

Everyday Experiences: Small Stories and Mental Illness on Instagram

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ABSTRACT

Despite historical precedence and modern prevalence, mental illness and associated disorders are frequently aligned with notions of deviance and, by association, abnormality. The view that mental illness deviates from an implicit social norm permeates the CHI community, impacting how scholars approach research in this space. In this paper, we challenge community and societal norms aligning mental illness with deviance. We combine semi-structured interviews with digital ethnography of public Instagram accounts to examine how Instagram users express mental illness. Drawing on small stories research, we find that individuals situate mental illness within their everyday lives and negotiate their tellings of experience due to the influence of various social control structures. We discuss implications for incorporating ‘the everyday’ into the design of technological solutions for marginalized communities and the ways in which researchers and designers may inadvertently perpetuate and instantiate stigma related to mental illness.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)**.

KEYWORDS

Mental illness, small stories research, social media, Instagram, social control

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1 INTRODUCTION

Over the past decade, research on the online expression of mental illness has increased exponentially. Digital spaces provide opportunities for researchers to examine communities and practices previously inaccessible or difficult to reach. Social media and online health communities provide traces of subjective experience, archiving aspects of life with a mental illness through posts, comments, and accounts that are often available for public consumption. With respect to these online spaces, researchers in HCI have attended to sensitive disclosures [6, 7], audience support and engagement [17, 38], and classification of mental illness and associated behavioral traces [25, 27, 34, 35]. In the context of this prior work, researchers frequently extract posts related to mental illness with surgical precision; severing them from other aspects of life and experience that may provide additional, invaluable insight. Missing from the current literature is a nuanced understanding of how mental illness relates to surrounding content and interactions, both online and off.

Through a holistic approach to analysis, we extend prior work by contributing a perspective in which mental illness is part of everyday experience. We use small stories [43] as an analytic framework to understand how people express mental illness within the context of their lived experience and negotiate tellings of mental illness on Instagram that are shaped by elements of social control. Small stories research focuses on understanding non-linear events, world-making (i.e., “ordinary, everyday events” [43]), story recontextualization, and story co-construction. In this paper, we argue that small stories is a useful analytic frame for understanding expressions of mental illness on social media.

We draw on interviews with 18 people who self-reported having, or having had, a mental illness, as well as public accounts of Instagram users who, in some capacity (e.g., living or coping with illness, recovery, relapse), posted about

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mental illness. Using small stories research as an analytic framework, we demonstrate how mental illness is contextualized within everyday experience, which has implications for understanding timescales, disruption, and the ways individuals must negotiate audience and platform social control structures. We argue that the pervasive view of mental illness as deviant sensationalizes and decontextualizes certain facets of experience. This can inadvertently contribute to public stigma associated with mental illness, as well as the continued marginalization of individuals with mental illness. We discuss how social interactions between individuals with mental illness, audience members, and Instagram create new instantiations of traditional social control structures.

We make three primary contributions. First, we extend prior work by centering our analysis on individual experience through semi-structured interviews and digital ethnography of public user accounts. Though growing in frequency, first-person accounts of mental illness in conjunction with social media analysis are still uncommon. Second, our work situates mental illness as part of everyday and ordinary, albeit not insignificant, experience. This position stands in contrast to prior work in which deviance and disorder frame analysis or are otherwise conceptually linked. We argue that an alternative view of mental illness can expand the design space aimed at supporting individuals living with mental illness and change current research practices that inadvertently contribute to harmful stereotypes. Finally, we discuss the ethical implications of research and design with respect to social media and mental illness. Specifically, certain Instagram features, such as content moderation and helpline resources, reinforce power dynamics that marginalize and unjustly disadvantage certain user populations. By attending to the ways individuals express life with illness in conjunction with other daily routines and activities, we contribute a new understanding of mental illness in the everyday, including how users are subjected to social control through audience member interactions and Instagram as a platform.

2 RELATED WORK

We bring together work on narratives, mental illness, and marginalized communities online to inform our analysis of expressions of mental illness on Instagram.

Health and Illness Narratives in HCI

Interpersonal, everyday stories provide ways to share with others, construct identity, and understand experience [45, 59, 73, 76]. In studying illness, scholars often use narrative as a means of understanding the subjective experience of being ill. Seko and Lewis’s study of self-injury narratives on Tumblr [79], as well as Holmes’s analysis of anorexia narratives on YouTube [51], are two recent examples demonstrating how

scholars leverage components of narrative research to examine mental illness and the online construction of narrator identity. Few researchers within HCI and CSCW have drawn on narrative research or analysis to examine lived experience with illness. A recent exception includes Eschler et al.’s examination of how cancer survivors strategically use tattoos to recover from trauma associated with cancer diagnosis and the subsequent treatment process [39]. Similarly, Michie et al.’s research on reproductive rights [61], though examining a highly stigmatized health decision rather than illness, draws on certain pro-life narratives (e.g., trauma, regret) and the ways that pro-choice stakeholders come to challenge them. Recent studies examining mental illness online within CSCW [7, 89], though not calling upon narrative research explicitly, incorporate notions of storytelling to describe how individuals share their experiences with others.

To date, scholars studying illness online have predominantly focused on the content of personal illness narratives. We extend this research by using small stories as an analytic framework for exploring how narrative activity is accomplished through interaction [43, 71] on Instagram. Developed in opposition to the ‘big stories’ (i.e., stories often narrated in the retrospective, in which individuals describe prominent life events or their life stories for the purpose of connecting particular components into a descriptive whole [10, 71]) typical of narrative research, small stories prioritize interactional aspects of the everyday. Specifically, small stories “refer to stories told during interaction, generally within everyday settings, about very mundane things and everyday occurrences” [71]. Small stories research provides an opportunity to examine commonplace, interactional exchanges, such as those shared via social media, ongoing events or stories that may unfold across the span of multiple tellings without a particular beginning or end, and co-constructed experiences and identities that demonstrate the influence of social and power dynamics. Here, we also view narratives as “located in particular times and places” [76] with regard to how storytelling is not only influenced by individual and collective experience, but also “cultural evaluation of what can be narrated and how that can be narrated” [9].

Mental Illness on Social Media and In Online Communities

There is a rich history of mental illness online with respect to traditional definitions of online communities [25, 56, 89], as well as contemporary notions of support networks [69]. Scholars studying mental illness online address a broad range of topics, including self-disclosure [7, 31], content moderation [26, 28], audience engagement and support [38, 64], content detection and behavioral prediction [24, 25, 27, 35], and community norms [23]. In this work we observe several practices regarding how researchers conceptually link

mental illness and deviance. For example, in some work, these concepts are explicitly linked [24, 28]. In other work, however, the connection is implicit through association with medical disciplines. For example, Pater and Mynatt [68] call upon psychiatric definitions of mental illness to promote interdisciplinary dialogue with medical practitioners and advocate for contextualized understanding of mental illness online. Though we extend this work to examine the everyday experience of living with and posting about mental illness, we do not align our work with clinical paradigms [25, 68, 69]. Underlying these perspectives are implications for the ways in which mental illness may be viewed as deviant or disordered [24, 28]. Specifically, clinical definitions of mental illness have conceptual links to deviance and disorder, as well as associated illness narratives [42, 54], such as suffering. While deviation from cultural norms is not inherently negative [53], the motivations researchers use to support their work [24, 25, 81] suggest that deviance, in this context, is often a problem.

In trying to address this ‘problem’ researchers may extract content related to mental illness from other aspects of community and individual life [23, 24, 58, 69]. This separation neglects a holistic examination of the ways in which context [7] plays a role in understanding illness and the subjective experience of being ill. As other researchers note, mental illness does not exist in a vacuum [68]. While we do not contest that aspects of illness may be inherently harmful or destructive, we do question the appropriateness of technological solutions addressing the ‘problem’ of mental illness online and potential contagion [18, 89]. Many solutions (e.g., content moderation, health interventions) limit the personal agency of individuals with mental illness, who are often subject to policies put in place to ‘help’ them, but that are not informed by them (cf. [67, 70]). Researchers have begun to examine the ethical and social ramifications of technology in this domain (e.g., censorship [69] on marginalized communities). In this paper, we aim to advance a new perspective by foregrounding the subjective and idiosyncratic experience of illness rather than traditional societal perceptions (e.g., deviance, treatment).

Marginalized Communities Online

Prior work examines how members of marginalized groups find and form communities online [47, 74]. The view of individuals with mental illness as marginalized [64, 69], however, has not been widely adopted by researchers studying mental illness online. We extend this perspective by joining our understanding of mental illness with that of previous work examining the ethics of studying marginalized communities online [14, 48]. Others have argued that scholars should be mindful of the ways in which researcher norms, as well as societal ones, differ from those of the ‘subculture’ being studied

[21, 48]. Similarly, prior work has asserted that researchers should aim to address digital divides [72, 83]. While internet access has improved over the past decade, some of the most marginalized communities, including politically disenfranchised religious and ethnic groups, are the most excluded [60, 84]. Though social media and online communities have the potential for empowerment and activism [3, 5, 16], recent work suggests that marginalized communities face additional oppression online [87]. Through our analysis of mental illness expressions on Instagram, we address the ways that researchers and designers contribute to oppression and discuss how we can mitigate harm inadvertently caused by the technologies we create.

3 METHOD

To examine the subjective experience of life with mental illness, we combined semi-structured interviews with digital ethnography of public Instagram accounts. Interview participants, as well as accounts included in our Instagram corpus, shared content related to various facets of mental illness, including living or coping with mental illness, recovery, and relapse. Our analysis draws on small stories research [43] and multimodal discourse analysis [32, 55] to understand how individuals express mental illness on Instagram.

Interviews

We conducted semi-structured interviews with 18 adults (ages 18 – 36; $M = 29$ years; 14 female) who post about mental illness on Instagram. For this study, we were interested in understanding experiences with mental illness. However, due to the colloquial equation of mental health with mental illness, participants frequently used these terms interchangeably. Therefore, our interpretation of mental illness derives from participant references to low mood, named disorders (e.g., anxiety, depression), and aspects of recovery, such as clinical treatment (e.g., medication, therapy) and self-care. Though all of our participants self-reported experiences with anxiety, depression, and eating disorders, only several indicated receiving a diagnosis. Per our human subjects protocol, we did not interview individuals who self-reported currently practicing self-harm or experiencing suicidal ideation. However, we did analyze public user accounts with posts related to these topics. In the instance that any participant had self-reported current experiences with self-harm or suicidal ideation, the interview would have immediately ended and our study’s mental health consultant would have reached out in accordance with our IRB protocol and her own set of practices. Our study’s mental health consultant (i.e., an art therapist and licensed counselor by training) was an important member of our team who was available as a participant resource. This team member’s information was included in

our study's consent documentation. We also informed participants that they could contact her at any time. Per our IRB, we emailed a document of mental health resources (e.g., hotlines, practitioner locators) prior to the interview.

Participant recruitment occurred through websites, such as Instagram and Craigslist, and word of mouth. We reached out to Instagram users who posted publicly about mental illness; however, none of these individuals responded to our recruitment email. We only interviewed individuals living in the United States, though our Instagram account corpus includes users from other countries. We conducted 30-minute semi-structured interviews through phone calls and text-based mediums, including email and Skype. Text-based interviews typically lasted longer than 30 minutes due to the asynchronous back and forth nature of question and answer. These interviews allowed us to speak with individuals who were otherwise off-put by verbal discussion related to mental illness. To mitigate potential confusion between a research interview and talk therapy, we clarified our roles as human-computer interaction researchers, rather than mental health practitioners, prior to the start of the interview.

Our interview protocol was specific to Instagram. We asked participants about posts, including images, captions, hashtags, and comments, as well as Stories, a feature on Instagram that allows users to share content for up to 24 hours. Though we focused on Instagram posts that included some element of mental illness, we asked participants to describe the type of content they typically and recently shared. Prior to the interview, and when possible, participants shared their Instagram accounts with the study team. