

“I See Me Here”: Mental Health Content, Community, and Algorithmic Curation on TikTok

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ABSTRACT

Social media platforms are a place where people look for information and social support for mental health, resulting in both positive and negative effects on users. TikTok has gained notoriety for an abundance of mental health content and discourse. We present findings from a semi-structured interview study with 16 participants about mental health content and participants’ perceptions of community on TikTok. We find that TikTok’s community structure is permeable, allowing for self-discovery and understanding not found in traditional online communities. However, participants are wary of mental health information due to conflicts between a creator’s vulnerability and credibility. Our interviews suggest that the “For You Page” is a runaway train that encourages diverse community and content engagement but also displays harmful content that participants feel they cannot escape. We propose design implications to support better mental health, as well as implications for social computing research on community in algorithmic landscapes.

CCS CONCEPTS

• **Applied computing** → *Health informatics*; • **Human-centered computing** → *Empirical studies in HCI*; *Empirical studies in collaborative and social computing*.

KEYWORDS

Mental Health, Community, Social Media, Interview, TikTok

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1 INTRODUCTION

Online mental health content is an essential source of health information – individuals turn to social media as a reliable source of information [26], community [25, 62], and support [65]. In turn, this content can have positive therapeutic benefits for users [73, 80]. However, this content exists in a complex information-sharing environment with risks of harmful health content [16] and misinformation [46], and more significant challenges around context collapse and sharing/seeking health information [2, 50]. The tensions have come to a head with one particular social platform, catapulting it into the international spotlight: TikTok.

TikTok is a video social media platform where users can create, watch, and engage with short-form videos. Figure 1 shows an example of the application’s main feed. TikTok is now becoming a popular source of information [51] and is influencing socio-political discourse [29, 47, 71]. The platform has become known for user-generated mental health resources that improve mental health literacy [43, 66]. The app saw a significant increase in popularity in 2020 with 3 million downloads a day and now has more than a billion users [59, 72]. Many of these users are teens and young adults [78], a population that has seen a spike in mental illness in the last decade [3].

TikTok has become a significant hub for mental health discourse [21, 31]. A content analysis of just 100 popular #mental-health videos on TikTok shows that the videos have 1.3 billion views and over 266 million likes [4]. Recent research suggests that TikTok influencers impact perceptions of public health and mental health information [4, 52, 66]. Popular press reports also confirm the reach and impact of mental illness content via the sheer volume of exposure combined with the relatability and accessibility of the content [43, 68].

However, there are growing concerns about TikTok’s mental health content and its impact on user well-being. News reports and research suggest that people use TikTok to self-diagnose mental illnesses based on these short-form videos, with varying results about their accuracy and utility [14, 36, 77]. Young people turn to the platform to supplant clinical diagnosis for ADHD [14, 36]. However, the quality of health information may be suspect [42]. For example, early research on ADHD TikTok content, one of the most ubiquitous topics on the platform, suggests that half of the content was misleading [81].

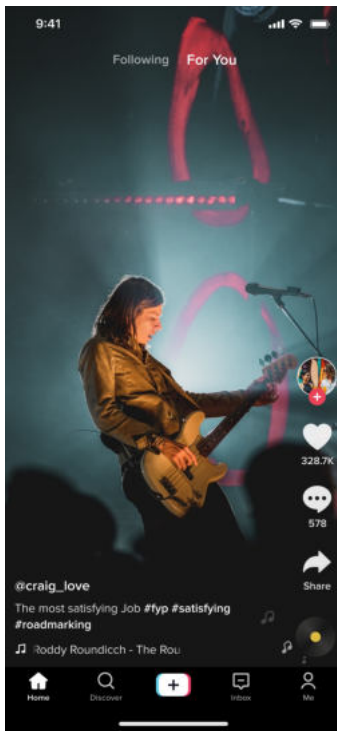


Figure 1: An example of the TikTok For You Page (FYP), the algorithmically curated main feed of TikTok. Each post that comes through the feed has a profile, like, comment, bookmark, and share buttons along with the creator’s name, post description, and sound information. Image by Pixsellz, used under the Creative Commons License by 4.0

If TikTok is being appropriated for mental health content and support-seeking, as these reports indicate, we must empirically understand how TikTok impacts users and their perceptions of their mental health. TikTok is almost entirely mediated through a broadcast-style feed called the “For You Page” (FYP). The FYP is a personalized (and proprietary) infinite scroll recommender system that dominates content delivery and prioritizes user attention, engagement, and virality [58]. Work on TikTok has consistently shown that community is algorithmically formed into user-perceived but informal identity- and topic-based “Toks” [29, 71], e.g., “ADHDtok”, “depressiontok”, or “transtok”. These Toks function as primary sources of community and social support for some users [41, 71]. Moreover, some marginalized users now view TikTok as a platform whose purpose and unparalleled primary talent is to identify and construct community along identity lines [29].

However, TikTok’s curatorial structure has also been implicated in altering one’s self-concept [70], to the extent that some users believe that what is delivered to them through the FYP is a direct statement about their identity or beliefs that they had not yet realized [22]. Research on TikTok points to the FYP informing identity and self-concept, both intertwined with mental health [79]. While the effect the FYP has on identity is complex in normal circumstances [6, 41], studying this is crucial in the current social media

landscape, where algorithmic curation has been implicated in actively harming user mental health and body image [34, 35]. In short, we argue that TikTok’s format and algorithmic curation influence mental health content and user self-concept in distinctive ways that must be understood, lest we risk harming users.

In this paper, we ask two questions: What about TikTok allows mental health content to thrive on the platform? What impact does this mental health content and perceptions of community/Toks have on people who use TikTok? We pose the following research questions:

- RQ1: How do users engage with mental health content on TikTok?
- RQ2: Do users perceive that TikTok has communities? Are mental health Toks communities?
- RQ3: How do users assess the information they receive about mental health on TikTok?
- RQ4: What is the role of the For You Page (FYP) in curating mental health content?

We interviewed 16 TikTok users who have interacted with the mental health content on the platform. Our semi-structured interviews consisted of two activities and questions about community, mental health, and TikTok. Activities included a visual elicitation exercise [39] and a video review session with content submitted by the interviewees. We analyzed the resulting transcripts and visual elicitations using constructivist grounded theory [17, 18].

Our participants had divergent views on the kinds of mental health content and whether communities existed on TikTok. The distinction between community and content does not align with topical information about mental health. Those who perceived mental health communities on TikTok described them distinctively from the existing literature on online health communities (OHCs) – but the support participants received was almost indistinguishable from that provided by traditional OHCs. The definition of community by participants depends less on the structure and allows for community voyeurism to diversify knowledge and understanding about mental health. To describe this new definition of community, we coin the term “permeable” communities. Our participants also identified a tension between the perceived inability to call out misinformation in moments of vulnerable self-disclosure and that many content creators chase social prestige and virality, or clout, through the same content. Aligning with prior work [71], our participants indicated that the FYP heavily mediates peoples’ experiences with mental health content and community on TikTok. Users felt the algorithm develops quickly and that they cannot control what content or community they are seeing, thus creating what we call a “runaway train” for mental health.

These findings suggest that while TikTok is creating a space where mental health communities can thrive, there exist crucial concerns about the impacts of the algorithm on perceptions of community and well-being. We present design implications to better support mental health for users and communities on social platforms with such strong connections to algorithmic curation. We also discuss what community means, expanding on current definitions of online communities in HCI/CSCW, and this definition’s impact on platform development and management.

2 RELATED WORK

2.1 Online Mental Health Content and Communities

The study of online mental health communities (OMHCs) has been a rich area of study in HCI, with practitioners looking into questions of why, what, and how users talk about mental health in communities [38]. We overview previous work on online mental health content, OMHCs, and their connection to our study.

People use OMHCs to discuss their experiences with mental illness for many reasons. Research has shown that users self-disclose to gain support from others in similar situations [7, 32, 57], even with the risks they open themselves up to [7]. Many individuals look for support from others with the condition of interest [4, 57] instead of professionals [27]. A study of the Twitter hashtag "#WhyWeTweetMH" discovered that users tweeted about mental illness despite the risks due partly to a sense of community [5]. However, the lack of professionals can lead to issues with credible health information – a review by Suarez-Lledo et al. [74] found a large amount of misinformation surrounding eating disorders.

