10 different videos, relating to the three mental health conditions: attention deficit hyperactivity disorder, autism, and borderline personality disorder. As a result, we present three implications for future work.

For the first implication, we believe that future work may benefit from looking into if being a part of a community such as this can obstruct the members' drive to seek professional help, on the basis of becoming healthy, rather than getting a diagnosis. The second implication concerns that the information regarding more serious topics, such as mental health, may be jeopardized at the cost of creating entertaining and relatable content. We believe that clear guidelines, easy methods for fact-checking, tags, or disclaimers could be directions to look to when exploring how to accommodate this. Lastly, both Wenger and the first psychologist state the importance of leadership in a community, for aiding it forward and helping it develop. The third implication states that features to support and guide community members, such as leadership and vision could provide directions on how to improve and develop.

Welcome to #mentalhealth-tok: A deductive analysis of the mental health community on TikTok

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ABSTRACT

Adolescents are experiencing mental health difficulties more frequently, and sharing medical information online via social media is becoming more widespread. Peer-to-peer support has developed in self-forming online communities as a result of this. While existing studies demonstrate the dissimilarity of informational quality in such communities, we still know very little about the communities and behavior within them. We performed interviews with two psychologists to discuss their professional views on such communities as well as their members. Furthermore, we used Etienne Wenger's communities of practice theory to carry out a deductive analysis of 10 videos using a digital ethnographic approach. Our findings show that the members have a safe space where they can give and receive support. To strengthen the positive and mitigate the negative aspects, we present three implications and future work directions.

CSS CONCEPTS

- Human computer interaction(HCI).

KEYWORDS

tiktok, mental health, communities of practice, digital ethnography

1 INTRODUCTION

Mental health is increasingly becoming an issue among adolescents and young adults, while social media platforms are growing more popular as a medium to share medical information online. Evidence suggests that the internet is a significant, if not the main, source of information for adolescents on health-related concerns. In addition to acting as a tool for an online support group, it provides access to sources of knowledge about preventive care and healthcare [7]. People are continuously using social media sites as platforms for self-expression, spreading awareness, and breaking down barriers to mental health. Seeking aid through social media has resulted in peer-to-peer support in self-forming communities online [9, 15]. There is growing evidence of high rates of social media use among people with mental illnesses, including research that looks at involvement with these popular platforms in a variety of situations and conditions. Although there is consolation in such online support communities, it has been found that a great deal of advice given is potentially harmful [3]. At the same time, studies show a high presence of misinformation spreading in such communities [21].

TikTok in particular has risen to become one of the biggest of these platforms in recent times. Adolescents and young adults flock to the platform to share personal experiences through the use of popular video formats, short storytelling, and the creation of educational content [10]. Research points to how TikTok's algorithm constructs communities around particular topics, such as mental health, and even more specific diagnoses like depression and ADHD [2, 20]. There is a need for understanding TikTok users that are struggling with their mental health. Their demeanor, attitudes, knowledge, and participation within the community are essential to identifying how to design for these users as well as how to reinforce the positive aspect of the mental health community of TikTok. In light of this, the research question we address in this paper are as follows:

- **RQ:** *How is a mental health community on TikTok considered a platform for support and information, and how may design further strengthen the positive aspects and mitigate the negative aspects of the community?*

To explore this, we followed a digital ethnographic approach and investigated the mental health community on TikTok. We conducted interviews with two psychologists to learn more about the mental health community as well as its members. To understand and analyze the community, we looked to Etienne Wenger's theory on communities of practice(COP). Wenger created a framework that describes fundamental elements of social learning systems, one of which assesses the modes of belonging combined with the dimensions of progress in a community. By adjusting this framework to fit an online community, we performed a deductive analysis of the 10 videos we acquired. Findings show that engagement and imagination have a high presence within the community, however the alignment is lacking. We present a set of implications for future work on how to improve such a community.

2 RELATED WORK

Studies on mental health and social media have researched the impact social media has on mental health, the mental health societies that are made within social media, as well as the language within the society [6, 8, 11, 14]. Several platforms have been studied in relation to mental health, such as Instagram [14], Twitter [6], Reddit [5, 8], and TikTok [2, 9, 10, 20]. The primary emphasis of these studies is the community the self-disclosure of users creates.

The audience, spectators, or listeners whom the individual interacts and shares their experiences with, are an important construct in the process of "making the self known to others", a process that is also called "self-disclosure" [6]. Self-disclosure is a common coping method for people who are dealing with stigmatized disorders like mental health issues. The disclosure process assists not just in bridging social capital, i.e., making new friends who can provide access to new knowledge and resources, but also in bonding social capital, such as reciprocity, support, and companionship. In terms of better health and psychological well-being, self-esteem, life-satisfaction, and reciprocity, people benefit from their interpersonal interactions and social networks [6]. Ernala et al. researched audience involvement, and its effects on disclosures. A year-long investigation was made on Twitter with data of 400 disclosures and their 400 thousand audiences. During the analysis, the authors characterize and model the audience engagement, and found evidence of mutuality in the disclosure process between the disclosures and their audience. By using Twitter features such as *favorites*, *retweets*, and *mentions*, the audience can engage with the disclosures in a variety of ways, such as providing support, sharing personal experiences & online help resources, and conversing about everyday difficulties [6].

With TikTok being a relatively new social media platform, the literature on mental health content is lacking in the published domain. In 2020, Herrick et al. made an inductive thematic analysis of eating disorder recovery content on TikTok. According to their results, TikTok creators communicate personal experiences through the use of trending video formats, short storytelling, and the creation of informational content, [10]. Erin Harwood wrote a paper in 2021 about TikTok being a third-place for adolescents struggling with their mental health. She states that the easy access to support on TikTok means that young people can get support any time of the day from total strangers and that they can bypass telling their parents or seeing professionals [9]. Basch et al. published a study of the content in TikTok's mental health hashtag in February 2022. By doing a cross-sectional, descriptive content analysis they searched for the mental health hashtag on the discover page, and found that 61% of the videos were offering support or validation, 49% were describing other mental health issues or struggles, and 16% were sharing coping strategies, experiences of healing or ways to feel better [2]. In another article, published in March 2022, Yeung et al. studied the qualities of videos within the ADHD hashtag on TikTok. The quality of the videos was assessed by utilizing DISCERN, which is an instrument designed to measure: 1. the reliability of health information given, 2. how good the information about treatment choices is, and 3. the overall quality of the publication or media as a source of information. Yeung et al. classified 52% of the videos as misleading, 27% as personal experience, and 21% of the videos as useful. According to their findings, none of the misleading videos advised viewers to seek professional help before attributing their symptoms to ADHD [4, 20].

Similarly, other researchers have studied the quality of information given on illnesses on TikTok, by utilizing DISCERN. Kong et al. assessed the diabetes-related videos and found that the overall quality of videos was acceptable and that the videos created by for-profit organizations had the lowest information quality [13]. Zheng et al. studied the content quality of TikTok videos about acne. They state that the information given in the videos has *"serious to potentially important"* shortcomings [22]. The quality of TikTok videos about chronic obstructive pulmonary disease

was assessed by Song et al. They found that even though the quality varies, the information quality is satisfactory [22]. Xue et al. assessed cancer-related videos' quality and found that 36% of the videos were misinformative, and their testing revealed that 96% of the videos were of poor to mediocre quality [19]. Aesthetic surgery procedure videos on TikTok were quality tested by Om et al. The four types of surgery videos assessed (rhinoplasty, blepharoplasty, breast augmentation, and abdominoplasty) showed the authors that the quality in the videos was very poor [1]. Regardless of the focus these studies show on physical ailments, the findings could be applied to general health information.

While the existing studies show the divergence of content quality, as well as their subject, in health videos on TikTok, research about the community and users' behavior within it are absent from published literature. We seek to contribute to the literature by providing an analysis of the mental health community in TikTok.

3 METHOD

3.1 Ethical considerations

This research studies and analyzes comments from TikTok's mental health community. While published and accessible social media posts are considered to be public domain, ethical considerations should be made. To help preserve the identities of the community, no information such as usernames or other identifying information has been disclosed in this article. Furthermore, we chose not to reach out to any users. We are not experts on mental health, and because multiple users have publicly disclosed that they struggle with mental health, we chose not to reach out.

3.2 Digital ethnography

In their book *Digital Ethnography: Principles and Practice*, Pink et al. describe an approach to doing ethnography in a contemporary world. The book asks about how digital environments, methods, and methodologies are redefining ethnographic practice, and accounts for how the digital, methodological, practical, and theoretical dimensions of ethnographic research are intertwined [17]. The authors state that the book's content might be used for different purposes, such as using the concepts they introduce as templates for developing projects or theses. Or using it as an introduction to understanding how we live and act in a context that is almost always co-constituted and entangled with digital technologies, content, presence, and communication [17]. We identify with the latter explanation and understand digital ethnography as a way to consider and make use of digital technologies to take part in and observe the mental health community on TikTok. We study the communication between users by analyzing their community and environment rather than bringing them to us. By utilizing TikTok as a platform to examine the community, we learn about their routines and communication styles, as well as their values and what they find meaningful.

3.3 Semi-structured Interviews

We interviewed two professional psychologists in a semi-structured fashion online, as part of understanding more about the topic of mental health and the users of TikTok's mental health community. This allowed us to ask in-depth questions on the go as a response to the psychologist's answers. Prior to the interviews, we had scoped out some videos to give us some ideas for what to talk about.

The first psychologist is a specialist in clinical adult psychology. She worked for five years in pediatric psychiatry and is currently a private practitioner. The second psychologist has been a private practitioner since graduating and began sharing videos relating to his practice on TikTok in 2020/2021. As of now, we will refer to the first psychologist as P1 and the second as P2.

The choice of interviewing a psychologist specialist and a psychologist on TikTok was to see if their experiences and views on the mental health community differ.

3.4 Communities of practice framework

Building upon our prior study completed in the 9th semester, we seek to determine how TikTok's mental health community fits in the context of Etienne Wenger's theory on communities of practice. The theory looks at three fundamental elements of social learning systems: *community, boundary, and identity*. These three elements are made up of three modes of belonging: 1. *Engagement: doing things together, talking, producing artifacts*, 2. *Imagination: constructing an image of ourselves, our communities, and of the world, to orient ourselves, to reflect upon our situation, and to explore*

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possibilities, and 3. *Alignment: making sure that local activities are sufficiently aligned with other processes so that they can be effective beyond our engagement* [18].

Each element has its own table, which is made unique by its three dimensions of progress. The community element table serves as a framework for assessing the communities of practice, and consists of the three dimensions; *Enterprise - learning energy: How much initiative does the community take in keeping learning at the center of its enterprise, Mutuality - social capital: how deep is the sense of community generated by mutual engagement over time*, and *Repertoire - self-awareness: how self-conscious is the community about the repertoire that is developing and its effects on its practice*. We chose this element in particular because it assesses the community by looking at how the community learns, how it engages with each other, and how it understands its state of development. Furthermore, the study in our 9th semester showed how an understanding of the boundary and identity element is limited by a digital approach to Wenger's communities of practice. The table consists of nine different cells, the cross-sections between the modes of belonging and dimensions of progress [18].

Community element	Enterprise	Mutuality	Repertoire
Engagement	Are there characteristic comments showing reflection upon gaps in their knowledge and work towards a common understanding?	What types of commitment/interactions take place to create and develop trust? Is there an ability to raise troubling issues during discussions?	To what extent have shared experiences, language, histories, and coping methods developed over time? And with what potential for further interactions and new meanings?
Imagination	What potentials of the community inspire/motivate participation from the users? And what pictures of the world serve as a context for these visions?	What do people know about each other, and about the meaning their participation in this community takes in their lives more broadly?	Is there any self representation to see the community in a reflective way? Any discussions with the goal of questioning individual views?
Alignment	Is the learning energy centered on driving the community towards a shared understanding, vision, or purpose? How distributed is the leadership?	What definitions of shared roles, norms, codes of behavior, principles, experiences, commitments, and expectations hold the community together?	Are there any behavior patterns in the community, and ways to behave/talk about certain topics?

Table 1. Our adaptation of community element table

3.5 Data collection and content analysis

Lazar et al. describe thematic content analysis as a qualitative method for extracting common themes and types of interactions [12]. Guided by Etienne Wenger's theory on communities of practice, we apply this method to deductively analyze the mental health community on TikTok.

In this research, we wish to study the public comments of members of the mental health community on TikTok. This means that the people who participate in this community, exclusively through watching and/or liking the videos,

209 are excluded. Additional exclusion criteria are comments consisting only of emojis, foreign language, and incoherent
210 comments such as people tagging other people or agreeing to the video by commenting "*yes*" or "*same*". Based on
211 this, we define the members of this community as the users creating video content, as well as the users posting public
212 comments in the comment sections of these videos. Their comments are the data set we wish to collect and analyze.

213 We initiated the analysis by searching for videos that related to three mental health conditions that were frequently
214 discussed during the interviews. These conditions were attention deficit hyperactivity disorder (ADHD), autism, and
215 borderline personality disorder (BPD). We searched for these videos by using tags such as: "*#bpd*", "*#autism*" and
216 "*#adhd*", which progressed into more specific tags we discovered underway such as "*#adhdtiktok*", "*#actuallyautistic*"
217 and "*#bpdtiktok*". We saved the first 35 videos that were English speaking, contained tags related to ADHD, autism,
218 and BPD as well as those that had 100 or more comments. We then began a selection process to find 10 videos that we
219 wanted to analyze first, and if time allowed it, add more later. To provide variance, similar videos with the same trend,
220 expressions or messages were reduced to one-of-a-kind.

