



Discussing Social Media During Psychotherapy Consultations: Patient Narratives and Privacy Implications

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Social media platforms are being utilized by individuals with mental illness for engaging in self-disclosure, finding support, or navigating treatment journeys. Individuals also increasingly bring their social media data to psychotherapy consultations. This emerging practice during psychotherapy can help us to better understand how patients appropriate social media technologies to develop and iterate patient narratives – the stories of patients' own experiences that are vital in mental health treatment. In this paper, we seek to understand patients' perspectives regarding why and how they bring up their social media activities during psychotherapy consultations as well as related concerns. Through interviews with 18 mood disorder patients, we found that social media helps augment narratives around interpersonal conflicts, digital detox, and self-expression. We also found that discussion of social media activities shines a light on the power imbalance and privacy concerns regarding use of patient-generated health information. Based on the findings, we discuss that social media data are different from other types of patient-generated health data in terms of supporting patient narratives because of the social interactions and curation social media inherently engenders. We also discuss privacy concerns and trust between a patient and a therapist when patient narratives are supported by patients' social media data. Finally, we suggest design implications for social computing technologies that can foster patient narratives rooted in social media activities.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; • **Empirical studies in HCI**;

Additional Key Words and Phrases: social media, mental health, psychotherapy consultation, patient narrative

ACM Reference Format:

Dong Whi Yoo, Aditi Bhatnagar, Sindhu Kiranmai Ernala, Asra Ali, Michael L. Birnbaum, Gregory D. Abowd, and Munmun De Choudhury. 2023. Discussing Social Media During Psychotherapy Consultations: Patient Narratives and Privacy Implications. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW1, Article 46 (April 2023), 24 pages. <https://doi.org/10.1145/3579479>

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2573-0142/2023/4-ART46

<https://doi.org/10.1145/3579479>

1 INTRODUCTION

“Often, I find memes really communicate something I’d like to convey. Or when someone [online] expresses a feeling that I’ve had, and puts it in a very concise and artful way, I think [discussing social media] is a great way to get something across to my therapist that resonates with my experience.” – Participant #2

Patient narratives, how patients explain their experiences [66], are crucial in psychotherapy consultations because therapists mainly rely on patients’ own explanations to assess their mental health status and make treatment decisions [35]. The current lack of objective measures (e.g., lab tests) illuminate the importance of patient narratives [3]. As recent research [28] as well as the above quote from one of our participants in this study shows, digital versions of patient narratives have begun to permeate psychotherapy. Often, these digital narratives are constructed out of patient’s social media and are initiated when patients bring their data to the consultation setting [8, 115]. Social media platforms increasingly complement offline interactions and the lives of people. They provide a form of expression that contains personal thoughts and feelings, a means to share and cope with deeply personal anxieties, conflicts, and desires, and the opportunity to express satisfaction or dissatisfaction with other people’s content [9, 68].

Human-Computer Interaction (HCI), and Computer-Supported Cooperative Work and Social Computing (CSCW) researchers have studied how individuals with potential mental health conditions utilize social computing technologies to express their narratives. This work focused on how individuals use social media related to their mental health [91], how online narratives reflect everyday experiences outside of illness experiences [43], and how content moderation shapes narratives in online mental health communities [44]. We see an opportunity to deepen our understanding of how these online narratives impact treatment journeys. We expand this line of research by seeking to understand why and how mental health patients bring up their social media activities during consultations as well as how social computing technologies may better assist patient narratives.

Clinical researchers have also paid significant attention to this emergent culture in psychotherapy practice. Balick [6] called this a “virtual impingement”: the offline clinical encounter is impeded, modified and influenced by something happening in the online world, violating a dyadic relationship that has historically been considered intensely private [46]. A variety of therapist views have been enumerated – while some therapists have adopted an open mind because patients’ social media may hold significant emotional triggers and hooks, others have found social media to be intrusive and threatening to the clinical practice [5, 61]. However, patients’ perspectives are less understood, including both their motivations and intentions behind contributing to these new types of patient narratives, as well as the implications this practice holds for future technologies in mental health. These perspectives are critical to gaining a better understanding of how mental health patients utilize social media in their treatment journeys. Therefore, we focus on two questions:

RQ1. *How does discussing social media support or hinder mental health patients in conveying their narratives during consultations?*

RQ2. *What are the challenges and concerns that surround the practice of discussing social media during psychotherapy consultations?*

To answer these questions, we interviewed 18 mood disorder patients regarding their experiences in discussing social media during psychotherapy consultations. From the interview data, we consolidated three themes. 1) We found that social media helps to augment different types of narratives, such as narratives for interpersonal conflicts, narratives for digital detox, and narratives for self-expression. 2) We found that this new practice can complicate or even exacerbate patients’ perceived power dynamics between themselves and their clinicians. 3) Although our data shows that

patients do not have many privacy concerns because they consider psychotherapy consultations to be safe spaces for expression, sharing social media might alter the context of collaboration with their clinicians, which can increase privacy concerns in certain situations.

Using our findings, we discuss implications surrounding the appropriation of social media in shaping patient narratives, and how these narratives deepen our understanding of patients' privacy concerns during consultations. Finally, we conclude with implications for future technologies that can support the unfolding of narratives, while also navigating the complexities that this new practice presents to the therapeutic relationship and privacy.

Privacy and Ethics. This study was conducted with the approval of the relevant Institutional Review Boards. We took additional measures to mitigate any potential risks and to ensure the safety of our participants, which are elaborated in Section 3.2. To protect participants' privacy, we deidentified and altered their quotes to the level where the rich accounts of their lived experiences were not compromised. Please note that this paper presents mental health patients' accounts of their experiences, which can trigger readers who are sensitive to mental health related issues.

2 BACKGROUND

2.1 Mental Health and HCI

Growing HCI research has explored the topic of mental health, such as technology use [14, 16, 33, 34, 39, 41–43, 91], online communities [17, 44, 92, 93, 101, 125], inferring mental health status [21, 22, 119] and technology use in treatment contexts [59, 84, 90, 124]. This paper is part of an ongoing communication with this evolving research in HCI and mental health to deepen our understanding of how technologies impact, shape, and sometimes hinder users' mental health states.