The next big question then becomes how users further build communities around it, which is an active area of research, with work from both quantitative [15, 25, 32] and qualitative [12, 35] perspectives. Several prior studies focus on elements of community that influence how people discuss their illnesses. For instance, users with schizophrenia consider the perceived audience of disclosure before making it [32]. Feuston and Piper [35] explored how users talk about mental illness and found that the structure of Instagram plays a role in how users talk about mental illness experiences [35]. In addition to signaling with hashtags [15, 16], some users infrequently use hashtags [7, 34] to indicate that their posts are related to mental health. Instead, these users use signals and visual aspects [34]. Hashtags are commonly used in analyzing mental illness on social media [5, 45]. Still, if users are not employing them, they must use other means to find mental health communities on social media platforms.

Across all of these works is the importance that OMHCs provide people in seeking support and finding similar others to discuss their experiences with. Our work builds on this by studying how people use TikTok for mental health.

2.2 Definitions and Perceptions of Online Community

What does it mean to be part of a community? The concept and definition of community are contentious, especially regarding the community in online spaces. This section discusses competing definitions of community and their connections to TikTok.

Early definitions of community in psychology and sociology heavily relied on physical location as a critical element to their success [53, 60]. With the advent of the Internet, however, physical closeness was no longer necessary for communication, and the notion of online communities was born [63]. A new definition of community was added to the mix as what Bradshaw [10] describes as "post-place communities" took root. There has been much discourse around if online communities were "real" communities without the dependence on face-to-face interactions [63].

People experience a "sense of community" in online communities, which later emerged in social media [44, 64]. McMillan and Chavis [53] outlined criteria that must be met for a sense of community to be established, including membership, influence, fulfillment of a need, and a shared emotional connection [53]. Follow-up work confirmed that many of these community and social aspects apply in online spaces [8]. However, the definition of offline to online community is not one-to-one. Previous work has attempted to understand if offline community structure applies to social media communities and has found that the formation, maintenance, and disintegration of social media communities differs from that of offline communities [19]. Even within social media, different communication formats exist; for example, Twitter is a mainly text-based platform with a robust following system while YouTube is a video-based site with options for subscribing or commenting [67]. The different affordances for community on social media have also led to different types of users who interact with communities. For example, lurkers are a particular group of users that do not necessarily interact via major functionalities (posting and commenting) but are active in other ways [75].

TikTok is a new video social media platform that has risen in popularity in the last few years. The platform has a unique feature called the For You Page (FYP), an algorithmically curated content feed. Simpson et al. [70] explored users from the LGBTQ+ community's experiences with trying to domesticate the FYP. They found that even with users trying to tailor their experiences, there was a disconnect between the platform and the user's digital selves [70]. The freedom and versatility of TikTok provide numerous opportunities for traditionally stigmatized communities to flourish online [29, 30]. Similarly, DeVito [29] found that users employ a diverse set of folk theories to try to navigate the algorithm, to varying success.

Our current work dives into how communities exist on TikTok due to its lack of traditional community structures. Community on TikTok seems to be facilitated via the FYP, an endless scroll recommendation of posts. We explore how this notion of community intersects with mental health and the outcomes we see on the platform.

2.3 Research on TikTok

With TikTok being a relatively new platform, most of the current work is focused on identity and information on identity [6, 29, 41, 71], as well as COVID-19 information [49, 61]. In this final section, we discuss research on TikTok that is most relevant to our research interests.

As mentioned earlier in the works by Simpson et al. [70] and DeVito [29], many studies about TikTok have focused on the relationship individual users have to the platform and their identities. Simpson and Semaan [71] found that there is a duality in LGBTQ+ users' FYP with simultaneously supports identity work and affirms LGBTQ+ identities as well as transgressing and violating the same identities. In addition to work on identity, social activism is a popular movement on TikTok which was explored by Le Compte and Klug [47], as is identity-related content investigated by Karizat et al. [41] and Bhandari and Bimo [6]. TikTok also facilitates knowledge

spread, especially for stigmatized identities, because finding information related to them can be challenging, if not dangerous, in some situations. In the health domain, Messina [54] explored how health information is shared between LGBTQ+ youth using TikTok as a medium for dissemination. However, the spread of medical information in this way can be dangerous given the potential for misinformation and product promotion [82].

Much existing work highlights how TikTok interacts with queer identities and the spread of queer-specific and COVID-19 information. However, the prominent mental health presence on TikTok has not been studied from the user's perspective, with most studies focusing on public health and content analysis [4, 52]. Thus, our current work investigates users' perceptions of community-related to the mental health community.

3 METHODS

To answer our research questions, we conducted 16 semi-structured interviews with individuals aged 16 to 54 who engage with mental health content on TikTok. In these interviews, we ask about their perceptions of community on TikTok, specifically mental health communities. We guided them through 2 activities: visual elicitation and video review, during a 60 to 90-minute interview. The study was approved by the Institutional Review Board at all author institutions. In the remainder of this section, we will describe our recruitment and interviewing methods and provide information relevant to our participants.

3.1 Participants

Participants were recruited across multiple social media platforms including TikTok, Twitter, and Instagram, and via flyers and word of mouth. Interested individuals were asked to fill out a survey via Qualtrics which checked that they meet our eligibility requirements: 16 years of age or older, regularly used TikTok in the last six months, and have engaged with mental health content on TikTok. If they meet these requirements, they proceeded to our consent form and an initial demographic and TikTok use survey. Researchers followed up with eligible participants to schedule interviews. We also asked participants to supply videos to prompt discussion, requesting 1 or 2 TikTok videos related to mental health that gave them "a sense of self", "a sense of community", and a video that "seemed out of the blue".

All participants consented to record the interviews and be contacted as needed for study completion. All interviews took place over Zoom from April to July 2022. Individuals who completed the interview were compensated with \$25 Target or Amazon gift cards (participant's choice). The first two authors conducted these interviews, supervised by the last two authors. We continued to recruit participants until theoretical saturation was reached [18]. Our sample falls within the average sample size for interview studies conducted in the human factors domain [13].

Our participants ranged in age from 17 to 53 ($M=31.8$) and were predominately female ($N=11$) and white ($N=11$). Table 1 shows a breakdown of participant demographic information. Note that we allowed for self-identification and multiple selections, thus some standardization of terms has occurred (i.e. woman and female collapsed to female) and counts on demographic characteristics will

not always sum to our number of participants. All participants had been using TikTok for at least four to six months, with the majority using it for more than a year. In Table 2, we report how often users took advantage of different affordances of the application. Most notably, the majority of our participants do not usually create content on the platform but regularly view, like, and comment on videos.

3.1.1 Recruitment Integrity and Online Participants. During our recruitment processes, we encountered challenges around recruitment integrity and concerns about repeat participants. We received 73 responses to our recruitment survey. During initial interviews, the research team saw indicators that some volunteers were attempting to participate in interviews multiple times under alternate names and email aliases. We based this on behaviors witnessed in interviews (e.g., changing their Zoom name from an old participant's name to a new participant's name) and participants' refusal to speak about mental health content on TikTok, suggesting they did not match our screening criteria. We changed our recruitment protocol to screen for repeat participants more effectively, with all changes approved by our IRBs. We describe this process for transparency and usefulness for the HCI community, which may deal with similar problems as research moves online during and after the COVID-19 pandemic.

As an initial check on volunteers, we enabled two measures of duplicate tracking on our signup form, the Qualtrics-provided FraudScore and DuplicateScore¹. About 60% of our survey responses were flagged as having high scores in one or both of these metrics. Because the exact mechanism for calculating the metrics is proprietary, the research team tried to conduct interviews with several participants at the threshold. All interviews where participants had scores close to the thresholds failed our expanded screening process (described below) and were not included in our analysis.

