

Seeking in Cycles: How Users Leverage Personal Information Ecosystems to Find Mental Health Information

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ABSTRACT

Information is crucial to how people understand their mental health and well-being, and many turn to online sources found through search engines and social media. We present an interview study ($n = 17$) of participants who use online platforms to seek information about their mental illnesses. Participants use their personal information ecosystems in a cyclical process to find information. This cycle is driven by the adoption of new information and questioning the credibility of information. Privacy concerns fueled by perceptions of stigma and platform design also influence their information-seeking decisions. Our work proposes theoretical implications for social computing and information retrieval on information seeking in users' personal information ecosystems. We offer design implications to support users in navigating personal information ecosystems to find mental health information.

CCS CONCEPTS

• **Social and professional topics** → *User characteristics*; • **Human-centered computing** → *Empirical studies in collaborative and social computing*; • **Information systems** → *Web searching and information discovery*.

KEYWORDS

Mental Health, Information Seeking, Social Media

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1 INTRODUCTION

People seeking answers about their mental health concerns often consult the Internet for knowledge and insights about mental illnesses [43, 82, 83]. High-quality, accessible information is important, given the prevalence of mental illness – estimates suggest more than 1 in 5 US adults live with a mental illness [76]. In this pursuit, online mental health resources direct people to medical professionals, therapists, or crisis centers. However, lack of access to health care [69] and mental health stigma [3, 22, 78] can obstruct individuals' access to these offline resources and may not be appropriate for their information needs. Even those with available care may bring the information they find online to medical and therapy professionals [54]. In short, the quality of, and access to, online information about mental health is crucial in helping people and filling the gaps in offline resources.

The Internet, however, is not a single “unit” of mental health information in the modern era; information-seeking naturally happens across multiple platforms to fulfill information needs. Indeed, most adults use search engines at least once a month, and studies from Pew Research show that many engage with multiple social media platforms [11, 113]. People turn to search engines like Google or Bing for information [8, 54, 107] as well as social platforms to hunt for mental health information (e.g., Reddit, Instagram, and TikTok) [25, 67, 85, 92]. However, much of the previous research on information-seeking only considers a single context, either search [25] or a single social media platform [67, 99], or in the rare case both are considered selecting a single search and social media site [26]. While information-seeking models have helped frame the conversation about this process [81, 112], they often focus on models that do not explore why people look for information, the complex processes they take across platforms, and the outcomes of those journeys to find mental health information. To this end, communication scholars and technologists have called for expanding the study of information-seeking outside single-site studies [61, 65]. As such, we posit that seeking mental health information on the Internet must be studied as an interconnected process among platforms rather than separate entities to better support users in information-seeking in times of need.

To advance the study of information-seeking and platforms in a connected manner, we offer the following framing question: *How are users leveraging their personal information ecosystems to*

find information about their mental health? A personal information ecosystem is defined as “a system of devices and applications that are present in the information environment of a user...to help [them]...fulfill their information need” [109] – here, we focus on the applications of interest. We adopt this term from Tungare et al. [109] and Pérez-Quinones et al. [80] as it helps describe the ecosystem of information people seek and account for the complex, overlapping, and multiplatform model people use, as suggested by Marler [63] for cross-sectional research. We use this framing to examine existing models of information seeking [81, 112] as they apply to the current-day information-seeking process users employ for seeking mental health information. By merging information seeking with personal information ecosystems, we can consider user interactions between multiple platforms for finding information about mental health and characterize the structural, environmental, and personal factors that go into platform use.

To unpack the concept of a personal information ecosystem and its interaction with mental health information, we pose the following research questions:

- (1) What mental health information are users looking for, and how do they assess its quality?
- (2) How and where do users look for mental health information?
- (3) What influences how users interact with platforms when seeking or sharing mental health information?

We interviewed 17 participants with a mental health diagnosis (or self-diagnosis) and who reported interacting with information platforms. The semi-structured interviews included questions about the information and social support they sought and got from their personal information ecosystems. We used thematic analysis to analyze each interview [74].

Our participants looked for many kinds of information about their mental illness, from symptoms to daily lived experiences. Participants used platform affordances and alternative information sources, including website design and profile bios, as indicators of the trustworthiness of information. Participants utilized platforms in their personal information ecosystems cyclical “journey” that incorporated both search engines and social media platforms to find information about their mental illness. Participants started on either search engines or social media but ultimately would use the knowledge gained from one platform to seek more information on another. Participants also shared what influenced their use of platforms, citing concerns over their privacy and the design of platforms, with a few sharing what they wanted to see changed to better support them and others in the future.

Our findings suggest that people use and design their personal information ecosystems—using these platforms together, not in isolation—to fulfill their information needs. However, users still face challenges finding information due to sociotechnical barriers and platform design. We propose a holistic model of information-seeking behavior in personal information ecosystems for mental health, accounting for the cyclical use of multiple platforms. Our model provides a more up-to-date visual understanding of users’ complex navigation process in seeking mental health information online. We offer design implications for information-seeking models and platform mental health intervention strategies to ease the burden on users looking for this information at a vulnerable time.

2 RELATED WORK

In the following sections, we first outline the work about online health information content and its quality and accessibility. Then, we discuss the information-seeking process related to people finding online health information and the digital ecosystems with which people engage.

2.1 Online Health Information: Quality and Accessibility

The study of online health information is an active research area in HCI, information retrieval, and information science. What kind of online health information content people look for is wide-ranging [36] but is generally related to their ailments or those of the people close to them [68]. Many users are trying to find information about life-threatening health conditions like cancer [23, 38], or lifelong chronic conditions like diabetes or mental illness [36, 98]. For mental health, people look for information about symptoms, treatments, and diagnoses [42] as well as coping mechanisms [4], personal experiences [37, 67], and sources of community [116]. People also seek affirmation of their own experiences from others [85] and information on access to health care and support [42].

Quality of information is a priority for people when looking for mental health information. Studies have found that the quality of mental health disorder information websites varies depending on the disorder of interest [24, 43, 91, 115]. Factors contributing to the varied quality included readability, reliability, treatment choices, objectivity, and transparency. Further, sources of mental health information can contain conflicting information [17, 62]. Even though many people use search engines and websites for mental health, they are wary about the accuracy and quality of the information they find [82]. When assessing quality, users look for indicators such as trustworthiness, expertise, rank, and objectivity [1, 36, 79, 105]. They also look for other structural cues on digital platforms for its truthfulness, such as Unkelbach et al. [110]’s notion of “truth by repetition” reaffirming a piece of information and its trustworthiness by consensus.

Much of the mental health information online is inaccessible to many people due to several factors. Many sources of information are above the reading level suggested by US health agencies [101], making them overly complex for much of the population. Social media has become a vehicle for accessible information [84] via mental health influencers who provide information and express experiences in a way that is both easier to understand and more relatable to a general audience [37, 67]. While providing information in a more accessible manner, the utility of personal experience for mental health information is controversial. Studies have found that personal experiences can make users question the validity of the information [46, 67, 88], while another found that people prefer and purposefully seek out such content for entertainment [51].

While past research has looked at aspects of mental health information, few have examined the interaction of users’ information needs and juxtapositions of their preferred platforms. Given this research landscape, we ask where users are currently looking for mental health information and why they are choosing the platforms and mediums they are.