First of all, there are several inspiring studies that investigated how individuals with mental health use technology in their daily lives and how that technology use impacts self-management of their mental health conditions. Eikey and Reddy interviewed individuals with a history of eating disorders to understand how people use weight loss apps [34]. They argued that technologies should not be viewed as either good or bad because the roles of technologies can change over the course of users' journeys. By juxtaposing interviews with participants' own social media trace data, Pater et al. revealed that eating disorder patients' perceived impact of their online behaviors may not be fully manifested in their social media activities because their own perception of benefits and harms can be more complex than what appears on social media platforms [91]. Based on the concept of small stories, Feuston and Piper investigated how people's experiences of mental health and illness are represented in public Instagram posts, which led to their suggestions for non-binary perspectives for mental health technologies [43]. Based on the enlightening findings from these studies on how individuals' everyday lives meld with their online stories, this paper focuses on the contexts where everyday lives are restructured during clinical conversations.

We note that these emerging technologies have been studied in the context of mental health treatment. Ng et al. conducted an interview study with mental health providers to understand how they would incorporate patient-generated passive sensing data into their work practices [84]. Relevant to this paper in terms of the scope of technology (i.e., social media), Pater et al. investigated clinicians' perspectives regarding utilizing patient online behaviors when they assess their eating disorder patients [90]. Even though the clinician participants acknowledged the importance of online behaviors when it comes to eating disorder recovery, there are no standardized clinical procedures for understanding how patients utilize or are impacted by their social media usage.

Finally, there is an increasing number of studies in HCI that infer or predict mental health status [117] from diverse types of data, such as passive sensing data [119] and social media data [22]. Because of the self-curated nature of the content and the richness of the written text data, social

media has been suggested as a promising avenue for understanding people's mental health [80]. However, there have been reflections on this emerging research practice of utilizing social media data in predicting mental health status. Feuston and Piper pointed out that these quantitative analyses might miss the nuanced and complex nature of individuals' experiences, which may result in a limited understanding of mental health experience [42]. Our study continues Feuston and Piper's poignant critical argument of "coded gaze" by understanding how individuals with mental health conditions leverage social media when they communicate with their clinicians. We discuss how individuals curate their social media behaviors to better represent their stories, which can hint at how we should understand and respect the autonomy of individuals when it comes to understanding their mental health status from their digital traces.

2.2 Patient Narratives in Mental Health

Patient narratives are meant to convey core elements of patients' everyday lives, such as symptoms, feelings, and social functioning, that are often impacted or shaped by their illness experience [66, 94]. Patient narratives are important not only because they are a cornerstone of understanding patients' illnesses but also because treatment initiates and evolves when patients build and convey their narratives to their clinicians [73, 105]. Therefore, due to the subjective nature of mental illnesses, patient narratives and the clinicians' interpretations of those narratives are the most important elements during the clinical reasoning process [98]. Moreover, researchers have pointed out that when patients and clinicians collaboratively construct narratives, power is shared between them, which can facilitate the therapeutic alliance during treatment [13].

Narratives are different from stories because narratives have plots wherein the sequence of events are arranged in a logical rather than a chronological order [81]. People convert stories into narratives by restructuring a sequence of events. These concepts of narrative form have been deeply investigated by HCI and CSCW researchers in regards to collaborative information seeking [62] and healthcare [81]. Monsted et al. revealed that physicians create preliminary narratives even before they meet their patients using available health records; the preliminary narratives are then restructured through conversations between clinicians and patients during consultations [81]. In essence, preparing, unfolding, and iterating narratives based on patient-clinician collaboration has received a significant amount of attention from HCI and CSCW researchers [7, 12, 116]. We echo previous research in that patient narratives evolve throughout iterations during consultations, and future technologies should support the iterations of patient narratives to achieve successful patient-clinician collaboration. Expanding on this research, we examine instances where mental health patients bring up social media and the implications for future technologies to facilitate patient narratives emerging from social media discussions.

Stemming from the widespread adoption of social media platforms, people with mental health conditions have utilized online media to structure, refine, and communicate their own narratives. By analyzing the 'my anorexia story' videos on Youtube, Holmes revealed that those videos highlight "the polysemic qualitis of the starved female body" and juxtapose individuals' own narratives with dominant medical narratives on anorexia [56]. Those videos considered anorexia as both a clinical entity and an everyday construction of femininity, which hints at online illness narratives possibly being able to complement communications during treatment. From the analysis of photo posts on Tumblr, Seko and Lewis revealed that "memes conveying hopeless moods" are most widely used among self-injury related posts, suggesting use of memes to communicate illness experiences [103]. HCI and CSCW researchers have also explored narratives in different contexts, such as in advocacy for civil rights [78] and cancer survivorship [40]. This existing literature calls for the attention of HCI/CSCW researchers in fostering patient narratives when designing technologies for patients.

We expand this line of research by exploring how patient narratives are impacted when patients bring up their social media activities during consultations.

2.3 Patient-Generated Health Data (PGHD) in Mental Health

Another line of research that expands our understanding of social media based patient narratives is the use of patient-generated health data (PGHD) during consultations [27, 57, 74, 121]. Due to the proliferation of patient-facing health measurement devices, such as glucometer monitoring devices and fitness tracking devices, patient-generated health data, from clinical level data to non-clinical level data, have been widely investigated in HCI and CSCW studies [64, 95]. Li et al. and Epstein et al. proposed personal informatics models that explain how individuals purchase, utilize, and lapse from health tracking devices [36, 72]. These individual self-tracking cultures, such as the quantified self movement [20], were investigated in different settings such as the workplace [99] and college campuses [63]. Over the years, this line of research expanded to consider different stakeholders of data either because the individuals who collect PGHD have needs for sharing their data with their family [96], or they have needs for having feedback on the data from health experts [23]. This body of work also suggested that PGHD can be discussed during medical consultations [23, 65, 79]. Kim et al. developed a dashboard that represents different types of PGHD using human-centered design approaches and evaluated it [65]. Mishra et al. explored how patients would like to share their PGHD during consultations using design probes [79]. Chung et al. used the concept of boundary negotiating objects – artifacts that are used in collaboration between different communities of practice – to analyze the PGHD in patient-clinician collaboration [23]. They provided both harmonious as well as conflicting collaborations surrounding the use of PGHD in clinical encounters, thus providing a deeper understanding of the personal informatics model suggested by Epstein et al [36]. In summary, the rich body of HCI research regarding PGHD has suggested that the use of PGHD during consultations represents different aspects of patients' daily lives outside of consultations, which can help clinicians' decision making. However, these PGHD studies have not fully considered narrative-based approaches in their design process. We believe that how PGHD impacts patient narratives during consultations can bring unique and enlightening perspectives to PGHD research.