We also adjusted our interview protocol to quickly establish if a participant was genuine. The TikTok links for the video review activity were initially due at the beginning of the interview, but we changed this "due date" to 24 hours before the interview so the research team could screen them. Similarly, we asked participants to verify their answers to our screening criteria and reorganized our semi-structured interview guide to ask questions about mental health content on TikTok early in the interview. If the TikTok content or immediate interview responses were unrelated to mental health content, we terminated the interview due to the participant not meeting our screening criteria. Finally, for all interviews, if we completed an interview that we later realized was not relevant to mental health, we compensated participants for their time.

3.2 Interview Procedures

We conducted a semi-structured interview with all participants that included two activities, visual elicitation and video review, along with questions. Each interview started with participants reconfirming that they met all the eligibility requirements for the study and ensuring that they consented to participate. Participants

¹These proprietary features use metadata about the survey takers (e.g., speed of completion, IP address) to assign a score that evaluates whether the survey taker is genuine in their survey taking. See <https://www.qualtrics.com/support/survey-platform/survey-module/survey-checker/fraud-detection/>

Demographic Variables	N	Percentage	Demographic Variables	N	Percentage
Age			Employment status		
16-19	2	13%	Employed full-time	5	31%
20-24	5	31%	Employed part-time	6	38%
25-34	5	31%	Prefer not to answer	0	0%
35-44	3	19%	Retired	0	0%
45-54	1	6%	Self-employed	2	13%
Gender			Student	4	25%
Female	11	69%	Unemployed (looking for work)	1	6%
Male	3	19%	Unemployed (not looking for work)	1	6%
Non-binary	4	25%	Income		
Transgender	2	13%	0	2	13%
Sexuality			1 - 9,999	4	25%
Asexual (inclusive)	2	13%	10,000 - 24,999	2	13%
Bicurious/Bisexual	7	44%	25,000 - 49,999	1	6%
Gay	1	6%	50,000 - 74,999	5	31%
Heterosexual	3	19%	75,000 - 99,999	2	13%
Lesbian	2	13%	100,000 - 149,000	0	0%
Pansexual	4	25%	150,000 and greater	0	0%
Queer	2	13%	Relationship status		
Ethnicity			Divorced	2	13%
Asian	1	6%	In a relationship	6	38%
East Asian	1	6%	Married/ cohabitating	7	44%
Middle Eastern	1	6%	Other	1	6%
Prefer not to say	3	19%	Prefer not to answer	0	0%
Scottish	1	6%	Separated	0	0%
White	11	69%	Single	3	19%
			Widowed	0	0%

Table 1: Aggregated Demographic Information of Participants

How often do you :	Weekly or less	A few times a week	Daily	A few times a day	Hourly	Multiple times an hour
Create content on TikTok	14	0	2	0	0	0
View content on TikTok	0	5	0	9	0	2
Like content on TikTok	1	5	1	8	0	1
Comment on TikTok content	1	5	1	8	0	1
Share content on TikTok	3	5	3	5	0	0
DM users on TikTok	12	0	0	4	0	0

Table 2: Aggregated TikTok Usage Information of Participants

were asked to think about and answer questions concerning mental health and mental health communities.

3.2.1 Video Review. The video review studied what gave participants different feelings about content and community. This review used the TikTok videos the participant sent in advance of their interview. We asked them to send one or two TikTok videos related to mental health that “gave them a sense of self”, “a sense of community”, and a video that “seemed out of the blue.” Participants were asked what specifically in the videos gave them these feelings, how videos differed from each other, and the kind of interactions they had with these videos. Most participants displayed a common understanding of the three kinds of content we asked for. When clarification was requested, we provided further explanation of “a

sense of how the content relates to you”, “a sense of how the content relates to a community”, and “content that seemed out of place in your feed”, respectively.

3.2.2 Visual Elicitation. For the visual eliciting activity [39], participants were asked to draw, via a Google Jamboard, what their TikTok experience looked like in terms of community, mental health, topics, or creators, and any emergent relationships they saw. The goal was to get participants to highlight differences, similarities, and connections between communities, particularly related to formal and informal mental health support.

3.2.3 Semi-Structured Interview. Interviewers asked questions about communities, in-groups, and out-groups to ask for more formal definitions of community and mental health, what it meant for

the participant to be a part of a community, the progression of a sense of community, and the difference, if any, between online and offline perspectives². During the interview, the interviewer listened for perceptions on communities and mental health on TikTok and would follow up on these ideas or request further explanations.

3.3 Analysis

For our analysis, we used constructivist grounded theory [17, 18] facilitated by MaxQDA software for qualitative coding. The first two authors of this paper coded, wrote memos, and made comparisons to allow themes to emerge from the interview transcripts. For the duration of data collection, all authors of this paper discussed emerging concepts and adjusted the semi-structured interview protocols to probe new areas of interest.

The first two authors conducted open coding, which consisted of labeling concepts that emerged from the interview transcripts [55]. These open codes were ultimately refined into axial codes through discussions among all authors to relate codes to each other to find key themes and concepts [55]. Through further discussion of codes by the first two authors, all interviews were combined, and a final selective coding round was done, which included re-coding when necessary. A last confirmatory pass was completed with all authors to verify our shared agreement about the findings.

3.4 Positionality Statement

We had both active-member-researchers and peripheral-member researchers of mental health communities as part of the research team [1]. Having team members who were active in or at least familiar with the domain of mental health and TikTok were important. Most authors are active members of mental health communities and have prior experience researching mental health. All authors were involved in the design and refinements of the study, while the first two were responsible for the implementation.

The positionality of the research team is both an asset and a limitation in the execution of this work. The authors have lived experiences with and inside knowledge of mental illness and mental health communities, which gives valuable insights into the experiences our participants discussed. However, the involvement also suggests that our personal experiences with mental health undoubtedly influence our work.

4 FINDINGS

4.1 RQ1: Mental Health Content on TikTok

Our first research question (RQ1) asked how users engage with mental health content on TikTok and, by extension, *what* content users engage with. All participants regularly saw or interacted with mental health content, though what they considered related to “mental health” varied widely. For our participants, the concept of “mental health content” goes beyond videos directly related to mental health, e.g., people talking about mental illness explicitly or topics such as diagnosis. We found that users engaged with three types of mental health content: informational or clinical content,

pragmatic content, and comfort content. Each type of content plays a distinct role for the users.

4.1.1 Informational or Clinical Content. All participants engaged with **informational or clinical mental health content**, or content directly related to clinical mental health experiences and knowledge. This includes symptoms, diagnosis, therapy, treatment, and other content specifically about the clinical and informational aspects of illness. This aligns with what we know about content on online mental health communities [62]. Participants frequently mentioned videos where content creators express their experiences with specific mental illnesses. For example, P11 showed us a video about rejection sensitivity dysphoria³. In this video, the creator recorded themselves at their desk crying with captions explaining that they knew logically that canceled plans were not a rejection. However, they still had to argue with themselves that it was true and how exhausting and emotional it was⁴. This example was a direct reference to the experiences of having this disorder. Many participants found these types of videos helped them process their own experiences, as P25 explained:

“[A video] put into words what I feel...and then sometimes they’ll say maybe why and it makes me realize, Oh, I feel the same way...Then I reflect and see if that’s why, and then it actually helps me...so I can talk about it in my therapy group or in my individual therapist”

Several participants even said they sought diagnoses for specific mental illnesses after encountering related videos on TikTok. For example, P1 felt they “*recognized themselves*” in these types of videos and credited TikTok with their ADHD diagnosis. P25 had a similar experience, using these videos to initiate a conversation with their therapist:

“TikTok is not an official thing. But I have a psychiatrist, so I brought [these videos] up to him. He’s like ‘yeah I kind of noticed that you do these things too’. Then he put me on a list to get tested and then I got tested, and I do have ADHD”

Outside of diagnosis and personal experience, information about mental illness and therapy, in general, is also common mental health content on TikTok. One participant felt like labels for the specific mental illness were not important, but found it helpful to embrace content that was useful, regardless of the label:

“Without picking a label, I think allows me to look at content, not just on TikTok but even medical content about PTSD without having to agree on this is true of me or something without having to say anything to me about me or about what I should do. I can take it or leave it.”

While many videos our participants discussed came from the general public, mental health professionals also publish mental health content. For example, P34 recounted finding content⁵ from a psychologist talking about coping strategies and therapy techniques:

²The interviewer used what they had learned from the video review and visual elicitation exercises to tailor the semi-structured questions to each participant based on their experiences, perceptions, and talking points.

³rejection sensitive dysphoria is an intense emotional reaction due to the perception that a person has been rejected [9]

⁴<https://www.tiktok.com/@elle.argent/video/7080209086180085035>

⁵<https://www.tiktok.com/@therapyjeff/video/7125511003986562347>

"Some of the other therapy videos, they are not therapy videos - I [think there's] a psychologist who is saying, you know what should you do when your parents blow up at you"

4.1.2 Pragmatic Content. While the above quote is an example of informational/clinical content, it also showcases **pragmatic mental health content**. Pragmatic mental health content is content that, while not explicitly about clinical mental illness treatment or care, is integral to how mental illness and well-being impact people's daily lives. In the current study, participants discussed how supportive this content was for their everyday experiences and how it helped them manage mental illness symptoms and behaviors. Our participants were not alone in this sentiment as existing studies found that people wanted support from others with the same condition [57] and when sharing most people situated their experiences in their day-to-day lives [35]. For example, P3 highlighted the importance of this pragmatic content for their mental health, like using chewable jewelry to help with sensory processing:

"I asked them [a creator] how they deal with their chewy during the pandemic. I was afraid to wear my chewy necklaces out during the pandemic. They gave me some great tips for jewelry necklaces and cleaning them and things you can put on them."

P3 also talked about how they see content about "cleaning tips for ADHD and anyone who struggles with executive dysfunction", which both the content creator and the participant called "struggle care". P3 implied this was important because the tips were tailored to their mental health state and helped them with their daily life. Other participants found that some mental health content makes great motivational tools. P25 talked about how helpful "nudge" videos were to help them feel "seen":

"You feel very seen and motivated because maybe I didn't drink water that day. So now, I have to go do it because somebody called me out, [and they] don't even know I exist. I didn't eat or drink [today] and then someone on...my for you page, and I'm like fine I'll go do it again"

4.1.3 Comfort Content. Finally, we address the third kind of video for our participants, **comfort content**. Comfort content is content that is not directly or deliberately related to mental health, but nonetheless impacts individual mental health. Several participants pointed to content involving kittens, puppies, or animals as examples of comfort content. This is a broad category that is contextual to the individual. Comfort content represents a useful mental break, as P4 explained, "it's generally like animals and stuff I love animals."

Others, like P34, were more fond of interactive content, such as that made by a creator known as "Korean dad"⁶:

"The Korean dad is more interactive. In the video that I sent you and he was enacting his kid breaking his favorite mug. Then he was saying "it's okay, you know a mug is always replaceable, but you are not and I'm more happy that you are safe"

P20 mentioned the positive impact that watching people experience joy can have on their mental well-being, citing a creator who shares new food experiences,

"his face when he's drinking coconut water ... I don't know what's better, learning about new things that I haven't experienced or their joy"

Art is another outlet that came up for comfort content for participants. P25 found poetry that helps them express their emotions:

"There is a poetry account on TikTok that I really love...and it helps me...put into words what I feel"

In summary, mental health content takes several forms, each engaging and assisting participants differently. Importantly, a single post can embody any number of these ideas and meet different user needs. As P33 highlights, all different kinds of mental health content are vital:

"Mental health content for me is specifically related to people processing mental health talking about their traumas talking about having ADHD, obviously that's a big trend, and TikTok is calling awareness to people who have a late diagnosis and stuff right now. Versus what I do for my mental health that's when the puppies and kittens come in. I know that I said that I searched out mental health videos to not feel so alone in it, but that's not me lifting my mental health that's me trying to process it, whereas I do it when I do it for my mental health like or not, we are trying to lift"

4.2 RQ2: Permeability and Mental Health Communities

Our second research question (RQ2) asked how individuals perceive and relate to mental health communities on TikTok. Recall that TikTok does not have structured communities, like other social platforms like Facebook Groups or Reddit. While all participants acknowledged that they interacted with mental health content, participant perceptions of mental health communities were mixed - either participants felt there were communities or that TikTok was an amalgamation of topics that were distinctively *not* a community. No matter which position they took, our participants described a vital aspect of TikTok as what we describe as "permeability" - loose definitions of boundaries and ease of access to content outside of a person's specific preferences.

4.2.1 Arguments for and Against Community. To begin, some participants felt that there were indeed mental health communities on TikTok. They specifically pointed to shared experiences and support they received from the platform, which are noted to be important in existing social support literature [2, 20, 37]. P4 showcases this when talking about the sense of community on TikTok:

"I think just the subject [mental health] and the way it's talked about naturally bring a sense of community...[Creators] are also sharing their own experiences, stories, or encouragement...which is helpful"

For many of our participants, these communities helped them feel "not alone" and "seen." Participants also used language like

⁶<https://www.tiktok.com/@yourkoreandad/video/7125117855258905920>

“like-minded”, having “shared experiences or interests”, and creating a “sense of belonging” when we asked about mental health communities on the platform. Participants were not bothered by the lack of strict boundaries/firm community structures associated with traditional community definitions and instead focused on the overlap of their identity and communities.

Some participants, however, stated that they did not see TikTok as having communities – but rather a bunch of topics. For example, P5 talked about finding the content they were interested in:

“It sort of seems like there are just these...pockets of...random topics on TikTok and... as the algorithm learns what you’re interested in, you get ...these other types of content get pushed out to you”

Though content appears thematically linked, P5 did not see this as creating the perception of a community. Similar participants compared TikTok and community engagement to more obviously community-centric platforms. For example, P7 did not feel comfortable using the word “community” about TikTok because they did not see a TikTok community form that is similar to how their professional community manifests on Twitter:

“I haven’t really experienced [community] yet on TikTok. I can’t imagine how it would exist on it, to be honest, I know communities on Twitter and LinkedIn even but I don’t know about TikTok.”

Further, P22 mentioned that they felt “like participation is important, at the very least commenting” was a necessary component of community membership. The perceptions of needing structure and engagement from some participants were not mirrored in others that valued shared experience and feelings of support. The differences in the conceptualization of community could also be seen in the visual elicitation activity. Participants were asked to visualize what they thought of landscape or community on TikTok. Figure 2 shows a few images from the activity.

The elicitations displayed the juxtaposition in the concepts of community seen by our participants. We draw attention to the messiness and overlap in P4’s drawing in Figure 2b. The picture resembles more of an abstract painting than what would traditionally be thought of as strict community elicitation. A similar theme can be seen in Figure 2d, depicting clouds and a stream. The abstract overlapping and the depiction of clouds lean into the idea of permeability in communities from a visual perceptible. Moreover, this led to ideas of adjacent communities, seen in the connections and spatial in all the figures in Figures 2. Figures 2a and 2c depict slightly more structure but the interconnected lines in P2’s drawing and the overlap of sections in P8’s, showcase that even in a more structured approach to thinking of community there is an underlying complexity.

4.2.2 Permeable Communities. Loose borders and lack of usability of traditional community indicators while still allowing for the benefits seen from traditional communities, creates the idea of *permeable communities*. Permeable communities are communities that both have loose definitions of boundaries and thus allow for easier entry, and the community structure allows for high transparency so people outside the community or topic can see in. TikTok has created a space for permeable communities – users perceive these

permeable communities which help to make themselves feel “seen” but also to “see” others and take in information from them. While permeability had the positive of discovery for users, it also has drawbacks showing users communities they may not want to see but are related to their other communities.

Importantly, this messiness and overlap cause difficulty for some participants in evaluating what and who counts as a part of a community, as P11 showcases:

“I found it [boundaries] hard to nail down – okay here’s the boundary or here’s how you get in and here’s how you get that content. So the best that I seem to be able to do is like if I drink up[watch] this content of that sort of like what I like then hopefully will send me more”

Two participants used the same analogy for communities on TikTok – that of clouds, in that they are malleable and overlapping. P11 showed how clouds fit into their view of community and on TikTok in Figure 2d. Participants also theorized on how they got into specific communities on TikTok using language around overlap and wandering. For example, P2 mused about how they got to the ADHD and autism communities:

“I think I got to ADHD autism TikTok because ... I will watch the entire video and ...usually I won’t like it, but I might watch the video more than once, because... I really want to understand this”

Permeable communities in turn showcase what our participants, particularly P11, thought was a form of “reciprocity” with TikTok – what users put into TikTok is what users get out. Participants described their relationship with the FYP as a reflection of users themselves and their communities. However, because TikTok communities are permeable, participants did enjoy seeing communities they may not currently be a part of. P2 explained this well concerning seeing content about bipolar disorder:

“There’s also an aspect of it that feels a little voyeuristic like, Oh, like what’s it like to have bipolar disorder? I don’t have bipolar disorder, I’m never gonna have bipolar disorder, but it’s really interesting sometimes to hear about the struggles that this individual has in their manic phase.”

4.2.3 Challenges with Permeability - Getting Out of the “Wrong Side of TikTok”. While not knowing how one got into certain communities can be confusing, participants also discussed a potentially more pressing concern: not knowing how to get *out* of communities. The feeling of lack of full control is echoed from the work by Simpson et al. [70], however unlike that work our participants did not feel they could “tame” the algorithm and thus ended up on the “wrong side of TikTok.” Some participants talked about “the wrong side of TikTok” in terms of communities they do not wish to be a part of, such as P11:

“I’m sure there are also people are getting flung into the wrong...front of a community that isn’t theirs”

Several participants also discussed the frustration of not finding the communities they were looking for. P33 explained how they tried to find and also avoid communities about mental health:

“Is it better to search directly for a hashtag or is that going to lead me to a lot of veteran PTSD which is not

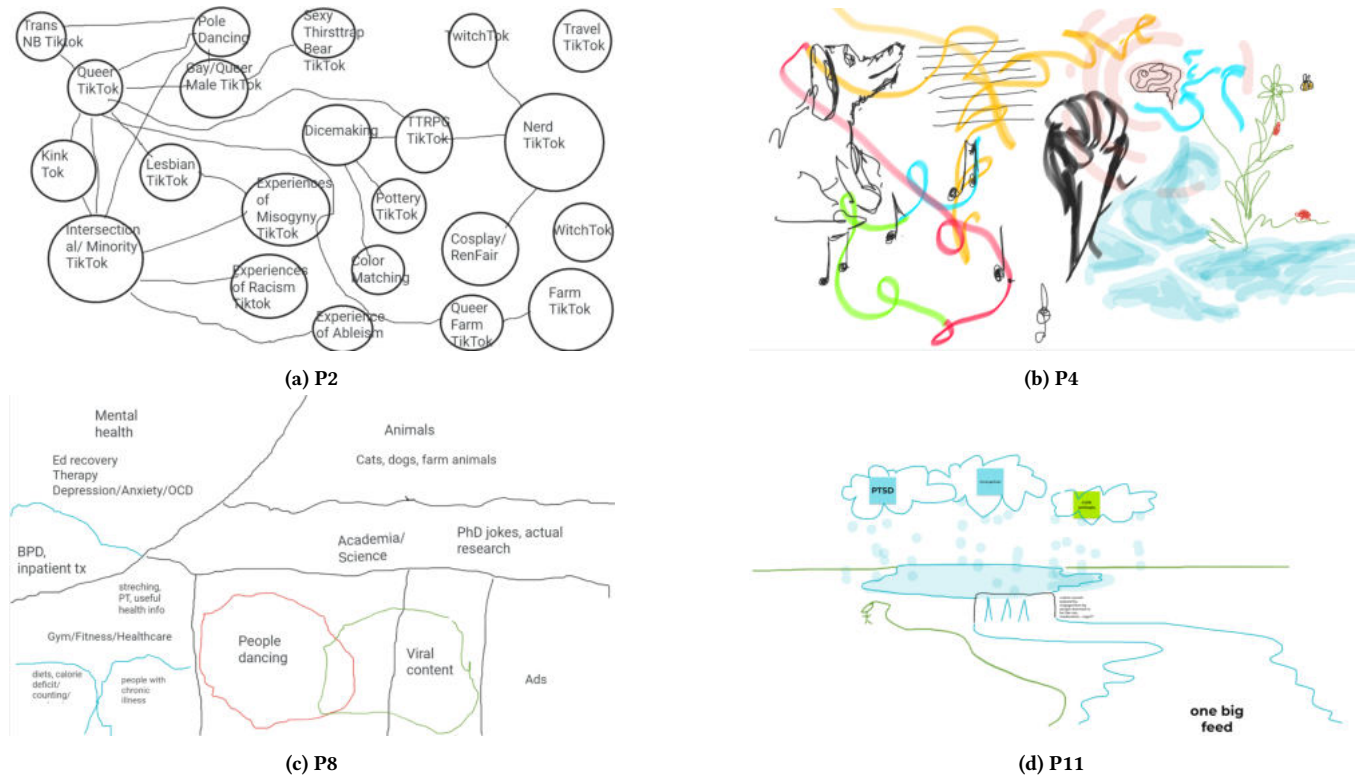


Figure 2: Visual Elicitation Figures from Participants Showcasing How They See Their TikTok Experience

what I have at all? When I'm trying to search for mental health things, sometimes I try to search for recovery, but then that can sometimes take you to addiction things. So it's been weird [to try to] add multiple hashtags to search."

Despite these navigation difficulties, many participants were not bothered by the lack of strict boundaries and, like P4, enjoyed potential benefits:

"there isn't really a hard boundary and I do think there's a lot of overlap. The nature of life is that you're not just one thing"

In summary, the definition of community was not consistent among our participants which lead to the realization that TikTok's communities are permeable. Permeable communities allow for community voyeurism but also makes navigating communities difficult.

4.3 RQ3: Clout, Credibility, and Relatability

Our third research question (RQ3) asked how users assess the information they receive about mental health on TikTok. We found that TikTok content resonates with them, creating the sense of being "seen" (as discussed in Section 4.1). However, we also found that participants struggled to navigate tensions between information quality/credibility and the vulnerability of content that seemed "genuine", which was complicated by the popularity and effectiveness of content where people share their personal experiences and views on topics that overlap with medical advice.

4.3.1 *TikTok Content is Relatable and Makes People Feel "Seen".* To begin, our participants all talked about how mental health content and communities on TikTok resonated with them, which comes back to the idea from Section 4.2 on feeling "seen". Participants, in general, shared the same sentiment as P11 did when they said:

"I felt like, oh this person really understands and experience that I also have and said it. It felt really like clear and kind of comprehensive"

Overall, our participants found TikTok content and communities to be more "raw" and relatable than content found on other platforms. Participants repeatedly pointed to videos that projected genuine vulnerability of the content creators, as P2 stated:

"You can tell when it's uncultured and when it's very much like this raw 'this is how I'm feeling', 'this is how I'm reacting to a situation,' 'this shit happened to me today', and this is what I did about it"

When it comes to mental health, our participants seemed to prefer information shared in the form of shared experiences. P4 stated that "genuine" content was "less cold" than when people presented the same information in a clinical way. P4 also pointed out that being exposed to this type of content allowed them to change the way they thought and "reframe" their opinions with more genuine content. Participants also stated that TikTok was not only providing relatable content but also delivering it in content formats that make the information easier to consume. P2 thought that TikTok is a "really interesting kind of way to consume information" and that

the presentation is “less arduous than like reading a journal article”, particularly on topics where they are not a part of the community, like “Disability Advocacy and disability rights”. In short, our data suggests that the more personally relatable and easy to consume the presentation of information is, the more participants were willing to take it in.

4.3.2 Credibility, Clout, and Relatable Content. However, this dynamic of vulnerability and relatability also has the potential for negative effects, as vulnerable and personally relatable content can mask issues with the credibility of content as well as the clout-chasing behaviors of creators. Participants acknowledged that TikTok may not be the best place to get information, with P5 stating:

“So TikTok is probably not a great place to get information from and learn, but I feel like I’ve definitely learned a lot from TikTok.”

One instance of what could make TikTok “not a great place” for information is overgeneralization in content. P15, speaking in the specific context of ADHD videos, pointed out how individual stories may be misleading:

“ADHD TikToks where someone will be like ‘do you do this’ very broad and innocuous thing, then you might have ADHD you know. Lots of people have trouble keeping track of time and that doesn’t necessarily mean that you have a pretty serious mental disorder.”

However, this vulnerability was also a major source of inappropriate or unnecessary self-diagnosis. For example, P24 mentioned witnessing a friend struggle with self-diagnosis through TikTok:

“I had a friend who had a family history of bipolar disorder and then she assumed that she had it. A lot of things she would see [on TikTok] read about said, ‘if you do this and this, it’s like a symptom of [bipolar]’. There’s a line between ‘this is something I watched casually’, and ‘this is something that I’m absorbing with my full being’ and I’m becoming what I consume.”

We want to point out here that P24’s friend may in fact have bipolar disorder; however, P24 was concerned because they were taking this information from TikTok and not a trusted medical professional. This interplay of personal experience and self-diagnosis worries a practicing mental health practitioner, P2. When talking about the availability of diagnostic information, P2 said:

“Diagnosis is diagnosis, for a reason. We go to school for a reason. We do good work and having all this information freely available...degrades the quality of the information”

P2 then explained that there are some areas where this kind of self-diagnosis is not harmful, but in other areas, it can even be a practical impediment to formal diagnosis and care. In this instance, P2 was concerned that the open availability of RAADS-R, a screening (not diagnostic) tool for autism spectrum disorder, harmed their ability to do their job:

“We have 30 more years of research [on] depression than we do on ADHD. That’s where the harm lies, when we have newer diagnostic labels, or we have newer information that we just haven’t worked out as a field, but

its passing onto the lay person...the RAADS-R is a new autism screener, but now all of these lay people have public access to it – you can Google RAADS-R and find it. Is that going to be a useful measure anymore, because it’s so salient in the community?”

As a clinician, P2 attributed much of this to the TikTok FYP, and what is pushed as popular and engaging rather than what is clinically effective:

“The algorithm does pull from a popularity standpoint as well, which can be dangerous when we are talking about things like mental health.”

4.3.3 Tensions of Vulnerability and Credibility. Through our interviews, our participants brought up this tension – between deeply personal, vulnerable mental health content and the influence of popularity on the quality and credibility of this content. This tension has also been seen in previous studies related to eating disorders and wellness content [16, 74]. One participant described this as “clout-chasing” behavior that necessarily puts popularity and view counts before verifiable information. P1 pointed out that some creators are “doing it for influencing factors” to make a “living doing it” and so it is “sometimes difficult to vet the information that comes out of that [creators’] community”. Along these same lines, P11 expressed how they have a hard time discerning “if it is just someone trying to get clicks whatever it is someone expressing their own experience”. P8 experienced how creators can glamorization in-patient care for views:

“There’s a lot of weird like glamorization of in-patient mental health treatment on TikTok. I don’t really like that ... because I feel like [that content] kind of trivializes it”

We want to note explicitly that many of our participants did not want to invalidate the experiences of peoples’ videos that they saw through their FYP, nor was it simply a matter of discerning what was true and what was not. It is the vulnerability of these personal accounts that both enable the creator to chase “clout” and make it problematic for users to evaluate the quality of the video *in situ*. This evaluation goes beyond truthfulness – it is a matter of discerning which information could be useful, how true it is in the specific context of the creator’s experience compared to one’s own, and what the creator’s motivations for sharing were in the first place.

As P11 pointed out, this evaluation is made even more difficult by a desire to not invalidate the experiences of others:

“People are claiming to be experiencing symptoms of Tourette’s while they’re cooking. It was compelling, but there was something about it that...feels really, really weird about saying that, and then classifying people. I don’t know how to tell people who are being genuine and people were making shit up”

However, other content overgeneralizes the symptoms of mental illness and pushes the narrative that everyone has a specific illness. P15 highlights how this over-generalization appeared for them:

“With like ADHD TikToks...someone will be like ‘do you do this very broad and innocuous thing’, then you might have ADHD”

P24 identified a specific viral video⁷ suggesting that crunching leaves while walking is an ADHD symptom:

"I just really related to it, but at the same time I'm like, is that really like an ADHD thing? Everybody likes stepping on crunchy leaves."

Further, P4 explained that content that is mostly about shared experiences can make it difficult to tell what is grounded in clinical advice, what is grounded in personal experience, or simply a way to facilitate engagement:

"You have to be quite cautious about what you're going to believe on apps like this, because people are either not aware or they're purposefully spreading misinformation"

To summarize, participants had trouble navigating the tension between perceived "clout chasing" but also valued people appearing to be vulnerable. Participants enjoyed it when information is easy to digest and comes from people that they can relate to – all of which the TikTok FYP delivers efficiently – but this focus on the personal, the relatable, and the popular also leaves room for information with questionable credibility to easily seep through. This tension puts users in an awkward place where they feel they can not call out misinformation for fear of being wrong but at the same time, users also want to hold space for people to express their own experiences.

4.4 RQ4: The FYP and "The Algorithm" as a Runaway Train

Our final research question (RQ4) asked what role participants see the FYP playing in curating and delivering mental health content. Many participants referred to the FYP as the "algorithm" and had mixed feelings about it – they felt they had no control over what content or communities they had access to. Additionally, participants were frustrated at the features provided by TikTok to regain control but that did not seem to work. At its worst, the FYP also led to participants having traumatic experiences with TikTok with no recourse for removing the content – what we call TikTok's "runaway train."

4.4.1 The FYP is not in the user's control. Many participants felt like they had no control over what was being shown to them on their FYP, which contrasts slightly with the findings in [70] of users "taming" their algorithm to some degree. P34 expressed confusion over what was appearing on their FYP:

"why the heck is this on my for you page? I don't watch any of those videos because I don't think they're engaging or funny at all, so I never know why those come up"

Some participants even spoke as if the FYP has agency, using terms like "it knows" when discussing the FYP or TikTok generally. This attribution of agency and personification of the FYP felt comfortable to participants like P11:

"I think it's very natural to attribute agency to...the algorithm that's picking what comes and what doesn't come to me. What I have been putting out there? Are

you receiving and telling me that this is the content I want?"

Sometimes participants saw videos from other communities as videos that did not seem to belong in their feed and could even cause concern, as P34 noted:

"The reason why it kind of freaks me out with TikTok specifically is because I know that their algorithm is one of the best..."

With an algorithm that is supposed to be "the best," one might think there is no need for users seeking mental health content to try and influence the algorithm.

4.4.2 Affordances To Regain Control Do Not Work. Many participants attempt to use platform affordances to tailor their FYP much like the participants in [70]; however, this often does not work as participants expect. One example of this is TikTok's "not interested" feature, a button that appears on a video that users can click if they are not interested in the content of a given video. Many of our participants did not know this was available or had forgotten due to its hidden location in the interface (at the time of writing, this feature is hidden through several menus). A few participants, including P3, noted that using this feature did not occur to them, saying *"I just tend to scroll past if it's something I don't want to see."*

Several participants were frustrated by the fact that "not interested" didn't seem to work as they thought, as it interferes with what users believe they need for their mental well-being and health. The combination of lack of control over one's feed and the continued delivery of unwanted content creates a problematic situation where the TikTok FYP is perceived to disregard a user's preferences, as P33 notes:

"It just feels like the content that I choose for myself isn't what [TikTok] wants me to choose. Therefore it's going to try to ask me to take in something else and I'm just annoyed by it."

P6 had a similar experience with autism content, but was more resigned about the situation:

"It doesn't bother me when autism stuff comes up... it's a matter of saying don't show me this anymore, or just skipping it and it's not that big of a deal to me."

For P34, this outcome was especially problematic, as it disregarded preferences related to psychological needs:

"I've also tried methods of clicking on 'not interested' but the thing is I don't actually know if that button works or if it actually does anything. Every time I've clicked on 'not interested' on domestic abuse videos, true crime, or [videos about] pedophiles or something like that...I don't like seeing that kind of stuff because it's upsetting. I'll try to click on not interested, but then [TikTok] still pushes those videos."

4.4.3 TikTok's Runaway Train of Content. In the most extreme cases, participants felt like the lack of control of the FYP led to harmful consequences to their well-being. We describe this as the FYP acting like a runaway train, a technological system that users cannot control but feel that they cannot leave or disengage from.

⁷<https://www.tiktok.com/@connorcallec/video/7110728158692855041>

For example, P33 sometimes sought out content related to their own traumatic experiences and decided to connect with other trauma survivors in the aftermath of the overturning of Roe vs Wade in the United States, which removed the federal right for women to have an abortion. They turned to TikTok to cope with resurfacing trauma for them:

“When Roe V Wade hit I sought out trauma survivors processing Roe V Wade...It changed my For You Page for a little bit. Then, when I go back out of the [trauma content] by starting to favorite[Like] more of the old stuff that I was following it [trauma content] kind of comes in waves, with my mental health. I feel safer that way...because otherwise I’m inundated [in trauma content] and I sometimes get and stay low [mentally] for longer”

P33 sought out and interacted with a broader range of trauma content because it was helpful at the moment to connect and share with others. However, once they were no longer in a place where that content was helpful, the FYP continued to inundate them with not just trauma content, but trauma content that was irrelevant to their own experience, causing them to be overwhelmed. P33’s only recourse was to try and slowly, manually steer their feedback to where it was before.

Some participants even felt that TikTok was doing this “on purpose,” reflecting a folk theory of agency on behalf of the FYP and algorithm [28]. When talking about their thoughts on the algorithm and their FYP, P34 stated:

“I think a lot of the algorithm runs on a lot of chaos, so it runs on whatever emotion it can elicit from the user. A lot of times what gets pushed I see is anger and violence...this underlying feeling of anger and guilt that [the FYP] relies on to push that content forward”

P2 summed up the feeling that participants had about the lack of control on the platform well when they said:

“A platform without control and a platform where people don’t necessarily know how those things work...not even the people who designed it know how it’s pulling information together”

This lack of control also impacts when content can be harmful to them. For example, our practitioner participant talked about how harmful these inaccurate representations of mental illness can be for diagnosis. Likewise, P8 noted the vague intersection between diet culture and healthcare content on TikTok:

“I get a lot of stuff about diets and calorie counting and calorie deficit [which is] stuff that I don’t necessarily want...And then there’s some useful doctors, dentists, and physical therapists that I’m actually interested in the health information that they’re sharing”

Moreover, people experience shared trauma of the world, which has negative effects when users’ feeds become inundated with it. Several participants, including P3 and P33, talked about when running across this kind of content how overwhelming it was:

“I had to put the phone down too often because I just can’t process other people’s traumas with them right now”

Other participants mentioned getting off TikTok or not using the app to get away from what they felt was a system that would not stop showing them this content.

With all the negative content and little control to do anything about it, we asked why participants still use TikTok. P1 explained their reasons for continued use:

“Because I see other people being messy sometimes, because I see other people struggling, because I see other people sharing their experience, because they see other people sharing their victories, because I see other people venting, I see me here.”

Our participants described the feeling of lack of agency and lack of control over what communities and content they are being exposed to. We argue that TikTok and the FYP are a runaway train, a metaphor where users are along for the algorithmic ride with little ability to affect what the train is doing. The train takes them to places they may not themselves want to be about their own past experiences and traumatic events, yet they cannot stop seeing it without a complete cessation of app use (which many are unwilling to do).

5 DISCUSSION

In this paper, we have investigated how mental health content and communities function on TikTok in light of the platform’s impactful presence in the mental health space. We structure our discussion into two main sections, theoretical and design implications, highlighting how our findings could be applied to future work in HCI, CSCW, and social computing.

5.1 Theoretical Implications

5.1.1 A New Way of Considering Community and Social Support. Our work suggests that HCI/CSCW scholars should reconsider and expand how online communities form, their structures, and how they provide support. Plant [63] defines an online community as “a collective group of entities, individuals or organizations that come together either temporarily or permanently through an electronic medium to interact in a common problem or interest space.” Classic definitions of belonging to an online community must meet the criteria for a sense of community which includes membership, influence, fulfillment of a need, and a shared emotional connection [53]. These definitions and requirements also imply a need for structure and barriers – to define a group, one must know who is and is not in the group.

Our participants had definitions of “community” that diverged from these definitions and previous work. Some participants expressed they did not think community existed on TikTok, and defined a community with strict boundaries and user interactions, paralleling the structural requirements in Plant [63]. However, other participants who felt community described them in terms of like-mindedness or shared experiences. Participants expressed how there were no clear boundaries between communities, and focused on how communities overlapped and changed. These definitions and understandings of community conflict with classic expectations of stability, membership, and shared space (whether digital or physical) [53, 63]. Further, our participants’ definitions specifically conflict with the idea of online mental health communities

(OMHCs) that rely on highly-structured and explicit norms for participation, organization, and little algorithmic curation (e.g., Reddit, PatientsLikeMe).

While the definitions of community differ between prior work and our participants, the social support they received was almost indistinguishable from that studied in traditional OMHCs. Participating in OMHCs has benefits for people with mental illness, such as stress relief and support through the mental illness journey [73, 80]. Prior work has often used Cutrona's model for social support [23], which relies on a dyadic model of someone seeking support and a provider, who knows *who* they are providing support to and the norms of what to provide. Prior research on social support in HCI operationalizes social support along this dyadic dimension [2, 20, 37]. However, social support on TikTok often manifests as creators broadcasting their experiences with mental illness to an abstract audience [57] – where providers provide support but to no particular seeker or user. This is more akin to Ernala et al. [32]'s notion of self-disclosure on Twitter, but to a much greater extreme because of the FYP. All participants felt like they received support from this model despite not posting or seeking it out explicitly, as assumed in prior work. Our results suggest that TikTok provides many of the same social support benefits of OMHCs and communities, but how it does this is in sharp contradiction to traditional notions of health support.

As such, we recommend expanding the definition of an online community, membership in such communities, social support in communities, and how we think about an online community to include permeability and how it impacts these relationships. If classic definitions of community necessitate structure, what does it mean when people move and experience community as a fluid, permeable experience? Or when people disagree on if community exists on a platform? Even becoming part of the community and receiving social support is different in our participants' definitions as they did not require that they interact with the communities outside of liking or even just consuming content, which is behavior typical of "lurkers" [76] and throwaway accounts [48]. We believe that TikTok facilitates a new way to conceptualize community and our expectations of how communities and social support are structured, operated, and engaged.

5.1.2 Personal Experience, Narratives, and Credibility. Our findings strongly suggest that a critical reason TikTok has such a presence in mental health is the relatable, personal nature of the content, whether that is storytelling or sharing advice. Previous work has established the importance of personal sharing and narratives for mental health [24, 84] – our participants were clear that they found this kind of personal content valuable and essential. These findings align with recent work that has qualitatively shown that about 40% of content under the #mentalhealth hashtag on TikTok was personal experiences [4]. However, our practitioner participants were concerned about the potential for personal content to overpower scientific information. Some participants suspected that specific creators propagated misleading information to get views and build social prestige on the platform, thereby chasing clout. The nature of personal content and the vulnerability involved in sharing one's experiences made participants hesitant about calling it precisely misinformation, especially for health information.

Although we organize the content that participants discuss into three clean categories, the line between scientific information, personal experiences, and deliberate mis/disinformation is unclear. Are genuine personal mental health experiences "misinformation" if they disagree with official mental health policy or diagnostic criteria? How do we respect individual experiences while effectively providing spaces for people to discuss scientific information? How should platforms facilitate credible information while balancing these tensions? We do not want to invalidate the experiences of individuals discussing mental illness. We also want to recognize that an algorithmically-curated site with few checks on credibility will facilitate extreme viewpoints that get more clicks and attention.

In future work on TikTok and on social platforms which host mental health content, we must carefully approach personal experiences in the online mental health community space with both the positive and negative effects of personal narratives in mind. HCI, health informatics, and psychology researchers will need to join platform designers and administrators to strike the right balance between credibility, personal history, and algorithmic amplification of that content. Likewise, design intervention will need to balance the rights of people to share their experiences and the importance of credible health information. The solution for this problem is out of the scope of a single paper, but we encourage future discussion on this pressing issue.

5.2 Design Implications: Content Management and Mental Health

Our findings suggest meaningful diversity within mental health content on TikTok, including informational or clinical content, pragmatic content, and comfort content. Previous work on mental health communities has found similar results about content diversity – Chancellor et al. [15] found that the vast majority of content posted by people who use mental illness hashtags was not clinically dangerous [15]. Further, work by Feuston and Piper [35] found that when users talk about their mental illness on Instagram (even when severe), they situate its discussion in the same feed as their everyday experiences.

However, most content policy takes a "one-size-fits-all" approach to defining and managing mental illness content [33, 34]. We argue that platforms and communities should consider more nuanced design and policy strategies around these differences. We propose several ideas to implement this in practice:

Detection of types of content: Automated content detection tools often focus on a binary representation – related to mental illness or not – and this is not precise enough to understand the nuances of *content type and intention*. Prior work by Chancellor et al. [15] identified the severity of content on Instagram, and we envision modifying their approach to the content types we identified in Section 4.1. These could incorporate natural language processing, computer vision, and machine learning to differentiate these types of content. Instead of sweeping policies, more nuanced attempts at content moderation can be established. For example, for people seeking social support [35], heavy-handed removal or banning strategies may be avoided.

Verification of Clinical Content: As noted earlier, there is a tension between credible scientific information and narrative storytelling on TikTok. One solution to amplify professionals' voices without heavily moderating personal accounts would be for platforms to expand their verification systems to include mental health credentialing. While such systems are primarily used for celebrities (e.g., Twitter's blue check verification), a similar system could identify users with verified credentials as legitimate mental health practitioners. YouTube has begun doing this for videos uploaded by licensed health experts, and we imagine a similar system for TikTok. Users would then have this source of information to help assess the integrity of the content.

Reaction Types To Facilitate Crowd Credibility: Our participants were hesitant to question personal experiences on TikTok, even if they believed it was being done for clout. One design solution is considering different reaction types to content to indicate various kinds of attention, such as the downvote on Reddit or reaction types on Facebook. These interactions could be used to consider content ranking and curation algorithmically, i.e., whether content should be promoted through the FYP based on the reactions. This could help manage concerns about questionable incentives with content driving engagement.

5.3 Design Implications: Controlling the Runaway Train

In our results, we referred to the FYP as a “runaway train” to reflect participant experiences where positives, such as exposure to new communities and delivery of desired mental health content, eventually turn to negatives at scale, such as exposure to unwanted communities and the continued delivery of content once a topic became harmful. We view this runaway train effect as the content consumption-side counterpart to what DeVito [29] refers to as a problem of decontextualization. Decontextualization is where content creators are exposed to harmful audiences and extreme moderation due to the system's inability to understand and account for context clues when judging what is engaging or relevant. In both cases, the user's inability to add context to the FYP's inputs results in misinterpretation. For creators, this often takes the form of attempts to counter hateful and misinformation content interpreted as a request to bring more of an audience like the one being rebuked [29]. In our case, this usually takes the form of temporary engagements with content and communities being read as longer-term commitments which are reinforced over time, potentially causing harm. Pragmatically, There is no way for the consumer of mental health content to tell the system, “Please ignore the last day of my interaction.” Therefore, there is no way for the FYP to serve the user's mental health content needs. Moreover, prior work shows ample evidence that users are eager to exercise more control over their feeds [70, 83], to the extent that users form complex folk theories about the FYP to guide their attempts to take back control [29]. We propose several design solutions to help reign in this “runaway train”:

Quick and Effective Outs: We found that some users attempt to counter this runaway train via features such as the “not interested” button, but find it ineffective. We believe that an easy solution is improving the “Not Interested” button to remove the same content

that engagement promotes on the feed, making it a rapid and effective “out” for undesirable content. Doing more extensive testing and improvement on this tool would be our next step in meeting these participants' needs. Likewise, many our participants had no idea this was an option on TikTok because it is relatively hidden on TikTok's interface. We imagine user interface improvements that makes the “Not Interested” button easier to find and use. Finally, we envision a system that allows one to temporarily “pause” content delivery along these same lines, essentially a consumption-side counterpart to the at-will “algorithmic emergency brake” proposed for creators by DeVito [29] in prior work.

Using Comfort Content: Considering the functionality of the FYP, another potential design implication to counter the runaway train effect is showing comfort content intermittently and switching to lower stakes content when users engage with the “not interested” button. To do this effectively, TikTok would need awareness of and personalization of positive comfort content to a user's preferences, a core task in recommendation systems research. This would build on TikTok's current efforts to promote well-being on its platform. We think this benefits platforms like TikTok in places other than mental health. Instead of over-prioritizing new content on the FYP, platforms could broadly bring up relevant older content related to well-being.

Evolve Recommendations For User Needs: Recommendation systems, like the ones that power the FYP, are the technology that supports permeability and also meets user needs and interests – in essence, made “for you”. However, previous work confirms what we also show – TikTok's recommendation system is challenging to change once it becomes personalized [29, 70]. This is particularly salient when considering user characteristics (like mental health) and identity writ large [29, 41, 70, 83]. Although it is technologically the most difficult, we believe that recommendation systems like TikTok should change with user changes and their needs [56]. For instance, recommendation systems can be tuned to have varying levels of diversity, serendipity, novelty, and coverage [40]. Depending on how a user responds to the content the algorithms can be switched to best match the user's current behaviors or values, like more serendipitous discovery. Suppose a user's behavior deviates enough from the established baseline. In that case, the algorithm currently responding the best to users could be used to “reset” the others to create a new “baseline” of personalization.

Direct Contextualization: Finally, we advocate for future design work that explores ways to allow users to add context to their interactions directly. For example, to deal with the problem of decontextualization on the creator side, DeVito [29] has proposed a flagging system where creators could specifically mark interactions with bad actors as corrective or defensive. We believe that such a system could be expanded to help contain the runaway train, and could help contextualize content consumption at the level of individual views or an entire viewing session. Imagine an end-of-session flag that lets the user communicate “I was in a bad mood” to the FYP, or a per-video ability to say “this made things worse for me,” with a corresponding drop in the weighting of that new data by the algorithm. Moreover, this kind of system could help solve participant hesitancy to question personal experiences on TikTok in concert with the expanded reaction options noted above.

6 LIMITATIONS AND FUTURE WORK

As mentioned in our methods, recruitment for this study had integrity challenges in recruitment and inclusion screening. The filtering process may have deterred some participants from enrolling. Additionally, our participant pool was skewed female and white, reflecting documented issues with recruiting men and racial/ethnic minorities in mental health studies [11, 69]. This makes further examination of the problems faced by these specific groups crucial for future work. Finally, we did not collect any information about mental health conditions to respect participants' privacy. Although participants volunteered this information to us (depression, anxiety, ADHD, PTSD, and ASD), they do not represent all mental health communities fully.

We are excited about future work in several directions. Many of our design suggestions are built on our participants' ideas. We are eager to explore the design space with probes or co-design sessions. Of course, participatory design is essential when working with stigmatized communities like mental health. We could implement these changes using participatory methods and evaluate their effectiveness. One dimension would be with people diagnosed with mental illness to ensure that any design would work for the mental health communities and individuals with mental illness. We also look forward to more research on how a community is defined and enacted as TikTok becomes more entrenched as a platform. More work will need to be done to see if this phenomenon is contained to TikTok or a more significant movement. There is also an avenue for future human-centered recommendation system design and computational work to improve the recommendation system as our participants have given us design suggestions [56].

7 CONCLUSION

This work explored the mental health content and communities on TikTok from a user perspective to find out what about the platform that allows mental health content to thrive and how it affects users. In doing so, we found that how users perceive communities on TikTok, paired with how content is presented on the platform, creates a space where users feel they belong. We have discussed how our findings can be used to design social media platforms to better support mental health communities. This paper is not intended to attack or dismiss mental health spaces. Participants frequently spoke of how the mental health communities on TikTok and the social support they have received have helped them. The authors share the positive sentiment of how beneficial these spaces can be despite the issues that have also been pointed out. By instituting infrastructure to support users in mental health communities and adjusting the systems to mitigate algorithmic harms, platforms can become safe havens for mental health communities and other stigmatized communities.

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