2.2 Information-Seeking Behaviors: Search and Social Media

Research on information-seeking has roots in library and information sciences [52, 53]. However, fields such as IR and HCI have contributed significantly to understanding how people look for information through technology. Notably, the prevalent IR model proposed by Wilson [112] emphasizes a linear approach focused on posing a question and obtaining an answer. Updates to this model have been proposed as well [40]. In HCI, the information foraging theory [81] is prominent, with recent considerations to update the model for users from newer generations [44].

People seeking online health information primarily use two platforms: search engines and social media [25, 26, 67, 75, 99]. For search, previous work highlights search engines as access points to mental health information, driven by both online and offline barriers, like stigma and health care access [8, 10, 42]. The search typically involves users providing one or two search terms, selecting a single website from the first page, and then rephrasing their query [35]. People inherently trust search engine rankings and weigh first page and top results more heavily [79]. However, the abundance of online health information provided by search engines can also lead to information overload for users [42]. Personal factors such as privacy and identity disclosure concerns further contribute to the complexity of health information seeking online [34, 72]. Mental health information seeking is affected by additional variables such as seasonality [12, 118] as well as trends and celebrity effects [118].

As social media has grown in popularity, it has become a source of health information, mental health content and information [57, 73, 100], and peer support [45, 57, 73]. However, social media platforms introduce complexities of mental health self-disclosure, (pseudo)anonymity, and community interactions [25, 83, 85]. Health information seeking on social media involves people asking questions of their peers and for recommendations or opinions, as well as focusing on daily life activities and experiences [59, 70, 120]. Algorithmic curation on some platforms serves as a passive means of information seeking, transporting users to new information without actively seeking it [67, 89]. However, the reliance on peers has drawbacks, as people are less critical of personal experiences, creating less of a focus on credibility [67, 92]. Certain design features on social media platforms can also create barriers to finding information. The lack of certain affordances, such as anonymous posting, can keep people from seeking information due to safety concerns [27, 89]. Moderation on social media platforms can also create barriers, with bans on hashtags about severe mental illness resulting in censorship and isolation of individuals with such experiences [97].

Prior work has focused on either search engines or social media for health information-seeking, with only a few looking at both together. A systematic review of online health information seeking identified facilitators (e.g., sense of community, privacy) and barriers (e.g., accuracy, accessibility, and censorship) across information technology and social media [48]. However, a missing component from previous work is how seeking behavior differs between the two system types. Cross-platform studies on mental health information considering social media and search engines are

rare and usually adopt a linearity and quantitative approach [65]. For example, De Choudhury et al. [26] considered the information-seeking and sharing behavior on Bing and Twitter for general health information via surveys and interaction logs. The work is quantitative and uses a linear approach to characterize the differences in motivation and use of the platforms, seeking vs. sharing. Few studies take a circularity approach and qualitative method to a cross-platform comparison where the relationship across platforms is considered [65]. We build on the work of De Choudhury et al. [26] by taking a user-focused circularity approach to explore how a user's full personal information digital ecosystem is leveraged to seek mental health information.

2.3 Digital Ecosystems for Information Seeking

Empirical studies of platform and technology usage behaviors often focus on one platform of interest [65, 119] – however, prior work has amply shown the heterogeneity of peoples' device, platform, and inter-platform use [65, 119]. This section discusses the research on digital ecologies of technology use and its relevance to our interest in information-seeking [90].

Digital ecology builds on the seminal work of McLuhan [66]'s media ecology, where “personal and social environments [are] created by using different communication technologies.” Simply put, media ecologies focus on the many sources of engagement with media [90]. Similarly, communication and HCI research have adopted this concept to suit the unique ecosystems of digital technologies. Raptis et al. [90] outlines different kinds of ecologies in HCI, including product, personal, and information ecologies. Studies on ecologies are common in HCI [61], covering heterogeneity of device use [109], media [108], and communicative techniques [49, 119]. One area of great interest recently has been social media ecologies, including self-branding [33], self-presentation [29], content creation [9] and users' decision-making for posting [49]. Close to our work is the personal social media ecology proposed by DeVito et al. [29], which builds on social media ecologies to center the user and their strategies to disclose identity-sensitive information.

We focus on information ecologies that individuals use to find, evaluate, and process information [61, 71] – specifically, the wide sources and strategies to find and process mental health information. Related to our work, Tungare et al. [109] presents the concept of the “personal information ecosystem”, where “a system of devices and applications that are present in the information environment of a user ... help the user achieve the goal of fulfilling their information need”. Similar device-style framings have been used for information-seeking [63]. In health, research has investigated the ecologies of health scientists' dissemination of research [39] as well as the quality of health information in digital ecosystems for webpages [50]. For mental health, researchers have proposed that framing digital ecosystems and social media ecology in health research [18] and resource building [16] would be beneficial, though left as areas for future work.

Our work builds on these ideas to examine information-seeking practices for mental health information, specifically by merging Tungare et al. [109]'s concept of the personal information ecosystem with DeVito et al. [29]'s notion of the personal social media ecology. Rather than focusing solely on information as individual units or a

linear process, we seek to understand information’s interconnected and multidimensional nature from a user’s perspective. This fills a gap in the existing framing and research around digital ecology for mental health.

3 METHODS

We conducted 17 semi-structured interviews where we asked participants about their experiences finding information and support for their mental health online. We asked about social platforms, search, and the Internet more broadly. The study was approved by the Institutional Review Board at the University of Minnesota. We describe our participant information and recruitment and interview methods.

3.1 Participants

Demographic Variables	N	Demographic Variables	N
Age		Gender	
18-20	5	Agender	1
21-25	4	Female	12
26-30	6	Male	3
31-35	2	Non-binary	1
Education		Sexuality	
Associate degree	2	Asexual	1
Bachelor’s degree	1	Bisexual	7
Doctorate degree	1	Heterosexual	6
Master’s degree	7	Lesbian	1
Some college, no degree	6	Prefer not to answer	1
Ethnicity		Queer	1
Asian	2	Income	
Indian	1	0	3
Pakistani	1	1 - 9,999	5
Prefer not to answer	1	10,000 - 24,999	2
South Asian	1	25,000 - 49,999	5
Thai	1	50,000 - 74,999	0
White	11	75,000 - 99,999	1
		100,000 - 149,000	1

Table 1: Aggregated Demographic Information of Participants

We recruited participants on multiple social media platforms, including X (formerly Twitter), Instagram, Reddit, and Facebook Groups, and via flyers posted around the University of Minnesota and the local Minneapolis area (a large, urban city in the United States). We also contacted past research participants of our research group, who consented to be notified of future study opportunities. Anyone interested was provided with a Qualtrics survey that screened for our eligibility requirements: 18 years of age or older, diagnosed or self-diagnosed with a mental illness in the last year, and used at least 1 of the six platforms (Google Search, X, Instagram, TikTok, Reddit, and Facebook) during their mental health journey. Per our IRB’s requirements, we also assessed participants’ ability to consent using a modified University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) [47]. This was done to ensure that potential participants had full decisional capacity and capacity to consent. Only people who met all three eligibility

requirements and scored above 15 on the UBACC proceeded to our consent form and demographic survey and could schedule an interview.

All interviews took place over Zoom from October 2022 to February 2023 and were recorded with participant consent. Participants were given the choice of a \$25 USD Target or Amazon digital gift card for compensation. The first two authors conducted interviews until theoretical saturation was reached [19], and no new themes emerged for several interviews. In total, 17 interviews were conducted for this study.