221 A method called web scraping was employed to extract the comments from the TikTok videos, into a Google Sheets
222 document, from which we exported them into a NVivo project.

223 A video's comment section is constructed of *comment threads*, which are comments posted directly to the video,
224 and *sub-comments* which are nested within and posted in response to comment threads. The most popular and active
225 threads are prioritized by TikTok and displayed at the top of the comment section, and are hereby more visible. We
226 therefore considered these to have more discussions and chose the most visible threads and their sub-comments as
227 the point of analysis. We had to set a limit on the number of comments we would analyze since the videos contain
228 hundreds or thousands of comments. To determine which method of data gathering would result in the most continual
229 discussions, we conducted three pilot tests on three different videos.

230 In the first test, we chronologically coded the 100 first comments of a video, independent of their threads. This
231 method would end at a random point and could cut off conversations or leave out other interesting threads further
232 down. In the second method, we coded the 10 first comment threads, along with the 10 first sub-comments. This had
233 a similar impact as the first method because the threads contained more than 10 sub-comments. Finally, we tested
234 a method where we coded the 10 first comment threads and every sub-comment of the 10 respective threads. This
235 method allowed us to look at the 10 most visible and active threads, without cutting off ongoing discussions. Based on
236 these pilot tests we decided to proceed with the last method for our analysis.

237 To ensure a mutual and coordinated consensus of our coding, the comment sections of the 10 videos were jointly and
238 manually coded in 10 individual NVivo project files. Individual comments were examined and discussed to determine
239 which of the nine cells within the community element they matched. In case of disagreement of a comment and its
240 matching cell, the comment would be coded in multiple cells. In some cases, a whole thread had to be read first to
241 decide upon matching cells for the comments.

4 RESULTS

4.1 Interviews

Mental illnesses as a trend

When we talked about how open people are on social media about mental health difficulties, both psychologists agreed
that this is a healthy trend that has grown more acceptable in recent times. However, P1 also believes this has caused
people to talk about natural feelings and reactions, as illnesses. She thinks that both small and big situations in our
lives are being discussed in a diagnostic language, and states that: "*you are no longer shy or nervous, you have anxiety*".
We call this way of talking about natural emotions "self-medicalization", which refers to the medicalization of oneself.
Medicalization is defined as "*a process by which human problems come to be defined and treated as medical problems*" [16].
Conversely, she believes that if we talk about these feelings as normal events in our lives, we will carry it easier, and
hereby make it easier to share how we feel. Moreover, she states that she experiences adolescents as more interested
in having diagnoses. In an example, she mentions that some adolescents come into therapy and state that they have
depression, thereby already having diagnosed themselves before they arrive. When she subsequently asks them how
it is to have that diagnosis, they have to find the words to describe how it feels. Furthermore, she states P1: "*There is
something in the way we talk about the experiences we have, that paradoxically takes us further away from the experience.*

We are not getting any better at articulating it, because we use words that are very far away from the personal and the experiences. And by this, we become worse at articulating our feelings, when using a diagnostic language".

P2 stated that there are a lot of misrepresentations of mental health illnesses on TikTok and that a great extent of the information can be more harmful than beneficial. However, he also states that if the opposite pole is that we can only talk about mental disorders if they are correct, we can expect them to be discussed much less. We would then return to a time when seeing a psychologist or receiving mental health treatment was much more uncommon, perhaps 10-20 years ago. To quote him: "*I think we have to [...] take the sour with the sweet. [...] I think it is important that we dare to talk about it even if we are not experts, one could of course wish that people turned down the hunt for likes and were more aware of what they said was right though*". He states that what is common for every creator on TikTok is that they want their videos to be shared and liked, and to achieve this you must create relatable content and something people can see themselves in. Moreover, he told us that when he makes content about how one can improve their situation, the videos manage poorly, linking this to the videos being too general instead of focusing on specific illnesses. When talking about the more specific subjects like suicidal ideation, bipolar, and BPD, he says: "*[...] people will always do harm to themselves, there will always be sicknesses. The question is just are we going to store it away like we did before and hereby lose more people, or should we in a way dare to talk more openly about it*". We did ask him if he had ever been requested to diagnose anyone on TikTok, but he said no, and that if he ever did he would direct them to a professional for an evaluation in an appropriate context.

When talking about the video trends in the community, P1 was surprised to hear how lightly some users talk of diagnoses such as BPD and bipolar disorder. She believes that talking about them in such a way can be a problem because the respect and seriousness of it disappear. Furthermore, when speaking about self-diagnosis and the issues it might cause, she says: "*It almost does not matter, if the treatment of it in social media is superficial and somehow too easy, it does not matter if there is a proper diagnosis at the bottom, but that you decorate it. That is, for those who look at it*".

Creating a community through mental illnesses

When speaking about the positive and negative parts of participating in a community that revolves around mental health and diagnoses, we talked about how the users listen and comfort each other. P1 stated: "*Then there's the question of how simple it is to get well if it's such a pleasant place to be. What does belonging to a group do if you are a little lonely and alone in your own life, and alone in your situation. How easy is it to stop self-harm and get well? Because then you do not share that community anymore*". Moreover, she says that the positive part is that adolescents that do not have their own environment, get new friends online, and that everything is not negative. Quoting her: "*but what is perhaps one of the big problems is the 'disease identity', which I think may be alluring, also because there are such high demands, adolescents feel that there are high demands for them [...] and being sick is an opportunity to get away from that, you are kind of allowed to*". Additionally, she was concerned with the group processes of the community, stating that in group therapy and group sessions there has to be a leader. She states that without a leader in group therapy "*[...] they rapidly become malignant, and that's the problem with such communities: there's no one to take responsibility for them [...] I have no faith that humans in groups develop in a good way, in and of itself. It is a high-risk endeavor.*".

P2 describes the positive parts of being a part of the community as being a place to find support. He brings forward the example of self-harm and says that it is more likely to expect that people and users support one another in these contexts. Furthermore, he says: "*A downside here is that when you get well, you are no longer a part of the community anymore, and this probably creates a bigger risk for relapse since you in reality only engage in sickness. It becomes their commonality*".

4.2 Community element analysis

We went through 1125 comments in total and coded 491 of these in our framework of the community element. The remaining 634 comments were comments that did not match our criteria for the community element.

Video 1-10	Enterprise: Learning energy	Mutuality: Social capital	Repertoire: self-awareness	Total:
Engagement	97	72	11	180
Imagination	82	70	68	220
Alignment	46	37	8	91
				491

Table 2. Our adaptation of community element table

Engagement - Participation with one another toward a common understanding

Engagement in communities of practice is a mode of belonging about the manner in which we interact with one another. It concerns how we work together, communicate, and create objects [18]. In the *engagement - enterprise cell*, comments are showing different levels of reflections about gaps in their knowledge where users work towards a common understanding. Typically it is small and short interactions, such as one user inquiring about something related to the video or comment section, and another user providing an answer. An example can be seen in the comment section of video 1, about how people with ADHD experience dysfunction in their brain: "*Does this relate to not going to bed at a reasonable time? Every night I plan and want to, every night fail..*". The user initiates the comment thread, asking about a personal issue. Another user responds with: "*This actually sounds like Delayed Sleep Phase Syndrome which is extremely common in people with ADHD*". The initiator then responds with: "*Thank you! I just looked this up and it is me 100%*"

Another example of a more in-depth reflection can be seen in the comment section of video 7, about a girl stating that you can have both BPD and autism since BPD is a trauma response, and growing up autistic is traumatic. The comment states: "*you literally cannot be diagnosed with both omg you need to think/research before u talk*". The creator of the video responds with "*Me who's professionally diagnosed with both :o*". The initial poster then responds: "*i looked it up and you're right, my old psych lied to me i guess?? mb tho!*". The creator then answers: "*Hey at least you can admit you were wrong! A lot of psychs and therapists are super biased towards both diagnoses so thats likely why :(They don't want to diagnose you with something they can't throw pills at, it's only improved by therapy practices*". This interaction shows how the initial poster can learn about this topic by addressing their knowledge gap, reflecting upon it, and in collaboration with the creator, work towards a common understanding. However, this level of self-reflection has rarely been observed.

Engagement - mutuality concerns the type of interactions that contribute to developing trust and raising troubling issues during discussions. It seems that self-disclosure contributes to creating a safe space for trust creation. In video 10, about ADHD and autism in young women, a user states: "*I would like to know if I have it or not but my mom simply does not care about my mental health only grades and my grades are fine so i must be fine*". Another user answered: "*..That's rough I am so sorry. Do you think if you were to speak to a guidance councillor about it they might outline how a diagnosis could be for future schooling (after you are out of the house) . Then maybe she would see it from a schools view ?*". Additionally, in video 4, about a woman finding out she has had undiagnosed ADHD for 34 years, a user asks: "*How did you do it? I have all the symptoms of undiagnosed adhd but not sure what to do*". When the user continues to

comment about the symptoms they experience, another user asks: "*Do you have a support system for when things get overwhelming? X*", and: "*If you need someone to talk to. I'm here xxxxx*"

Raising troubling issues during discussions usually happens when a user questions whether or not they may have a diagnosis. An example from video 6, which portrays a man mimicking a song that says "*I'm sorry it's just the chemicals*", with complementary text stating: "*splitting and not realizing the weight my words hold*". A user comments: "*bro I've never questioned whether or not I have BPD or not until this video... spot on me for, feeling like that now actually ..*". Another user answers: "*This isn't just a symptom of BPD and could be another disorder entirely. Perhaps talk to a professional and see if they can arrange a diagnosis Don't fkn self diagnose bpd*".