Therefore, we ground our study on the concept of narratives during consultations [18, 81]. Specifically, we explore how social media, a potential form of PGHD, can influence the unfolding of narratives. By providing empirical evidence of discussing social media during consultations, this study contributes to both the concept of narratives in medical consultations [81, 105] and how PGHD can better support clinical mental health consultations [24, 80].

2.4 Privacy, Social Media, and Mental Health Treatment

New types of patient-generated health data (PGHD), including patients' social media activities, have brought forward privacy related issues in mental health. Many researchers have raised ethical concerns, found disconnects to conventional psychotherapy practice, and, therefore, suggested remedial guidelines [25, 29, 60, 71]. These include avoiding accessing patients' social media without their permission, establishing institutional policies regarding communicating with patients via social media, such as by using a professional profile for clinical communication, and modernizing psychotherapy approaches. However, those guidelines focus only on asynchronous communication via social media. This paper will expand the privacy related discussion of social media from asynchronous to synchronous settings. Here, we explore privacy issues from a patient perspective when patients bring up social media activities during their clinical encounters.

Nissenbaum's contextual integrity [85] provides a way to interpret our patient participants' privacy concerns. Contextual integrity highlights the norms of how people exchange information

and it defines a breach of privacy as when the exchange does not comply with the established norms. This can be a useful lens here, because the purpose of the concept is to examine privacy breaches in the exchange of sensitive information (e.g., public surveillance via credit card usage information) and because it provides two specific tenets to consider – norms for appropriateness and norms for distribution. The latter deals with the context of the communication and the former focuses on the content of the exchange. We utilize the concept of contextual integrity to better understand the unique privacy concerns that emerge from social media derived narratives during consultations as well as to elaborate design implications for mitigating such privacy concerns.

3 METHODS

In response to our RQs, we conducted semi-structured interviews with 18 mood disorder patients. In this section, we describe the recruitment, safety measures, interview procedures, and data analysis.

3.1 Participant Recruitment and Interview Procedure

We recruited mental health patients who 1) have been diagnosed with major depressive disorders and/or general anxiety disorders (the two most common mental illnesses [100]) and 2) have brought up their social media activities during psychotherapy consultations at least once in the past year.

We posted our advertisement in Reddit mental health support communities (subreddits). We contacted the moderators of those communities and obtained approval to post our recruitment posts from three communities. We also posted our recruitment material on the classified advertisements website Craigslist. These recruitment strategies were chosen based on recommendations provided in prior research [53, 111, 123]. Specifically, due to the semi-anonymous nature of both of these online platforms, they have been noted to be more suitable for recruiting participants from stigmatized groups, such as the case in this work. This is because platforms like Reddit and Craigslist allow respondents to self-select into the specific stigmatized category, thus ideally helping them to feel more at ease about the subsequent study.

Participants who qualified via a screening survey that determined their age being 18 years old or older, as well as their diagnoses and usage of social media during consultations, were contacted by one of the research team members to schedule a one hour remote semi-structured interview. The remote format was chosen both because of the geographical distribution of the participants and the physical collocation restrictions imposed by the COVID-19 pandemic – a global crisis that coincided with the time period of this study. The interviews were held on the BlueJeans platform, a cloud-based video conferencing service (45 min-95 min). The participants were able to choose whether to turn on their cameras and the facilitator clearly notified them that it is perfectly acceptable to turn off their cameras during the interviews if they wished to do so. After the consent procedure, the facilitator asked questions regarding their mental health conditions, their on-going treatment, their social media usage, when and why they have brought up social media during consultations, how their conversations were impacted or punctuated by having brought up social media activities, and their experiences sharing social media data, especially focusing on challenges, concerns, and barriers. All sessions were audio-recorded with participants' permission. A \$25 gift card was provided.

We recruited 18 mental health patient participants, who from here on will be referred to by P#. At the start of the interview sessions, we asked participants to fill out a demographic survey regarding their conditions, social media usage, age, etc (Table 1). Note that our qualitative approach seeks a rich and transferable understanding of patients' experiences rather than generalizable knowledge [52]. Therefore, the demographic information is meant to support the transferability of our findings.

Table 1. Patient participant demographics including self-reported diagnosis, years of treatment, and use of social media. (Depression: Depressive disorder, Anxiety: Generalized Anxiety Disorder, PTSD: Post-Traumatic Stress Disorder, ADHD: Attention-Deficit/Hyperactivity Disorder, OCD: Obsessive Compulsive Disorder)

ID	Age	Gender	Race	State	Self-reported diagnosis	Treatment	Social Media	Visit	Post
P1	58	F	White	MS	Depression and PTSD	5 (years)	Facebook Instagram Twitter Reddit	once a day+ once a day+ once a day+ once a day+	once a day+ once a week once a week once a day
P2	32	F	White	NY	Depression, Anxiety, ADHD, and OCD	22	Facebook Instagram Tiktok	once a day+ once a day+ once a day+	once a week once a day once a day+
P3	39	M	White	CA	Depression and Anxiety	1	Facebook Instagram Twitter Snapchat Tiktok	once a day+ once a day+ once a day+ once a day+ once a day+	once a day once a week once a day once a day once a week
P4	47	F	White	MA	Depression and Anxiety Disorder	10	Facebook	once a day+	once a day
P5	49	M	White	WA	Depression and Anxiety	8	Facebook Reddit Tiktok	once a day+ once a day once a day+	once a day+ once a week once a day
P6	37	M	White and Hawaiian	GA	Anxiety, ADHD, and Bipolar Disorder	9	Instagram	once a day+	once a day+
P7	45	F	White	MO	Depression and Metastatic Breast Cancer	3	Facebook Instagram Twitter Reddit	once a day once a day+ once a day+ once a week	once a day once a week once a month once a month
P8	47	M	White	NY	Depression, Anxiety, ADHD, and OCD	20	Facebook	once a day+	once a day+
P9	46	F	Hispanic, Latino, or Spanish origin	TX	Depression, Anxiety, and Bipolar Disorder	5	Facebook Instagram Twitter	once a day+ once a day+ once a day+	once a day+ once a day+ once a day+
P10	26	F	Black or African American	GA	Depression, Bipolar Disorder, and Schizophrenia	8	Facebook Instagram Snapchat	once a day+ once a day+ once a day+	once a day+ once a day+ once a day+
P11	19	F	Prefer not to say	GA	Depression and Anxiety	19	Instagram	once a day+	once a week
P12	25	F	White	CA	Depression and Anxiety	5	Facebook Reddit	once a week once a day	once a month- once a month-
P13	34	F	Hispanic, Latino, or Spanish origin	IN	Depression	5	Facebook	once a day+	once a week
P14	27	F	White	MA	Anxiety and OCD	12	Facebook Instagram	once a day+ once a day+	once a day once a day
P15	34	M	White	RI	Depression, ADHD, and Bipolar Disorder	21	Facebook Instagram	once a day+ once a day+	once a day+ once a day+
P16	49	F	White	MA	Depression and PTSD	2	Facebook Whatsapp	once a day once a day+	once a month- once a day+
P17	30	F	White	GA	Anxiety	10	Facebook Instagram Snapchat	once a week once a day once a week	once a month- once a week once a month
P18	30	F	Black or African American	NC	Depression and Anxiety	16	Facebook	once a day+	once a day+

3.2 Participant Safety and Risk Mitigation Measures

This study was conducted with Institutional Review Board (IRB) approval from the relevant institutions. We were aware of potential safety risks for our participants because of their mental health conditions. We deployed several risk mitigation measures; at the beginning of the interview, the interviewer clearly explained that the participants could decide not to answer any questions if they were too sensitive or stress inducive; the interviewer clearly explained the participants could leave the interview session and compensation would be provided even if they were to leave the interview early; during the onboarding and consent process, we provided emergency resources, including 7 Cups of Tea, Crisis Text Line, and National Suicide Prevention Lifeline. In addition, at certain points during the interview, as well as when the interviewer felt the participants revealed some emotional agitation, the interviewer paused and ensured that the participants felt okay and were willing to continue [32]. At the end of the interview, the interviewer again asked whether the participants felt stressed or needed help. All participants answered that they felt fine at the end of the interviews. To protect our participants' privacy, personal information has been deidentified.

3.3 Data Analysis

The transcribed interview data was qualitatively analyzed using inductive and deductive approaches following Braun and Clarke [118]. The first and second authors individually generated initial codes. The initial codes were inductively generated because we did not have a predefined coding frame and focused more on the relationship among the data. They met after the first round of coding and discussed their findings until agreement was reached. This resulted in the establishment of six themes such as "sharing modalities and challenges" and "privacy concerns." After that, the first author conducted a deductive analysis using previous literature in patient narratives [66, 81] and patient information privacy [85, 110] to reorganize codes and themes from the previous inductive process. This deductive phase included team discussion to refine the initial six themes. Specifically, this deductive process helped us to refine one of our themes related to privacy concerns based on the concept of contextual integrity [85]. Through multiple rounds of discussions, we consolidated and reorganized our themes to highlight patient perspectives regarding discussing social media during consultations and the intertwined opportunities and concerns surrounding such practices.

3.4 Positionality

We are an interdisciplinary team consisting of HCI researchers, mental health clinicians, and medical researchers. Our team has a diverse demographic and cultural background, including people of color, LGBTQ+ people, and immigrants. Notably, one of the authors has suffered from a mood disorder for more than 15 years, which inspired this line of study. The personal motivation also harmonized with other researchers' professional experiences in mental health research and practice. Collectively, the diversity of both the professional and personal experiences of team members allowed us to navigate patient perspectives in this study, which have influenced our research questions and the analytic lens used to interpret the qualitative data. That said, the team members acknowledge their relative privilege within society that has provided them with certain advantages that participants in this study do not necessarily hold. Following Starks et al. [112], the team, therefore, used a Reflective Design Approach [104], pausing to reflect on these important points: Will this benefit us or our participants? Is this a savior's complex, or are we truly supporting and serving this community? What biases are we bringing to this work?

3.5 Limitations

Even though our interview study has revealed novel findings in social computing and mental health, we acknowledge that, although typical for qualitative studies, we worked with a small number of participants living in the U.S., who were recruited from anonymous or semi-anonymous online platforms. Our findings and suggestions are not intended to be generalizable and may be U.S.-centric; we sought rich accounts of patients' experiences that can be transferred to other situations [52], as noted above. Future research that aims to gain generalizability, could use complementary methodologies and epistemologies, such as survey studies, experiments, or alternative recruitment strategies suitable for studying stigmatized groups, such as respondent-driven sampling [48].

We worked with mental health patients because our questions are rooted in their own motivations and experiences of utilizing their social media activities during their consultations and because, we, as authors, value a patient-centered model of care [37]. Even though this helped us to deeply understand the shaping of patient narratives, we acknowledge that those narratives are a part of the interpersonal interactions between patients and their clinicians. Future research could explore the views of both patients and clinicians, including dyads of patients and clinicians working together, to further understand how social media activities impact the collaboration during clinical encounters.

4 FINDINGS

4.1 Patient Narratives that Emerge from Social Media

Our participants brought up their social media activities to augment different types of patient narratives: narratives for interpersonal conflicts, narratives for digital detox, and narratives for self-expression. We describe these findings in the next subsection.

4.1.1 Narratives for Interpersonal Conflicts. The most conspicuous pattern that emerged from our data analysis was around the various interpersonal issues manifested on social media. Interpersonal relationships are one of the important factors in maintaining mental health [102, 113], and interpersonal problems can provoke negative stress and related symptoms [82]. Therefore, examining interpersonal problems is a typical part of psychotherapy consultations. To augment their interpersonal conflict narratives, our participants verbally described their own posts and messages. They also used smartphones or screenshots to show exactly what happened.

When they brought up their social media activities, some patient participants were looking for confirmation of their interpretations of a given situation, while others were seeking emotional validation. Many participants mentioned that they were not sure whether they were overly sensitive due to their mental health conditions (P2, P7) and/or wanted to hear their therapists' opinions (P2, P3, P8, P14, P15). In these cases, they preferred to show their smartphones or screenshots during consultations to provide "more objective" contexts (P7, P14, P15).

"If you can read a conversation with someone, then you can see exactly what other person said and what I said in there. There is nothing that's left unsaid and you're being completely truthful." – P14

Speaking of emotional validation, when P7 felt she was suffering from confrontational arguments between her family members, her therapist told her that "it was valid to feel that way." P14 mentioned that her therapist would help to identify anxiety – one of her main symptoms – when her therapist read her conversations on social media.

"She [my therapist] will give me her take on things. And like she'll say, 'I think when you said that-that-that-that, it showed your anxiety there,' or something like that." – P14

In addition to validation and confirmation, our participants said that their therapists often provide different perspectives on patients' interpersonal conflicts [120]. P5's therapist suggested he put himself in the other person's shoes while maintaining his own position.

"Just letting me know, sort of, and giving me a different perspective. Like a more objective kind of perspective on what actually happened. [...] I was glad to get a different perspective."
– P3

Also, our patient participants felt that the narratives that emerged from social media activities could be used as a tool for review. After they explored alternative perspectives and coping skills, for instance as a part of cognitive restructuring of thoughts in cognitive behavioral therapy [31], they could go back to a specific conversation on social media to see where they could apply those new perspectives.

"That's a portion of the therapy at the end of the hour – I sit with [my therapist] and go over the social media stuff. It's that, that's actually been the most helpful I think of all the tools that we've used." – P5

4.1.2 Narratives for Digital Detox. Another noticeable pattern among our participants' responses constituted their needs for a balanced use of social media. Similar to the findings of Pater et al. where providers recognized both negative and positive impacts to patients' illness status [90], all of the participants acknowledged that social media can be both harmful and beneficial [108]. They mentioned the addictive nature of social media, misinformation, and misunderstandings in communications as some of the negative aspects of social media. At the same time, our participants mentioned the value of being connected to others and online support communities. In an effort to balance the negatives with the positives, most participants mentioned trying to avoid excessive usage of social media. Therefore, this point about digital detox [97] naturally came up in their conversations with their therapists. To augment narratives around this concept of digital detox, our participants showed screen time apps to share an overview of their social media use, or visited their social media platforms to discuss the detailed use cases with their therapists.

Augmenting narratives for digital detox usually began with the patients opening up about their negative experiences on social media and their therapists then providing advice on how best to reduce the amount of time they spend on social media:

"We had discussed that it probably will be beneficial to minimize my social media usage. [...] You know, so [my therapist] recommended that I kind of, not end my social media usage, just cut it down for a time." –P13

In some cases, the therapists reviewed the time their patients spent on social media using screen time apps or even set a goal for the next week to manage how often and how long they are on social media.

"[My therapist] will go over [the screen time app on my smartphone] and say, you know, let's see if we can reduce this by five hours or something, and give me some constructive things to do." –P5

Beyond screen time, therapists provided other advice on using social media, such as how to block someone who constantly caused stress for the patient or how to turn off the notifications of social media apps.

"[My therapist] said if you're embarrassed about it, it's okay... it's a normal human emotion, but you don't have to engage with that. You don't have to acknowledge you saw it even if your mother tagged you in these posts. So she actually showed me how to change the settings, she walked me through it." –P7

Screen time applications and notification settings for social media platforms are specific types of technologies that have not been fully explored in mental health literature as regards the use of social media during clinical consultations. This can be important because clinicians' knowledge and experience of social media can impact this type of collaboration. However, clinicians have different levels of familiarity with those new technologies [4]. We can imagine situations where a patient is suffering from difficult interactions with or addiction to a specific social media platform that their clinician is less conversant with. Our findings indicate that this gap in awareness and familiarity can lead to a less successful collaboration between the clinician and the patient when it comes to handling the negative effects of using social media. This might be a difficult gap to address considering the fact that new platforms are constantly emerging, existing platforms are rapidly evolving, and how best to utilize social media is not an area of expertise or priority for many clinicians. The concept of a "clinical technology specialist" [11] or a digital navigator [86] has been suggested by clinical researchers as a way to explore this challenge.

4.1.3 Narratives for Self-Expression. Self expression has been considered important in social behaviors [50] and mental health [88]. Previous HCI and CSCW work has focused on facilitating self expression and self-disclosure on social media, as it may include therapeutic benefits [38, 89, 114]. Feuston and Piper revealed that individuals with mental health conditions express their stories in part to get validation of their experiences from others and that this validation serves as an avenue for openness about personal experiences that are otherwise difficult to discuss [43]. Related to these previous studies, we found out that self-expressive social media posts may reveal patients' traits, such as what they like and what they care about. Our participants mentioned memes and posts they saw in order to augment their narratives for self-expressions during consultations. For example, one of our participants revealed how an ad helped her stay positive:

"An ad on Facebook was trying to sell something and I had brought it up because I like clothes and stuff, and because I do a lot of online shopping.. [...] It was a good conversation. It probably didn't last long, but it was a good one. I had to stay positive, with all the negativity going on, especially with this [COVID-19] virus going on, I feel I don't have the time for negative stuff right now." –P18

Our findings show that the self-expressive nature of patients' social media activities can mediate patients' experiences during consultations. This type of self-expression can be valuable because mental health patients often encounter challenges in explaining or articulating their negative experiences [70]. Explaining how painful their symptoms are is difficult because, in most cases, clinicians have not personally experienced those mental health illnesses [1], and every patient's condition or situation is unique. One of our participants, P2, poignantly illustrated how she uses memes she found on social media to convey her symptom experiences to her therapist.

"I think it helps because sometimes I get stuck – talking in circles, and trying to express a feeling. Because I know that [my therapist] doesn't have a lot of personal first hand experience with difficult feelings and mental health symptoms. [...] And so I feel I'm having a really hard time trying to explain my experience in a way that I feel he's understanding. In those cases, [social media] is like a really helpful shortcut." –P2

We believe this portrayal of symptom experience to clinicians can be important and therapeutic, however, we also had patient participants who clearly stated that they were not self-expressive on social media. According to P13: *"I don't really put personal information on my social media."* It is therefore safe to assume that narratives for self-expression will vary based on the patients' own preferences and patterns of social media usage.

4.2 Patients' Perceived Power Dynamics Between Patients and Clinicians

We observed through our interviews that discussing social media during consultations could more vividly portray a power imbalance between patients and clinicians. Prior work has observed that if clinicians are not supportive when patients unfold their stories, it may lead to a power imbalance between the two parties [10]. Our participants mentioned that they were worried about being minimized by their therapists when they shared their social media activities, and they were emotionally impacted when they felt that their therapist was neglecting what they shared from their social media.

"I think, I have sort of a huge concern with any therapist and anything I bring to them I doubt they're taking it seriously. Because I've had a lot of experience where I feel this happened. And then you've got that added layer of like "those kids with their social media and they're bringing me this like social media drama" and then you're like, okay, put that aside, please concentrate on, you know, the core issue here." –P12

In addition to diminution, our interviews indicated that if patients feel that their therapists are giving judgemental comments on shared social media activities, they will be less likely to engage with such content during their session, which can further exacerbate existing power imbalances.

"If I show [the therapist] something, without any judgment, no matter what it is, I feel they wonder "what do you show me this for?" But I am like "you're supposed to be the person that I talk to about anything. It should be no judgment or anything." –P18

However, we found that discussing social media data impacted power dynamics between patients and clinicians beyond diminution. In our interviews, we encountered two instances where patients felt obligated to share their social media with their clinicians. To better facilitate ease of access to P6's social media, his therapist would connect P6's smartphone to a TV in the consultation room and would go through each social media platform he used to check whether P6 had made aggressive posts or not. P6 did not have control over this sharing experience because the therapist operated P6's smartphone during the consultations. In a second instance, P10 and her therapist were friends on Facebook; the therapist had sent her a friend invitation. P10 clearly expressed that she did not want to be friends with her therapist on Facebook, but her therapist insisted.

"[My therapist] thought that [friending on Facebook] would be a good idea. I personally don't think it is a great idea. [...] but I accepted it because I didn't want any issue. [...] I brought up the issue multiple times though. You know what she said? That it's best that she be able to see how I feel, so she knows exactly what to talk about that next following week, or if she needs to call me. [...] it's fine, but it's not fun. To be honest, it's my personal business, it's my personal space. That's really how I feel about it." –P10

We believe that these kinds of monitoring of social media can negatively impact patients' autonomy and agency, which are important in both the therapeutic alliance and towards achieving positive treatment outcomes [58]. We conjecture that this monitoring might be related to the fact that both P6 and P10 were suffering from psychotic disorders, and the clinicians may have adopted these approaches to reconcile conflicting reports and recollections of incidents and experiences from the patient and other collateral information sources. Even so, we believe that patients' agency should be prioritized except for in the case of emergent situations.

P5 also had a connection with his therapist on social media, however, this was less coercive; his therapist used a professional social media account and clearly set the expectation of having a connection on social media:

"[My therapist] did tell me that this is not her regular personal account, that this is a separate account that she's using to connect with her patients. We went over it ahead of

time and she asked me if this was something that I would like to do. I know she's been doing that with some other patients, so at the time, I said yeah that sounds good. And she did say right off the bat she's not going to engage in any conversation on social media, you know, like messaging, and she'd kind of be a silent bystander, you know, to see what I post." –P5

Interestingly, P5 had no reservations or concerns about having his therapist observe what he posts on social media. He elaborated on the benefits of the experience:

"By having access to my social media, [my therapist] would know my interests and likes and hobbies and stuff. She can see the pages I like, the groups I follow, you know, friends, that kind of thing. So I think she gets a more complete picture of my life of things that I don't bring up in therapy, like I love cats – I'm in a lot of cat groups on Facebook. You know, so I think she has a more thorough picture of who I am." –P5

The P5 case echoes previous studies that suggested that using social media connections with discretion, such as with professional accounts, setting norms for social media connections, and agreeing on appropriate practices and uses, can have a positive impact on patient-clinician collaboration [45]. The key question would be how agreements regarding having connections on social media can be reached with a balance of power between patients and clinicians.

Finally, as a complement to these findings, we also observed that existing power dynamics between the patient and the clinician parties may be complicated or even reversed by the evolving landscape of health information seeking by patients. Recent research indicates that better access to health information can change the power equation between patients and clinicians because patients feel more empowered in their conversations with their clinicians [30]. However, disagreements may also arise – patients may sometimes trust online information over their clinicians' opinions [109]. In order to ensure that disagreements stemming from bringing up social media narratives do not negatively impact their therapeutic relationship, P12 explained her own strategy of adopting caution when she wanted to discuss health information she found on Reddit.

"Just to give an example, I felt like I always had this weird experience of feeling kind of out of body – like I wasn't connected with my body. I eventually stumbled upon dissociation on the Internet and through, you know, Reddit specifically, I was like, okay, wow that explains exactly what I was experiencing. But I didn't go to my therapist saying "hey I found this on Reddit and I think I'm experiencing dissociation." Instead I did the sort of roundabout thing where I described, all the symptoms in a way that I knew they would recognize, so we could open the conversation to it [...] I've done this a lot." –P12

Speaking of situations where social media narratives reversed the power imbalance between a patient and their clinician, some of our patient participants recalled sharing online memes with their clinicians as a vehicle to describe their feelings and experiences. However, clinicians are not always very familiar with online trends, such as new social media platforms or memes [55, 90]. Therefore, our participants revealed that they had to explain the meaning of memes during consultations.

"[My therapist] isn't so Internet savvy; so sometimes I've to explain the whole meme, its format, and all." –P2

Teaching something to their therapists can be a rare experience for most patients, however, it can provide them with opportunities to wear different hats during consultations, which can help mitigate power imbalances. However, considering the limited time and resources for psychotherapy consultations, finding the time for those conversations while not interfering with the main therapeutic goals can be difficult.

4.3 Privacy Concerns Exacerbated by Social Media Narratives

Because social media activities are sensitive information, we examined how our participants perceived privacy related issues when they discussed their social media activities with their clinicians during consultations. According to Nissenbaum's contextual integrity [85], privacy concerns are exacerbated when some specific content is not appropriate for a specific context (norms for appropriateness) and/or when information is exchanged in inappropriate ways (norms for distribution). In the case of social media derived narratives, the norms of appropriateness will be related to whether the social media activities are relevant to the consultations. The norms of distribution will be concerned with how those narratives are exchanged.

To start with, in terms of the appropriateness of the content, many participants stated that they consider bringing up social media to be pertinent.

"I think in order to have therapy work you know you kind of have to be an open book and I'm not, you know, hiding anything from anyone as far as, you know, what I post on social media or anything." –P5

In addition to P5, many patient participants echoed that they shared "everything they want to talk about" with their therapists, and if something from social media bothered the patient participants, they wanted to describe those social media activities to their therapists.

"It's important to be open and transparent with your clinician because I don't think a clinician could help you very well if you're not transparent or if you're not open to communication. [...] Social media is such an important aspect of life – I really think it is important to be transparent with your clinician about it " –P8

We found occasions where appropriateness had been breached because patients accidentally showed something they did not want to show. Participants said this could happen in various circumstances, such as when they were scrolling through their smartphone screen during a consultation looking for a specific item to show, accidentally revealing more than they intended to.

"One time I opened up my Internet browser to show him something and I had like a Google page open. Maybe it was something to do with mental health. But it was unrelated to what I was going to show him." –P2

Still, our participants felt that such mistakes and errors were not very important partially because their therapists "kind of [knew] everything that's going on in [their] lives (P4)" and because they have shared more embarrassing or sensitive stories with their therapists. However, more unclear situations emerged when they showed or shared posts including others' (social media friends' and followers') names, postings, or pictures. In verbal reports, participants said they could refer to someone who was not important or whose identity they did not wish to reveal using a vague term such as "they", however, showing social media activities could reveal more information than a vague moniker, thus creating a breach in appropriateness.

Gray areas can also emerge surrounding the norms of distribution. In the psychotherapy consultation context, confidentiality of conversations is guaranteed not just by laws such as HIPAA [2] but also by cultural underpinnings [75], which enable the sharing of patients' sensitive private information to improve their mental health states. Our data confirms that expected confidentiality sets a mutually agreed upon norm between patients and clinicians in our participants' cases.

"Well, I know it's never leaving that room. It's never leaving that person. So it's always my go-to." –P12

Nonetheless, we also found out that sharing social media during consultations may go beyond or may not necessarily fit within the existing norms in psychotherapy settings. Consequently, this disconnect may raise new privacy concerns. First of all, we found that it was not always clear

to the patient whether it was appropriate to directly show others' posts or conversations with their therapists. As noted above, often in typical psychotherapy consultations, a patient would describe their friends and family members' behaviors for treatment purposes. However, the norms of distribution could be breached when such a description involves the use of actual writings or pictures of those people on social media. Several participants pointed out this blurry area of privacy issues, including P7:

"If [I am showing] a post and they see the first and last name [of another person], I don't want them to research the person to find out more. I think it's just a little too probing, like you know, pry into somebody else's life that they don't really know anything about. I mean, it'd be one thing if [the other person in the post] was going to this same therapist and she was a patient. Even still, it's like private confidentiality that I don't think I would want to cross that line, you know." –P7

Furthermore, sharing social media during telehealth sessions – a practice our participants indicated as becoming more common during the COVID-19 pandemic – may give rise to situations where the norms of distribution of in-person consultations may not be applicable. Our participants noted concerns when they sent screenshots of their social media posts via email or text. They did not know whether and how their therapists stored or eliminated those shared records after the consultation, or the consequences when they sent the wrong information to their clinician.

"I think I would rather just show it to [my therapist] because I know that they keep files and charts, and to me, that's very personal and anybody can read the files and charts. So, I hadn't thought about it before now but I don't know if she's printing those off or anything. I don't know, [...] Well I guess her receptionist can go get it from the file room, and she could be like clicking on other people's names on social media, going and looking at their pages, don't you think?" –P7

We believe that future technologies need to support patients' control over diverse patient-generated health data during consultations to alleviate privacy concerns. We discuss privacy-related implications next in Section 5.2.

5 DISCUSSION

From the interviews with mental health patients, we learned three things: patients discuss their social media activities with their therapists during their consultations; the sharing experience can initiate or facilitate the unfolding of narratives, which can reveal patients' unique and uncertain symptom experiences; sharing social media can highlight a power imbalance between patients and clinicians that can hinder patient-centered care [70] or sometimes breach contextual integrity, which can present obstacles to treatment by increasing privacy concerns. With this deepened understanding of social media based patient narratives in consultations, we then discuss implications for social computing technologies and health informatics technologies.

5.1 Role of Social Media in Augmenting Patient Narratives

Our participants' accounts showed roles of social media data that support collaborations with therapists. We also found that social media can similarly be appropriated for use in a different communication environment (psychotherapy consultations). The narratives that emerged from appropriation of social media spanned a variety of topics ranging from interpersonal conflicts and digital detox to symptom awareness and self-expression. Our findings thus add to the HCI and CSCW literature on the roles of narratives in medical consultations – that narratives stemming from the use of social media in psychotherapy can be diverse and iterative, rather than focused, standalone, and completable [81].

Patient narratives are not just retrospective accounts of past events but also active reconstructions during clinical encounters [81, 105]. When patients develop their narratives, they select the more personally meaningful events over others to make their narratives more efficient and effective [81]. At the same time, they intend to deliver sufficient details of the events so that clinicians can provide their own interpretations to patients. According to our participants, patients bring up their social media activities to illustrate or summarize their stories. These somewhat contradictory goals (illustration vs. summarization) are rooted in one overarching purpose of patient narratives: initiating collaborative reconstruction of their lived experience with their clinicians. Therefore, understanding how social media activities augment patient narratives is important to better understand not only patients' experiences but also patient-clinician collaboration.

Further, in supporting patient narratives, our findings suggest that social media data can be different from other types of patient-generated health data (PGHD) in two ways: social interaction and double curation. Three types of narratives in our findings – narratives for interpersonal conflicts, narratives for digital detox, and narratives for self-expression – regard either social interactions or self-presentations in social settings. Essentially, social information has been less explored than symptom-related information in previous PGHD studies. However, especially in mental health, social behavior or functioning is an integral part of treatment outcomes [51]. Therefore, our findings suggest new directions for PGHD scholarship where symptom-related information is complemented by social behavior-related information to achieve treatment goals in mental health.

In addition, double curation happens when patients curate their experiences and post them on social media platforms and then re-curate them when they share those social media activities with their therapists. Our participants mentioned that they voluntarily chose what to share from their social media activities. These are different from passive sensing approaches in previous PGHD [26], where patient behaviors or physiological status are passively collected and rarely self-curated. A lack of familiarity with this passively collected data can make it difficult for patients to select what they should share with the clinicians. The format of social media data, on the other hand, is familiar as it constitutes voluntarily and consciously created and shared information, and patients are able to easily choose and curate their activities to better support their narratives and their collaboration with their therapists. This unique nature of social media data can highlight design implications for future technologies as well as ethical concerns, which will be discussed in the next three subsections.

5.2 Privacy Implications for Augmenting Patient Narratives

Per our findings, while bringing up social media activities appears to augment patient narratives, it may also raise privacy concerns in several ways. We believe a deeper understanding of the privacy issues of social media based narratives in mental health is critical in supporting mental health patients. We discuss our participants' privacy concerns from the perspectives of boundary management [54] and risk-trust analysis [87].

After the emergence of social media technologies, many researchers argued that patients and therapists need to pay particular attention to boundary management [54] because social media can blur the boundaries between patients and therapists [47]. Despite the numerous previous research in social media and boundary management [25, 29, 60, 67], P6 and P10 experienced involuntary sharing of their social media activities. Having access to the online trajectories of patients needs to be, therefore, treated with caution because, when it is not handled properly, the centralized nature and scale of social media can increase potential harms [19]. To lessen these harms, we highlight recommendations from previous research on boundary management [25, 29, 71]. When patients and therapists use social media during treatment, these prior works suggest treating online information as private and sensitive as the information provided during consultations, using professional social

media accounts, reviewing institutional policies regarding social media, and, most importantly, prioritizing patients' autonomy and control throughout the sharing process.

In patient-generated health data (PGHD) literature, risk and trust are important elements in understanding privacy concerns [49, 87]. From our participants' accounts, we found that risk, which involves potential negative consequences such as data leaks or third party access, is not clearly understood. Some of our participants mentioned they do not have privacy concerns, however, they also mentioned that they do not know how their therapists store or handle shared screenshots, which implies a nebulous understanding of potential risks. This nebulous understanding of risks may be intertwined with their trust toward their clinicians. Our informants who mentioned that they did not have privacy concerns also mentioned that they trusted their therapists.

Therefore, for future health informatics technologies, it is important to foster trust between patients and therapists while minimizing potential privacy concerns. We suggest three design implications for future health informatics technologies based on our findings. First of all, technologies for mental health patients should enable empathic interactions. Our participants repeatedly mentioned that being heard or being understood were very important for them during consultations, which resonates with previous studies in patient trust [107]. They also mentioned they were concerned about being neglected, especially when they wanted to share their social media activities. Technologies can be proactive in this aspect, for example, therapists can quickly react to shared content (e.g., adding a like or love emoji to content) via a sharing technology.

Secondly, it is important to transparently provide any information regarding third parties or other stakeholders surrounding the technologies, such as insurance companies or governmental agencies. Concerns regarding insurance companies are often mentioned in the previous studies in patients' information privacy concerns [106, 107]. Our participants did not mention insurance companies specifically, however, they did mention they are concerned about other people's access to their shared social media activities, such as staff members of the hospital. Technologies should thus proactively provide any third party or stakeholder information if it is relevant to both increase trust between patients and clinicians and minimize patients' privacy concerns.

Finally, future technologies should prevent poor privacy experiences. Previous studies revealed that patients' own experiences regarding privacy are the most influential on their privacy concerns [15]. To increase trust between patients and therapists, establishing a long term relationship without having negative experiences with privacy and confidentiality has proven to be important [77]. Therefore, preventing poor privacy experiences can be more important than providing positive experiences. To achieve this, a future technology can provide a privacy checklist to both patients and therapists. As was shown in prior literature [106], we acknowledge that fostering trust and addressing privacy concerns are challenging topics, and we envision the suggestions we made can be one of the many small steps that future research can continue to investigate.

5.3 Implications for Social Computing Technologies

Our findings add additional evidence to the emerging argument that social computing technologies enable individuals with mental health conditions to explore their identities and enrich their own narratives [56]. In addition to the previous studies in expressive writing [76] and peer support [83], this study reveals a unique context of patients sharing social media activities with therapists during consultations. Previous literature advocating the role of social media in empowering people with mental health conditions suggests that social media platforms should consider inclusive policies on "problematic" content especially when they are related to their mental health conditions. Moderation, such as automatic removal of content, can worsen stigmatization of people with mental health conditions and hamper developing their own narratives using social media [44].

In agreement with this position, we argue that social media platforms should be more inclusive in terms of content related to mental health conditions. As our findings revealed, some of the content related to participants' mental health conditions or struggles can be shared with their therapists, which can help them access better help. That said, we may need to provide better autonomy and agency to users who share their negative experiences because those need to be expressed to be found, heard, and helped. Instead of automatic removal, we could consider design features where posts to be moderated (e.g., when other users report a post to be harmful or a human moderator flags a post) are isolated so only the poster can access the content with the explanation of why the post had to be isolated. Further, the isolated post can nudge the poster to seek help from significant others or mental health experts if they need outside help. To foster this process, social media platforms can provide an "anonymize screen," which is provided by some Facebook extensions [69], to temporarily anonymize their social media content to safely take a screenshot or share their screen with others. This anonymization feature can not only assuage the privacy concerns of users but also promote supporting their narratives using their social media activities.

Ultimately, nudging users to utilize their social media activities to support their mental health narratives will not be easy to achieve due to several sociotechnical issues. Inclusive moderation [44] may increase the chance of harmful content negatively affecting users. It can be tricky to decide the criteria for content removal or content isolation in moderation decisions. There are also multiple stakeholders and social consequences that we need to consider. Mental health experts may need training or guidelines for situations where their patients bring their social media activities to them based on nudges from social media platforms. Finally, because social media content can be searched for and used by third party players for high-stakes decision processes (e.g., immigration processes or hiring decisions), this nudging feature can be exploited by entities with power (e.g., governmental agencies or employers) rather than empowering individuals who need help.

Despite these sociotechnical challenges, we foresee that the role of social media activities in people's narratives will become more substantial due to the proliferation of telehealth services that the COVID-19 pandemic has brought forth as a "new normal" [122]. Social computing researchers and designers should work with stakeholders to explore better ways for individuals with mental health conditions to utilize their social media data to support their self-management journeys.

6 CONCLUSION

This study explored how discussing patients' social media activities during psychotherapy consultations augment patient narratives. Based on semi-structured interviews with 18 mood disorder patients, we unearthed three areas that inform how such narratives unfold in consultation settings: interpersonal conflicts, digital detox, and self-expression. We found that these patient narratives not only support the unfolding of patients' experiences but also highlight existing power differentials and privacy concerns in psychotherapy consultation settings. Based on these findings, we discussed the unique role and privacy concerns of social media in supporting patient narratives. Finally, we suggested design implications for social computing technologies that can foster patient narratives and assuage potential privacy concerns.

ACKNOWLEDGMENTS

Yoo, Ernala, Ali, Birnbaum, and De Choudhury were partly supported through NIH grant R01MH117172. Yoo, Ernala, and De Choudhury were also supported through a cooperative research agreement between Northwell Health and Georgia Tech. We would like to express our gratitude to Qiaosi Wang for her valuable input in the conceptualization of this study. We also extend our appreciation to both Qiaosi Wang and Jiawei Zhou for their insightful feedback that helped to enhance the manuscript.

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Received January 2022; revised July 2022; accepted November 2022