Our participants’ demographics are in Table 1. We allowed for self-identification of ethnicity, gender, and sexuality; thus, this summary table includes overlapping identities depending on participants’ self-reports. We also allowed multiple identifications of ethnicity; therefore, the count will not always add up to 17. The participants’ ages ranged from 18-33 (mean = 24), and most identified as female (N=12). Our sample was relatively educated, with almost half having at least a master’s degree. While we did not require evidence of participants’ diagnoses, given the social and economic barriers to receiving clinical diagnosis [21], participants disclosed a wide range of times between reported symptom onset and diagnosis; some as long as a few years to as short as a few months.

3.2 Interview Procedures

All participants engaged in a semi-structured interview with questions about their mental health experiences, digital ecosystems, information, and social support. These interviews lasted 30 to 60 minutes. At the beginning of each interview, we had participants reconfirm they met our eligibility requirements and conducted a shortened UBACC to ensure they still could consent. We then asked them to reaffirm their consent to participate and reminded them that they could stop the interview at any time and decline to answer any questions they were uncomfortable with. Interviewers asked participants about platforms, information, and their seeking process to investigate participants’ personal information ecosystems and how they used them in seeking information about mental health. Our questions focused on how platforms supported and hindered participants in their information-seeking and the quality of the information they found. Given the semi-structured nature of the interview, the interviews would follow up on ideas and concepts posed by participants.

3.3 Analysis

The first two authors used MaxQDA to conduct an inductive thematic analysis [14, 20, 74] of all interview transcripts. The first and second authors open-coded the interviews and labeled common ideas across interview transcripts following guidelines suggested by [14]. The open codes were then collated and grouped into categories through discussions between the first two authors and the last author. A few of the key categories included "platform use strategies to find and categorize information" (e.g., use of tech to help with symptoms and treatment, strategy to categorize trustworthy information) and "challenges of using tech platforms" (e.g., triggering of negative episodes, barriers to access information, trust issues). These categories were reviewed and revised through discussions

among all authors to reach a consensus about the salient themes. This also included frequent check-ins with all authors to compare notes, triangulate data, and refine the final themes and sub-themes presented in the Findings section. All quotes have been slightly edited to improve readability and, if needed, help anonymize our participants for privacy.

3.4 Positionality Statement

Several authors of this study identify as active-member researchers or peripheral-member researchers for mental health [2]. Having researchers familiar with the domain of mental illness and the struggles associated with mental health issues helps us conduct more thoughtful research with this at-risk population [2]. However, being ingrained in the people and community can influence the work. As such, while the first two authors were responsible for the execution of the study, all authors, regardless of member status in the population, were involved in the study's design, interpretation of results, and presentation of the research in this paper.

4 FINDINGS

4.1 RQ1: Information Types and Trust

Our first RQ asked what mental health information users want and how they assess its quality. Participants looked for information ranging from symptoms of mental illness, social support, and better navigating daily life. To judge the quality of information, participants discussed their evaluation of signals of trustworthiness, including how information was written/presented and the creators' other content.

4.1.1 Information Types. Our participants looked for and found many types of information during their information-seeking journeys. This includes information on symptoms and treatment, coping strategies, and daily experiences/support.

Symptoms and Treatment. Participants sought information about the symptoms they were experiencing. Many people began on search engines like Bing and Google Search, which often surface basic diagnostic information directly from trusted sources.

However, some participants found that lists of symptoms did not provide the "information" they needed. For example, P2 found these lists hard to manage and contextualize. P2 perceived lists as a "checklist...to strike off the majority of symptoms." The lists could not show how people experience symptoms or how they manifest in daily life. In some cases, participants were confused by symptom information. One participant was initially confused about how symptoms overlap between disorders: "I would discredit sources just by thinking, oh, it's a symptom of this [mental illness], how can it be a symptom of that [other mental illness] as well?" (P2)

Social media filled these contextual gaps, showing experiences that explained what symptoms felt like; participants could see and hear others' descriptions of a symptom's sensation or experience. Participants discussed the value of this, particularly videos:

"It's helpful to see personal narratives and the day-to-day stuff that isn't going to...jump out in a list of symptoms. You can read the same thing on twenty

websites, but seeing the different permutations and people's narratives can tell you more." –P4

These accessible explanations were also helpful for those who did not yet have words to explain their experiences. For example, P3 found TikTok an important source of this kind of information:

"Video suggestions [on TikTok] started to get into the terminology of [a specific mental illness], so things like hyper-focus or object permanence, [or] time blindness. Suddenly, I had these words in my head, and I was able to use them."

Treatment of mental illness and associated symptoms also came up. Several participants discussed looking for treatment methods or therapists via search engines. While participants found search engines helpful for uncovering information on mental health treatments, search engines were often poor sources of complex information on health insurance coverage, therapy fit/specialization, and new patient availability. Participants described a cycle of using search engines to look for therapists, consulting websites to see which were taking new patients, and then calling to see if they could get in. Many encountered long waitlists or therapists whose "website[s] might say that they are [accepting new patients]" (P4) but are not. The process was challenging for participants who needed to see therapists specializing in specific disorders or therapy methods. One participant recounted how their therapist at the time thought that they had a particular disorder, but their therapist said, "I don't specialize in this, so I can't actually do anything about it." This led our participant to "start looking more and finding information myself" (P5).

Rather than deal with the arduous process of finding a therapist, some participants turned to technical solutions like self-care platforms and social support via social media platforms. On social media, they sought reliable information from professionals who posted about therapy and techniques for managing symptoms of mental illness. Participants mentioned trying to find information about therapy, what it was like, and what therapists would do, but were unable to find such resources – posts on social media by therapists filled that information gap. Some mental health professionals do post this helpful information, and P4 agreed:

"Getting therapists on TikTok into my algorithm did kind of help me. This is the first time I've ever sought therapy and I think [TikTok played] a role in...the normalization of hearing therapist talk and talking about their clients, and how you don't have to be in complete crisis [to seek help]."

Coping Strategies. Information on coping mechanisms was a popular topic that our participants wanted:

"I see a lot of other people online share their coping mechanisms. So if someone's like, 'these are the things that I do to help with my [mental illness],' okay, I'll try it, whatever you say, dude." [P9]

Participants did not tend to look for this information on search engines. In fact, they used search to navigate websites recommended on social media, such as subreddit resources sections. Multiple participants discussed using Reddit to find information on coping and advice for dealing with specific mental disorders. For

example, Reddit was a resource to “get new tidbits of information about [a mental illness] and how to handle [it]” (P1). A few participants praised the structure of Reddit and subreddits as to why it was a good place for finding this type of information:

“I went to r/ADHD, and I sorted by Top Post All Time and read their stories, their testimonials with their advice, and [I also read] their About section, which said ‘here are some really helpful resources.’” –P6

Daily Experiences and Support. Our participants were also interested in finding information on how to live their daily lives well. Most participants looked for and found this type of information on social media; in contrast, static text of websites did not accessibly provide the information. Information on daily experiences took several forms on social media, including how people adapt to complete tasks that they struggle with. P10 discussed how these sources of information were helpful:

“There were a bunch of videos about how I manage my life with my [mental illness] because the [neurotypical] things don’t work for me. Before I even thought that label might apply to me, I just found those things helpful. I’m thinking specifically of [TikTok creator] domesticblisters. She does all of this home care workaround stuff, which is something that I’ve struggled with in the past. That was sort of my first exposure that I was like, well, I don’t know that [I have this specific mental illness], but it’s helpful for me to think about these things in a non-normative way.”

By seeing others live their daily lives with mental illness, our participants resonated with this information and felt a sense of connection:

“I remember the guy [on TikTok] who talks about what it is like to have [a specific mental health condition]. And he says, ‘Oh, that I need to do dishes but oh, there’s no soap’. So then he runs to one place and then realizes, ‘Oh, well actually here’s the garbage’, and then starts taking out the garbage and forgets about the soap, and so it’s a chain of events that end in disaster...I really identified with that.” –P3

Seeing others’ experiences made participants feel that mental illness was being normalized, helping to fight stigma and bring awareness to mental illness. As mentioned above, participants noted that content about therapy from mental health practitioners was helpful. More personal content solicited supportive feedback and comments, creating a sense of community that participants liked:

“I really like posts that are more personal, people my age, and in the comment section, other people are being supportive. I think that’s the most positive thing I’ve seen, and it became a support system...” –P7

Participants also highlighted the importance of information from ongoing online dialogues. One participant stated how reading and chatting with others who shared identities (such as sexual identity) was helpful:

“I’m part of lots of queer subreddits, and people talk about their experiences and problems with social interactions, particularly after the pandemic. That is a relatable experience for me, and people talked about that in conversation with their [mental illness] and how it made it so much more difficult. We don’t really have a script anymore, and not having a script really elevates those sorts of feelings.” –P10

These experiences could also teach others in the participants’ lives about what the participants were experiencing. Sharing videos about mental health was a popular way of teaching others:

“The things that I found more useful were videos that I could find to share with others. Hey, this is what it’s like for me to live like this because I think many people just don’t fully understand the struggle. It’s hard to communicate these things.” –P3

4.1.2 Trust. Participants valued trustworthy sources and information when finding mental health information on any platform. Our participants conceptualized trust as whether the information was factual or accurate. Although the quality of the information crossed our participants’ minds, they mostly focused on the medium/format in which it was presented rather than critiquing the information itself.

When static websites surfaced in search engine result pages, several participants said they “do judge the website based on how well it’s designed” (P5) as an indicator of the quality and trustworthiness of information. Furthermore, the writing style of the information altered the perceived quality. P11 reasoned about how writing and intention changed their evaluation:

“I would trust the information depending on how it is phrased. I won’t judge personal accounts the same way because that’s people describing their experiences, but if this is an article that is trying to provide information, you can tell by the writing style and how informal or how opinionated the writing sounds. That makes me take the writing more seriously.”

In addition to the writing, other aspects factored trust evaluations. Some participants were familiar with research and favored academic papers or information from Google Scholar. Other participants considered presentation and design in social media information, highlighting how “the person is presented in the environment” or “the way [information] is displayed” (P7) as strong indicators of trustworthiness. They also considered the ads accompanying the content, even though they acknowledge that the websites may not control what ads are shown. For example, P2 was “put off” by a mental health resource website showing ads for astrological signs.

Ranking of information on search engine results pages and social media indicated trustworthiness for our participants. Participants felt that the higher-ranking results were more trustworthy. Likewise, this expectation of highly-ranked information translated to social media through popularity ranking metrics, such as likes, upvotes, and video views. For example, one participant explained how they use Reddit’s voting system to find important and trustworthy information: “I would sort the post by top all-time upvoted posts

to see what the vibe on the subreddit is and what people thought was important” (P1).

Another aspect of popularity factored into the trustworthiness of information – repetition of information. Our participants described that the more frequently they saw “the same information just repeated in a different way” the “more solidified in my brain” (P9) it would become. This was not limited to just repeating specific information – participants began trusting creators more if they repeatedly provided accurate information:

“The first couple of things they post, I go check on Google. But after a while, if they’re like, this is feeling right, I’ve checked a bunch of times, It’s fine. Then I’ll start taking them at their word.” –P5

The most common trust evaluation was the identity of the creator posting the information. For search engines, this was located in about pages, authors’ credentials, and website URLs; in social media, this information was in profile bios and authors’ credentials. While some participants scrutinized the creator, some also evaluated the organization and stated they looked for its “media about pages,” to find their “agenda and their background” (P1). Some participants even considered the other content that a person created on social media as a credential:

“I would also go to their profile and see the other stuff they make. If they talk about a wide variety of mental diseases and the same symptoms for this huge range of diseases, I think this is probably not credible.” –P2

Participants talked about seeking out sources they perceived to be unbiased, as they felt they could trust them more than those they perceived to be biased or “trying to sell something”, which participants “don’t appreciate” (P7). One participant perceived overly optimistic information as biased and unrealistic. P14 put “more trust” in platforms providing “a mixture of both positive and negative stories.”

4.2 RQ2: The Journey for Information

Our second RQ asks *how* and *where* users look for mental health information. Our participants used multiple platforms - search engines and social media platforms - to find this information. However, the beginning of each person’s information-seeking journey was different; some started with a search engine, while others started on social media. Regardless of where participants began, they all cyclically used multiple platforms in their personal information ecosystems to fulfill their information needs. The quality and accuracy of information was also evaluated using this cyclical process.

Our participants described a recurring process of starting on a familiar platform and then branching to other platforms in their digital ecosystems. They would use platforms with each other to gain additional knowledge and assess the credibility of the information presented. We view this process as a cyclical information-seeking process with multiple starting points - a *journey of mental health information*. We visualize this process in Figure 1 and refer to it in the rest of the section as we explain our participants’ journey to fulfill their information needs on multiple platforms.

Our participants started their information-seeking journeys for mental health information on different platforms. Google Search was the search engine of choice for our participants, who reported

experiences similar to P3, “[I] would go on Google and just search the hell out of it”, or as P4 put it: “In the beginning [I looked at] general information trying to identify myself and these symptoms. I’m not even really thinking about getting to a place of getting help, but just where do I fit?.” In this case, individuals explicitly went looking for this information.

Others started their search on social media. Distinct from search engines, participants described a process that was less them looking for information and more the information finding them:

“On TikTok information found me on the For You Page... One video popped up and was like, hey, here is the list of the most commonly diagnosed disorders for young adults and adolescents, and one of them was ADHD. So I clicked on the comment section and saved it, which meant that [the videos] proliferated throughout my For You Page.” –P6

In this case, P6 was served this information by social media and, through saving one video, encouraged more of it to “find” them.

As seen in Figure 1, users started by expressing their information needs to a search engine or social media platform, which can infer a user’s needs. Our participants entered the cycle one of two ways: they either had an explicit information need expressed via a query to Google Search (but sometimes social media search), or the recommendation system of a social media platform inferred they had an implicit information need and presented information, prompting the cycle to begin.

Participants described using social media and search as a cyclical and reciprocal process for finding more information about mental health and using this information to draw reasonable conclusions. After initial information-seeking on a participant’s starting platforms, participants branched out and started using more platforms to develop their personal information ecosystem about mental health.

When starting their journeys on a search engine, most of the information participants found was clinical. As described, this is mostly general information about mental illness, lists of symptoms, and treatment options. In contrast, information from social media platforms focused on people’s experiences and provided participants with the terminology about mental illness. In Figure 1, this is the transition from the information gathered from a platform to the users, who then use the new information on a different platform for a different purpose.