We observed that some members state that they have similar experiences and histories, which seems to give users a new meaning to their situations. An instance of this is when a content creator gives a metaphor for what it is like to have ADHD, and one user comments: "*Omg I have not heard something that explains how I feel better. Like I WANT to, but physically can't make myself move*". *Engagement-repertoire* concerns to what extent this shared behavior has developed over time. We found little evidence for this type of behavior, as shown in the 11 codes out of 1125. However, the examples we discovered mainly concern shared language such as how language, experiences and storytelling have developed into an internal understanding within the community with abbreviations such as "*KMS*" (kill my self), "*TW*" (trigger warning), and "*AFAB*" (assigned female at birth). Special hashtags are also created such as: *#80hd* (ADHD), *#autusm*" (autism) and *#grippysocks* (mental health facility).

Imagination - Constructing an image of themselves and their communities

Building an image of ourselves, our communities, and the world, in order to orient ourselves, reflect on our circumstances, and explore options, is what the imagination mode of belonging is about [18]. The users of the community have a place where they are open about sharing their experiences with mental health issues. We found that a common conception among users in this community is that to be validated, you must have a diagnosis. As an example, the creator of video 3 posts about why she wants a diagnosis. Multiple users respond with comments such as: "*NO THIS. I want a diagnosis. So I can finally say somethings wrong with me. I have not been faking. This suffering isn't fake.*", or "*Doesn't it feel like your never gonna ge sick enough without a diagnosis*", and "*Because people don't take me seriously, if I have a diagnosis maybe they'll finally understand what I'm going through.*". In video 8, about what the creator's manic episode looks like, a commenter says: "*Omg honestly me too . It's crazy how I can relates so much to these videos… idk if I do have something that I'm unaware of or if it's just that*". And another comment: "*I do all these to a T but I've never considered that I could have bpd*".

Looking at *imagination - mutuality*, we see that users post comments about how their participation can be translated into their lives. Comments such as: "*This is what I need to show my family!*" and "*This is so me! I just get told I'm lazy.*" shows how members will bring what they have heard or seen on TikTok, back into their everyday lives.

We frequently observed discussions in which individuals are questioned about their statements, as well as others who defend one another or themselves. These discussions often include assertive language where the users do not listen to each other. In video 2, the content creator says that people who are not sure if they have autism or BPD probably have both diagnoses. The creator then receives backlash, and follows up in the comment section with: "*y'all PLEASE stop coming for me for how I worded this… I'm autistic and probably didn't do it "right" lmao I apologize for my definitive language, but again I remind you all that black and white thinking/wording is part of autism lol*". Another example from video 10. The content creator states that women often go undiagnosed because studies have primarily focused on ADHD in men and young boys. A user comments: "*Young white***** boys*", to which a user answers: "*You know a white kid and a kid of color are both equally kids. This meaning they're both human with similar traits. Race has nothing to with this.*". We found that a common occurrence is tha users often leave the comment section in the middle of a discussion and that they rarely find a middle ground.

Alignment - A mutual process of coordinating perspectives and interpretation toward a greater community

Alignment is a collaborative process that involves aligning perspectives, interpretations, and actions to achieve higher goals. It is about ensuring that local actions are sufficiently coordinated with other processes to be effective outside of our own engagement. The users' learning energy and interest in sharing their knowledge are frequently observed and coded. However, aside from venting, educating, and learning from one another, we observe a lack of goal to create a

vision. People act on their own accords and motivations, which can vary from education, support, entertainment, and so on, but there are no designated leaders to guide the community towards a shared purpose.

The community members share a lot of similar experiences in life, which contributes to the group's cohesiveness. The relatable videos connect the users who have it similarly. And based on this, the strangers in the community form a bond by sharing personal information, supporting each other, giving advice, and acknowledgment, solely through commenting. Comments that showcase these types of shared experiences and support can be: "*BRO i personally felt the same before and after you're valid no matter what and ily*", or "*Ooops, I hope it sorts itself out, if not just know you're never too hard, you're always worth it and not everyone will leave*", and "*thank you for telling me I don't need to be fixed. needed this video more than you even realize. always thought I had to be cured. thank you.*".

Videos where content creators or users post about their struggles in a serious manner usually receive a lot of support. As an example: "*I'm crying. cause there is something I badly need to do and I can't. no one understands except you*" where another user responds to the content creator about needing a diagnosis because nobody understands them, and they want to be taken seriously. Trends and music play a big role in delivering their message. There is a common understanding of how to behave, and this is upheld by the community almost naturally or intuitively.

5 DISCUSSION

Attachment to the community because of illness

While maintaining social ties can be challenging for people who are suffering from mental illnesses, TikTok facilitates effortless interaction between users, giving the community members various ways of engaging with each other. Ernala et al. talk about people and their need for 'sympathetic others', having someone that shares the same social stigma or similar experiences. Harwood describes TikTok as a third place, where young people can get support whenever they need it, without having to tell their parents or seek professional help. Similarly, Basch et al. did a study of TikTok's mental health content and found that 61% of videos were offering support or validation

This is reflected in our analysis and the high presence of engagement and mutuality. However, both psychologists raised the question of whether it is more difficult for users to break free from the community if their attachment to the community is based on their mental illness. This may point to an ambiguous nature of TikTok for young people as a place to express themselves. On one hand, TikTok functions as a space where they can feel safe and discuss difficulties, perhaps without feeling the same obligations to act upon their disclosures as when speaking to an adult, parent, or professional. This aspect of TikTok seems to be a motivator for members to use the platform, as well as a contributor to speaking more openly about mental illnesses. Furthermore, the aspect of anonymity can provide an additional layer of safety that allows them to speak freely without having to worry about being judged or told what to do.

On the other hand, breaking free from the community may prove challenging if the members see their mental illness as the link that relates them to the community. The psychologists questioned the motivation of members to seek professional help to improve their mental state if they fear it might mean them losing out on the community. Finding fellowship, or simply being heard and noticed within the community may provide a missing need, and cause them to not want to become healthy in fear of losing this form of support

Accelerated self-medicalization

Yeung et al. discussed that self-reporting of ADHD symptoms may be exaggerated, and because of this, there is a higher risk of overdiagnosis or misdiagnosis in people who seek health information on TikTok [20]. Similarly, we discussed with P1 that the members of TikTok speak in a diagnostic language that medicalizes themselves, and used the analogy "*you are no longer shy or nervous, you have anxiety*" to depict the situation. Furthermore, P1 told us she experiences adolescents as more concerned with diagnoses than adults, and that they want a diagnosis to justify not fitting in, or having problems with relations. This aligns with what we observed in our analysis. The users within the community frequently talk about diagnoses, and we often observed that when they relate to a video about a particular diagnosis, they would question if they might have the diagnosis themselves. In video 3, where the content creator states why she wants a formal diagnosis, users in the comment section could relate to this and discuss how they feel the need to get a diagnosis to be taken seriously and be validated.

Self-disclosure as factual evidence

Self-disclosure of personal experiences can help build trust and connections, as well as convey a difficult or complex topic in a more relatable and understandable way for others. Kong et al. and Zheng et al. used DISCERN to investigate the credibility of TikTok videos as a source of health information, the effectiveness of treatment options, and the overall quality of the publication or medium as a source of information. They found the overall quality acceptable and satisfactory. Conversely, Yeung et al., Zheng et al., Xue et al., and Om et al., used the same tool and concluded that the videos they studied on TikTok are misinformative or poor in quality. Furthermore, Yeung et al. classified 52% of the videos about ADHD as misleading, and that none of the misleading videos advised viewers to seek professional help. They state that viral trends on TikTok, echo chambers in social media, and romanticization of mental health symptoms may perpetuate the dissemination of misleading information on TikTok. These findings are similar to what P2 stated in the interview, about there being a lot of misrepresentations about mental illnesses on TikTok, that can cause more harm than good, and that he would refer any requests to diagnose someone to a professional.

This type of behavior is highlighted in our findings, such as in video 1, where a user was having trouble getting to bed at a reasonable time and another user indicated they might be suffering from delayed sleep phase syndrome. The user asking the question then praised them and claimed he could fully relate to that statement. A second example can be seen in video 6 where a man with BPD realizes he has said some harsh remarks as a result of his black and white thinking. A user comments "*bro I've never questioned whether or not I have BPD or not until this video… spot on for me, feeling like that now actually..*".

These examples highlight how self-disclosed experiences being used as factual evidence may impact members and viewers more than intended. It demonstrates how easily users in a community like this can be influenced by what they see on social media, and how it may contribute to strengthening misinformation. According to Basch et al., repetitive and extended viewing of TikTok videos might contribute to poor mental health outcomes [2]. The examples may also be a result of what P2 says about video creators being focused on likes and views, and that their videos must be relatable. Taking more responsibility for the content one creates, and the messages we publicly post, may be an important step to discourage the accelerated self-medicalization we discussed earlier on.

Communities of practice for social media analysis and design

Complimentary to Basch et al.'s study, we observed that the community shares experiences, language, histories, and coping methods. The users can also be given new meaning to their own experiences by seeing others talk about theirs. However, how this has developed over time is something we have not observed. As stated in Engagement in our results, the users have developed a common understanding of certain abbreviations as well as special hashtags. The deficient number of codes in *Engagement-Repertoire* can be a result of these abbreviations and hashtags mostly being used in the descriptive text of videos.

While the learning energy and knowledge sharing within the community can be said to be strong, we did not observe any goals to create a shared vision of where to guide the community. This might be because the community does not have any designated leadership. Wenger writes about the importance of internal leadership and states that a COP is dependent on enabling the leaders to help the community develop. Comparably, P1 stated that you will never find group therapy or support groups without a leader who maintains track of processes, because of its importance.

Definitions of shared roles and norms, as well as ways to behave and talk about certain topics, were not highly observed. The community is held together by the members' similar experiences of battling with their mental health. Behavior patterns we recognized were content creators' way of using trends and music as a way of delivering their message, which complements Herrick et al.'s findings in the ED-recovery hashtag on TikTok. However, since we focus on user behavior in the comment sections of videos, this was not frequently coded. Another reason for the lack of alignment could be that roles and norms are not written in the comments. The lack of alignment in this community can, according to Wenger, result in the community's processes being ineffective beyond their own engagement.

Implications and future work

We believe that our work functions as a guide for future design considerations, and that it may contribute to the development of a set of standards for developing social media platforms, particularly ones that feature community-supported features. Based on our findings and previous research, we present three implications and future work

directions. These concern the attachment to the community, how the community discusses mental health, and finally, leadership and vision of the community.

Firstly, we see that TikTok provides a missing need among the users as a space where they can openly express themselves and discuss their mental health problems. This supports the claims of Harwood and Ernala et al. However, P1 and P2 question whether users may not seek the professional help they need, for fear of losing their place in the community if they get healthy. We believe that future work may benefit from looking into if being a part of such a community may obstruct their drive to seek professional help on the basis of having a support system, instead of becoming healthy.

Secondly, while P2 states that what is common for content creators, is that they want their videos to be liked and viewed, he also believes it is important to dare to talk about mental health even if we are not experts. The community could benefit from ensuring that information regarding more serious topics, such as mental health, is not jeopardized at the expense of creating entertaining and relatable videos. Providing clear guidelines and easy methods for fact-checking such as links, tags, or disclaimers could be directions to look to when exploring how to accommodate this.

Lastly, our study of the community element found that the lowest presence of modes of belonging within the community was that of alignment. Both Wenger and P1 state that having leadership in a community is important to aid the community forward and help it develop and prevent it from becoming malignant. We believe that this is an area where future work should focus on, to improve the community's integrity. In terms of future design implications, features that support and guide community members, such as leadership, mentoring, and a vision could give the community directions on how to positively develop.

Limitations

We acknowledge that this research has its limitations in that we chose to study videos related to three mental health diagnoses; ADHD, autism, and borderline personality disorder, so the study is not a representation of the complete mental health community on TikTok. Furthermore, the study in the 9th semester showed us how identifying the boundary and identity elements of Wenger's communities of practice is limited by a digital ethnographic approach. Additionally, the study could benefit from direct feedback from the users of the community, however, we chose not to reach out to the users after discussing this with the psychologists due to ethical concerns.

6 CONCLUSION

In this paper, we perform a deductive analysis on the comment sections of 10 videos on TikTok, related to mental health. Moreover, we utilize Etienne Wenger's theory on communities of practice, to assess the mental health community by looking at how they learn, engage with each other, and understand their state of development. We found that TikTok facilitates a platform for the members where they can share experiences, support, and validation with each other. Based on interviews with two psychologists, related work, and our analysis, we were able to address the research question: How is a mental health community on TikTok considered a platform for support and information, and how may design further strengthen the positive aspects and mitigate the negative aspects of the community? To answer this we present three implications and future work directions. First, we suggest that future work investigate if the motivation for being in the community affects their drive to seek help and become healthy. Second, implementing guidelines and methods for fact-checking could accommodate the prioritization of correct information regaring more serious topics, such as mental health.. Third, features that support and guide members, such as leadership, mentoring, and vision can give directions to improve the community.

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