For those starting on search engines, participants moved to social media to find information that felt less clinical than what they had found on search, looking for more personal and digestible information:

“I had done initial Googling, but everything felt very clinical when you Google. On Instagram, it’s people talking about it, so it feels more personal. The information that I got from each [platform] felt very different.” –P5

Another interesting aspect of this cycle was the credibility of information and the cyclical evaluation of this data. Although participants enjoyed personalized content, they felt that the information they got from search engines was more credible: “I guess that’s just always been how Google has been in my brain that it is just

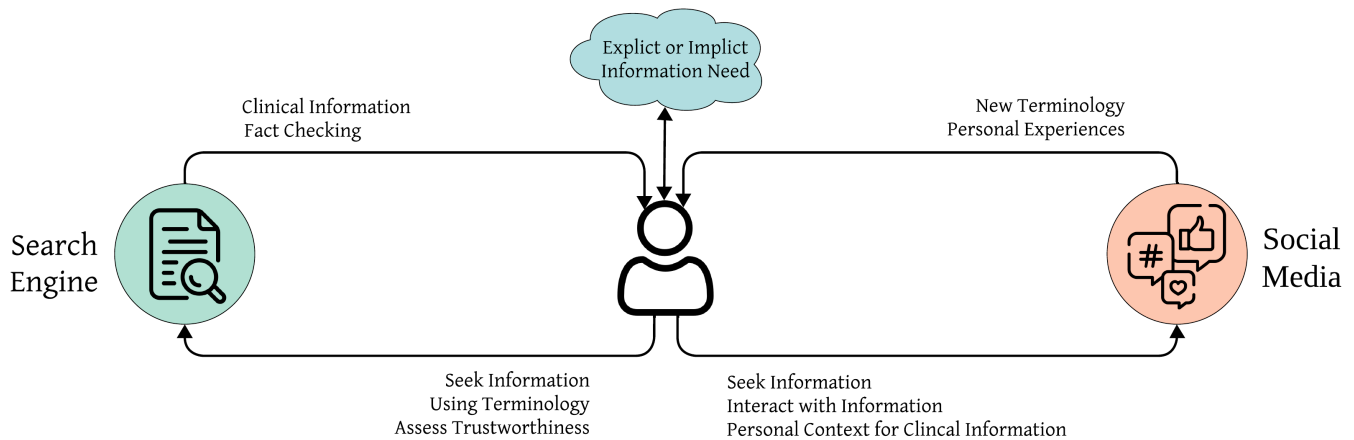


Figure 1: Cyclical information-seeking process for mental health information by participants

more credible” (P2). When prompted about why participants did not look for personal experiences on search engines, a few participants commented on how websites did not easily convey personal experiences, even if websites were perceived to be more credible:

“In my head, the blog is dead...there are a couple still hanging on, but you have to scroll through five million ads and five zillion paragraphs...It’s a lot less accessible and not scrollable...you can’t be in that endless loop on your couch where you’re going down and getting sucked in.” –P4

Instead of using search engines to surface personal stories, participants described fact-checking stories they found elsewhere with more trustworthy sources from search engines. Several participants described going back to search engines after seeing personal stories on social media to check the credibility of the information. P5 explained this process for a new creator they did not trust yet:

“The first couple of things [this specific creator] would post, I would go check on Google. After a while, if this feels right, I’ve checked a bunch of times, and it’s fine, then I’ll start taking them at their word.”

The cycle of going from one platform to another, gathering information, and leveraging it on the next platforms was persistent across all our participants. P8 showcased this cycle:

“I would see the TikTok of here’s this thing you might have, so I’d write that down so I can Google that. Then I would read through [Google’s] symptom list and go back to Tiktok and watch the video again to see if they match...”

A more specific example of this cycle unfolding can be found in participants seeking symptom information. They would find lists of symptoms of disorders on Google but would have trouble understanding what the experience of the symptoms was and were unable to relate, so they went to social media to find this additional information: “It wasn’t the list of symptoms that I connected with, it was the personal story, it was the testimonials” (P6). Participants gathered new terminology they did not have previously that they

could then leverage on search engines or other platforms to locate additional information:

“The most helpful videos were the ones that had some sort of situation that they then explained with a term. For example, there was one that was like, hey, things that I know about [a specific mental illness], time blindness, and they would [explain] people with [this specific mental illness] don’t have a sense of time...So those were the ones that gave me the anchor points with terminology and vocabulary that I can now start to look up. You can put into Google Time blindness, and you will get some results, right, maybe or not relevant, but at least now you have something to work with” –P3

When it came to ending their information-seeking process, most participants did not discuss stopping the cycle once their information need was met. Instead, they described switching to using almost exclusively social media and letting their feeds provide them with additional information. One participant referred to the shift as becoming “part of my online diet” (P10). This compares with our cyclic process on the right side of the cycle in Figure 1. After meeting the original information need, social media became a habitual source of ambient information until they either encountered a new information need (explicit or implicit) and started the cycle once more.

Where the Journey Fails. Sometimes, engaging with the information cycle detailed in Figure 1 failed to fulfill information needs. Participants identified a few types of information that they could not find and highlighted how some information was confusing or outdated. While many found personal experiences helpful, some commented on how the anonymity of people online made them wary. In some cases, the information was more to commiserate, and some participants felt “almost encouraged to get worse” by seeing “examples of [mental illness] that were worse than mine” (P10). Or the information was overly optimistic and caused participants to start “comparing my life to other people’s lives, which is not useful” (P14).

A common unmet information need was about therapy and counseling. This includes finding a therapist, what therapy is like, what it entails, knowing if a therapist is a good fit, and how much it costs: “I don’t ever see content that’s about how to find a therapist or how to figure out if you have a good match in therapy” (P4). Similarly, participants mentioned that the most challenging piece of information to find was about providers’ fit and specialization: “The hardest part is trying to find providers. There was a lot of Googling about what provider is going to be the best” (P5).

Some participants used online communities to attempt to find information, with varying degrees of success. While most participants had positive community experiences, a few found themselves in “echo chambers” for commiserating rather than improving. P1 struggled with a specific community:

“It can be a big echo chamber of people saying anything or people spiraling. Then, other people are spiraling alongside them. It’s this big community of people who need a lot of help but are not really sure where to get it.”

4.3 RQ3: Privacy and Platform Design as Barriers to Information

Our final RQ asks what influences users’ interactions with platforms when seeking or sharing mental health information. Participants worried about their privacy on platforms, which limited how they engaged with the platform in search of information. Specific features of platforms, including interventions and recommendation feeds, helped and hindered the use of platforms for information gathering. Participants offered ideas for improving platforms for seeking and sharing mental health information.

4.3.1 Privacy. Perceived privacy was the most significant factor influencing how people looked for and shared information on mental health. When participants mentioned privacy, they referred to controlling the visibility of information about themselves or that they produce.

Stigma was often cited as the reason for privacy – stigma was omnipresent and came from both online and offline comments [72]. Participants said they did not want to “identify as someone with a disorder in the first place” because it was “tied to social stigma” (P2). Mental health stigma was particularly hard for our younger participants, who managed generational differences in perceived stigma. One participant was frustrated that “the hardest part was the adults around me, either dismissing [mental illness] or refusing to take it seriously” (P6).

Culture also influenced the stigma that participants experienced. Several participants from non-Western backgrounds discussed stigma and how mental illness was perceived in their cultures:

“These are very much Latin American thoughts, like, ‘No, you can’t have [a mental illness]’ or ‘if you have [a mental illness] and you’re taking medication, it’s because you’re some sort of a crazy person’ ” –P3

Another participant discussed their experience in India, where even the act of reaching out for help was seen as an extreme action in the past:

“It was very stigmatized to get therapy. You would have to be on the extreme end of [mental illness] to be seeking professional help. Sadly, that is the case still in some places here.” –P2

Concerns about stigma meant that many participants were *consumers* of mental illness information rather than *producers*. Our participants noted they did not feel comfortable sharing personal information or posting about mental health. P12 said they did disclose their mental health status because “I’m afraid of the stigma associated with it, and I don’t want it to impact my professional career”, which may jeopardize their professional or personal lives.

These factors led some participants to favor private groups for their information needs. Private groups allowed our participants to share information and get personalized assistance without the fear of someone they know seeing.

“I like private groups. TikTok, Instagram, and Reddit are more public. Anybody can see what I post and comment on Reddit or Instagram. Whereas, Facebook has private groups and I like that.” –P13

However, not all platforms support private groups, which led to participants creating multiple accounts on some platforms, like fake Instagrams or “finstas” [30]. Extra accounts gave participants the freedom to choose what they engaged with on each profile, tailoring what their networks could see:

“I thought of creating a separate account partially for privacy reasons. I realized that my friends...could check who I follow, and...they will see that I’m following these accounts for [mental health condition]. They’re probably gonna know that I have [a mental illness]. Or at least that’s something I think about often, and I don’t like that.” –P12

This process is similar to context collapse, described by Vitak [111]; however, in our case, participants were worried about how merely browsing and following accounts might imply they had a stigmatizing mental illness. For some participants, having a second account prevented exposing their friends to the darker side of their mental illness that they do not want to share or “burden” their friends with:

“If you’re going through a tough time and flood the timeline with negative or dark thoughts... I want it to be contained somewhere else” –P1

4.3.2 Platform Design. Platform features also influenced how participants tried to find mental health information. Our participants described two primary features: crisis intervention strategies and control over content feeds. Given how forthright our participants were about features they liked or disliked, we asked for ideas for improving platforms to better support their mental health information needs.

Crisis Interventions. A few participants commented on how platform interventions were helpful to them. Mental health interventions are now ubiquitous across most big platforms and interrupt browsing with support information for mental illness behaviors such as disordered eating, self-injury, and suicidality [41]. Participants specifically mentioned helplines in response to searching.

They found this helpful, as it was a step forward from how platforms used to not respond at all:

“Instagram didn’t have safeguards in place when I was on it. I think now it does if you search for something a little concerning, they pop up at a helpline, which is good. Very glad that they do that now because I didn’t, I didn’t get that.” –P10

However, using these interventions was not unanimously valued. A few of our participants reported that the interventions made them feel self-conscious. One participant recounted their feelings when Instagram displayed a crisis intervention:

“The last time that it happened...I don’t want to say it made me feel bad, but I didn’t have good feelings about it because it popped up, and I was like, are people worried about me? Do they think that I’m not okay? Why does Instagram think that I need to be reminded of the suicide hotline?” –P8

It was not just the hotline interventions that participants had mixed feelings about but also gentle nudges to promote healthy browsing behaviors. For example, TikTok suggests a reminder video that encourages users to take breaks after long scrolling sessions, and Pinterest provides self-care prompts. Some participants found these videos to be patronizing as they did not seem genuine or know their circumstances:

“I would be on TikTok, and TikTok would be like, are you feeling more anxious than usual? And I’m like, guys, guys, I’ve been dealing with this for a hot second, it’s not anything big” –P9

Participants who discussed nudges and self-care interventions wanted platforms to “show more videos from professionals on TikTok trying to educate” (P9). They wanted this content from professionals, not from the platform itself. Several participants also wanted social platforms to give them control over what intervention looked like for them, such as not seeing mental health information for a period of time.

On search engine platforms, participants called out the lack of available interventions. Several participants described “going down a rabbit hole” (P4) when searching for information and not realizing it until much later. This behavior even caused symptoms to worsen for some participants:

“The phase I had when I was obsessively looking into symptoms - I wish there was some kind of an intervention then. It became a vicious cycle where I didn’t know my stress was feeding into more stress. Some sort of intervention that would have stopped me from just digging myself into a deeper hole...[that] would have been nice.” –P2

Content Feeds. Participants liked managing mental health content’s presence (and absence) from specific sources by blocking hashtags and accounts, like “the feature where you can block certain tags” (P1). Participants noted this was important on Tumblr, where certain sensitive content (such as eating disorders) would overlap with other mental illness content they were interested in. Our participants thought “better be safe than sorry, and just block so I won’t see it” (P1).

Several participants found that platform design and use of affordances helped them process the information they were seeking. TikTok was one platform that participants identified as helping keep information digestible:

“I get a majority of my information from TikTok because I have a short attention span, and it’s very fast. The way [TikTok] repeats the same kind of structure of videos [was helpful], so I consume a lot of them.” –P9

However, a few found the rapid information flow overwhelming, aptly comparing the information rate to “drinking from a fire hose” which made it hard to realize that they were “consuming something really heavy or something that needs processing” (P10). Participants wanted platforms to implement something to allow them time to process the information before continuing. One participant suggested something akin to crisis interventions, but after many mental health videos:

“Implement a similar popup where you watch a ton of videos on mental health, and then it goes, wait a second, maybe process this a little bit?” –P10

Participants did not just want help processing information but also wanted help in assessing its trustworthiness. Several participants asked for disclaimers on mental health content with a link to additional resources, much like that seen during the pandemic on COVID-19 information. Participants supported using the COVID-19 disclaimers and thought mental health information should be held to the same standard. As we discussed, participants regularly fact-checked the information they saw (see Section 4.1.1), usually going to a search engine to do so, and wanted a faster way to fact-check. One participant reflected on the complexity of this:

“At one point in the pandemic, Instagram started putting the COVID vaccine link on absolutely everything about COVID or Vaccines. If you’ve never read the CDC COVID-19 vaccine website, it is useful the first time you see it. I don’t know if that’s the best solution - you’re looking at something about mental health, here’s a link. But it perhaps would be better than just this completely freewheeling space with no checks.” –P4

Not only did participants have opinions about content, but also about the algorithms that platforms used. One participant described the Pinterest recommendation algorithm as being “very responsive”. Participants found that algorithms that they could “mold” were helpful because they could quickly control the information they wanted:

“I can mold [Pinterest’s] algorithm to whatever I want it to be within a couple of clicks. So if I wanted to see [mental health] stuff, I search for it, and then I click on two things, and now eighty percent of my suggestions are that with some other [content] sprinkled in.” –P5

Controlling the information was helpful to participants as it provided them with information implicitly without explicitly having to know exactly what to ask for. Traditionally, recommendation algorithms personalize quickly and thus become more difficult to tailor

to changing needs (e.g. [28, 67, 99]), whereas the responsiveness of the Pinterest algorithm was appealing.

However, participants also disliked recommendation algorithms. A few participants noticed how platforms were becoming more personalized and thought “having a better algorithm would be a good thing” (P3); however, P3 felt “fully surveilled”. P4 felt algorithms could “find sore spots so quickly” through personalization. Participants also felt that algorithms provided information without them asking for it, which they felt passively took away their autonomy:

“Instagram feels passive, which is why it felt worse. It felt like it was happening to me rather than me choosing to do it.” –P5

Passive personalization and interference for information-seeking made it difficult for some participants to step away from platforms. One participant lamented being unable to stop scrolling and waiting for the next relevant video, likening scrolling to a “dopamine slot machine” where the participant was waiting for the next video they liked:

“If I hadn’t felt so compelled to continue to stay on that platform and continue to scroll, there’s a much higher possibility that I would have exited and looked somewhere else. But instead, I just stayed there and scrolled and waited for the next video on mental health to show up. It was like a dopamine slot machine.” –P10

Participants had concrete design ideas for new models of recommendation algorithms that could support information-seeking on mental health:

“I wish you were able to customize it more. Pinterest lets you customize your explore feed a lot quicker...I wish I was allowed to have multiple feeds at once so that I could organize myself. I could say - this is the feed where I’m searching for this particular thing, and so you can suggest these particular things on this feed. [I’d also like] an explore feed where you could have specific tags or different algorithms for different subjects.” –P5

5 DISCUSSION

In this work, we examined how users with mental illness leverage their personal information ecosystems to find mental health information. Our interviews illuminated types of information about mental health and methods that people use to evaluate its trustworthiness. We also found a cyclical process of comparison, evaluation, and refinement of information needs that move between platforms (in our case, search engines and social media platforms). Finally, our participants provided recommendations to improve and overcome current policy and design barriers to information for people with mental illness. This section will discuss implications for theories of information-seeking behaviors, design implications for the field, and how our findings could be applied to future work in HCI, social computing, and IR.

5.1 Theory Implications: Mental Health Information Seeking and Personal Information Ecosystems

Our findings established a process that we call a *personal information ecosystem* for mental health [109]. This cycle updates and refines prior traditional information model commonly used in HCI and IR [81, 112], combined with insights from the ample research of media ecosystems [29, 111]. Our cycle specifically focuses on mental health information seeking, though we believe it may also improve other information-seeking models. We posit two theoretical implications of our work: first, integrating personal information ecosystems into future work for mental health information seeking, and second, the need for an interdisciplinary update and modernization of the information journey model incorporating HCI, social computing, and IR with findings like ours.

5.1.1 Ecosystems and Mental Health. Participants combined search engines and one or more social media platforms in their information-seeking journeys for mental health. Previous work on information seeking for mental health resources usually considers a single platform and in isolation of other types of information platforms, i.e., only on search or social media [12, 25, 55].

Given the interplay of platforms in mental health information seeking, our work updates current information-seeking models to visualize this complex, cross-platform navigation process better and frames this around a cyclical journey. Personal media and information ecosystems have been a valuable metaphor in HCI to examine cross-platform use [9, 29, 61, 80, 109], often on decision-making for posting behaviors [29, 49]. Our participants told us the complex ways they navigate the ecosystem of platforms to find information, filling in the deficits of each platform to meaningfully solve their information needs for mental health. Our interview study gives the field a more up-to-date and modern understanding of online users’ mental health information-seeking processes.

There are several benefits to this framing. First, the personal information ecosystem matches how people live in a multiplatform online world. Pew Research reported in 2021 that most adults use multiple social platforms [11], and some statistics indicate that 98% of internet users engage with a search engine at least once a month [113]. However, critiques as recent as 2023 indicate a need for more multi-platform studies [65]. We advocate for more multi-platform studies that can leverage and synthesize these single-site studies and adopt this updated model in their reasoning about information-seeking models.

5.1.2 Cyclical Mental Health Information Seeking. Our findings in Section 4.2 also identified a cyclical information-seeking process that our participants used to find mental health information, deviating from traditional linear models of information-seeking [112]. The information-seeking model proposed by Wilson [112] – where a user has a question and then collects and assesses information via a search engine – is used as a foundation in popular and modern papers about information-seeking in HCI [31, 87], IR [13, 94, 102, 104], and health papers [55, 87, 102].

A cyclical model of mental health information-seeking behavior differs from traditional linear models in a few key ways. First, our participants altered the order of their information-seeking and

their needs expressions. Very few of our participants started with a well-defined question, contrary to much prior work [106, 112]. Similar to [44] and [36], our participants used both search and social platforms, creating a cycle of information gathering, processing, and then iterating. Second, recall that our participants did not always express an explicit need, i.e., querying a search engine, but an implicit one, i.e., a need inferred by a system. Third, our participants described a cyclical model, interchanging between social media and search to support their information-seeking, often with no “formal” resolution. In Section 5.1.1, our participants had a habitual practice of passively gathering information rather than stopping their seeking entirely, which is similar to the “habitual practice” found by Fergie et al. [36], which our model accounts for.

Our cyclical model modernizes mental health information seeking and is in conversation with prior work. For example, very recent work by Hassoun et al. [44] on Gen Z (people born in the late 1990s and early 2000s) found that young adults opt for non-linear, exploratory, and dialogical information journeys incorporating both search engines and social media. Foster [40] also proposed a non-linear model for information-seeking behavior; however, this model is not widely used in describing information-seeking behavior and does not fully align with the cyclical process our participants described. The cyclical process is also reminiscent of the idea proposed by Richards et al. [93] of technology “scaffolding” the information-seeking process for parents seeking advice from medical professionals. In a sense, our participants are already using technology to scaffold their information-seeking without technology being specifically designed to do so. The changes in information-seeking of participants from both our work and the work by Hassoun et al. [44] suggest that current information-seeking models should be updated.

Future inquiry into new models of updating information-seeking models should be a larger focus of interest in HCI and IR [61, 65]. This is because social media and its multiplexity are an important source of information, and IR systems, like recommendation systems and search engines, are being integrated into social media platforms, intertwining social computing, HCI, and IR. HCI, IR, and Social computing are being brought together via their communication technologies for information, aligning with the idea of media ecology [66], influencing how people seek information online. As such, evaluating the current information and updating information-seeking models should be an interdisciplinary effort for HCI, IR, and social computing. We are excited at the potential of future work that can update these models, such as more empirical, experimental, and theory-building work.

5.2 Design Implications: Supporting the Journey

Our participants faced many barriers when using their personal information ecosystem to find mental health information. In this section, we distilled participant experiences and ideas into design implications to support the information-seeking journeys of people with mental illness. We focus on three areas: 1) supporting fact-checking, 2) engagement with information, 3) and well-being through intervention.

5.2.1 Supporting Fact Checking. Recall from Section 4.1.2 that participants had concerns over the trustworthiness of the information

on platforms, also shown in prior work about mental health information [46]. Our participants noted the lack of clear and consistent trust indicators for mental health resources across platforms. These problems often initiated the information-seeking cycle to fact-check, increasing their time and effort to find the information they sought.

One point of inspiration to solve this problem was platforms with community-based or crowdsourced evaluations of trustworthy content directly in the interface. Several participants independently mentioned COVID-19 disclaimers as inspiration, which initial research suggests some effectiveness at reducing information spread about COVID-19 [58, 60]. Similarly, X (formerly Twitter) used crowdsourced annotation of the credibility of information with Birdwatch/Community Notes [5, 86]. Our participants resonated with these systems and recommended similar methods for mental health information. They saw these as faster (so they did not need to toggle between search and social platforms) and valuable at reducing the “truth by repetition” cycle [110].

A community-based crowdsourcing model for fact-checking could alleviate some of the burden of fact-checking mental health information. Like Birdwatch on X/Twitter, now known as Community Notes, [58, 60] these systems should provide context for resources flagged as potential misinformation and allow for the intermixing of types of information between search and social media. Given the stigma of mental illness, we believe that the context should be provided by trusted community members, as also suggested by Milton et al. [67], or trustworthy mental health professionals. Automated systems could be leveraged here, albeit in a conscientious manner. Improvements must be made to current strategies for flagging content, i.e., hashtags, as these automated systems create many false positives [60, 117] and could quickly overwhelm new community fact-checkers [103]. Further, such a system must be careful in its presentation to not invalidate people’s personal experiences with mental illness.

5.2.2 Engaging with Information. Section 4.3.1 suggests that participants are concerned about the visibility and privacy of the information they generate while seeking mental health information. In some ways, this concern over visibility is self-apparent – stigma and the desire for privacy are well-known for mental health [95]. Prior work confirms this as well. Naslund and Aschbrenner [72] found that participants worried about mental health stigma and how it impacts their professional and personal lives, while other work has highlighted participants’ privacy concerns and its effect on safety [34] and access to information [7].

However, our participants were aware of stigma and how their platform use may communicate information to others through a new kind of context collapse [111], where simply browsing mental health content communicated to others their mental health status. Our participants developed strategies to hide this information from others. Take the example of P4, who tailored their interactions with mental health content to specific platforms, or P12, who made alternate social media accounts. These participants echo other studies, with users creating secondary Instagrams (“finstas”) as outlets for their emotional or unfiltered content [30, 114]. Recent work by Randazzo and Ammari [89] also found issues of safety and stigma in social media interactions of trauma survivors and encouraged follow-up work in this area. Both search engines and

social platforms do not have robust affordances that support users with mental illness to avoid these context collapses.

We envision design changes that can support users' privacy and promote their engagement with, and seeking of, mental health information. First, platforms could allow for multiple identities within a single account with easy ways to switch between the two identities. Some platforms, like Reddit and Instagram, allow users to make throwaway/secondary accounts [6, 30], which prior research shows facilitates self-disclosure [6, 56]. However, others, like TikTok, do not allow users to have multiple accounts. Users found multiple accounts cumbersome, so creating distinctive and easy-to-use identities for contextual management and information sharing could facilitate this. Second, another design implication for social platforms would be to control who could see specific posts and user engagement generated off them, i.e., consumption, likes, and follows. This expands on prior attempts to manage context collapse through posting management [64, 111]; however, we extend to cover passive engagement with other content (specifically about mental health), suggestions based on what your connections like/see, and what accounts you follow. This exists on some social platforms in a rudimentary way (X and Facebook allow users to specify who sees content, and Instagram allows you to make close friends for Stories). Still, few platforms enable blocking/restricting interaction information to specific topics or kinds of information or passive forms of interaction (like following or liking). A flexible combination of both systems would allow users to control their privacy and enable more information-seeking.

5.2.3 Well-being Through Intervention. Participants requested more control over their recommended and ranked feeds – and noted that current intervention methods vary in effectiveness depending on the user and their needs. These “one-size-fits-all” interventions often provide hotlines in response to hashtags or search queries about suicide or self-harm. However, Section 4.3.2 indicates that while it was helpful for some, for others, it harmed their self-view. Further, these interventions only cover crises, not less severe expressions of mental illness or the associated information-seeking behaviors that may be problematic. For example, one participant described going down information “rabbit holes” during anxious episodes, which may not raise to the level of urgency that most interventions currently target [41]. Building on our findings and prior work [67, 99], we propose that a comprehensive suite of interventions should be available so that users can control what they receive based on their mental health information needs. We leverage and extend our participants' ideas to two design ideas: feed control and pre-determined plans.

Feed Control. Most social media feeds use recommendation algorithms that personalize a user's inferred information needs. While participants found the recommendation systems helpful in finding information implicitly, they also found they had little control over when they saw certain content. Previous work has found the same for TikTok, where it was challenging to change the FYP [28, 67, 99].

Our participants wanted the recommendations to be more responsive to their changing needs, similar to the findings and suggestions from Milton et al. [67]. One design idea was the ability to have multiple feeds that could be customized to different topics, similar to “tabbed browsing”. Users could control when and which topics to

engage in, especially when content became overwhelming. Or if the recommendations on a specific feed were irrelevant or unhelpful, users could delete a flow of information without creating a new account to “reset” their feeds. Further, organization strategies to sort content into the appropriate feed (i.e., mental health content versus cooking content) would help curation on the user side and improve recommendations as feedback for the system. Better organization would also help keep users on a platform, as our participants may no longer have to choose between their well-being and continuing their information-seeking when overwhelmed by mental health content.

Pre-determined Plans. Our participants could recognize their own behaviors in their information-seeking on platforms that damaged their mental well-being. Most of these behaviors were not at the level of crisis and, therefore, not necessarily ones in which a system needs to intervene. Thus, we advocate for users to create pre-determined plans that activate in response to a pattern of individually specified behaviors during their information-seeking journey. For example, a user could specify (ideally in plain terms) that if they spend more than 3 hours a week on content with #anxiety, the content with that hashtag is blocked from their feed for seven days. Promoting autonomy in mental health interventions improves personal dignity and self-esteem and makes people feel valued and respected [77]. These feelings also help in reducing the negative consequences of stigma.

However, this approach would require platforms to support several ways of detecting behaviors and have multiple intervention options. This may involve more data collection about peoples' interactions on platforms, especially about sensitive topics like mental health that may be uncomfortable for people to share. For example, our participants discussed needing time to process after consuming too much information. Platforms may access the length of a user's session and what they have engaged with, but is it appropriate to analyze this data about mental health, even if the goal is to give control back to users? While this is a single example, the possibilities of detection and interventions under user control are vast, and it will be necessary for technologists to work directly with people with mental illnesses to ensure their needs are respected.

6 LIMITATIONS AND FUTURE WORK

We note several limitations of our study. In recruiting for this study, we used strategies for detecting and removing disingenuous participants. This included using Qualtrics' built-in fraud detection scores and asking participants to verify certain information to ensure consistency. We were also asked to design a longer-than-average determination of the ability to consent (because of the UBACC), which may have deterred some participants from enrolling in our study. Second, in trying not to limit the definition or representation of mental illness in the study, we allowed participants who were either professionally diagnosed with a mental illness or self-diagnosed with a mental illness. We did have participants who identified as having ADHD, which has been traditionally included in mental health studies but has been classified as neurodivergence in recent studies [32]. Finally, similar to other studies in mental health, our participation pool skewed toward people who identified as female and white or Asian, as well as being highly educated.

Prior work has documented the difficulty in recruiting men and racial/ethnic minorities in mental health studies [15, 96].

We have mentioned future work based on our findings, and we are excited that it has potential directions in both theory and application work. Further work is needed to investigate search and social media as personal information ecosystems to investigate the interaction between search engines and social media independent of users and how that may affect information seeking. Further examinations of the changes to the information-seeking process are needed, as the information landscape, where users turn for their information, and user behaviors have all changed over the last decade. In terms of design, our participants had many good ideas. We plan to move forward with some as starting points for participatory design sessions to create potential solutions to the issues that our participants face in future systems.

7 CONCLUSION

In this work, we investigated how users with mental illness use their personal information ecosystems to find mental health information. As a result, we found that users look for various types of mental health information, particularly information they could trust, which they evaluated using mostly presentation of the information. Rather than staying on a single platform, users utilized search engines and social media platforms in a cyclical information-seeking process. However, the process was not always successful, and users faced barriers from sociotechnical issues concerning privacy and platform design. Our findings have implications for information-seeking and personal information ecosystem theory and platform design.

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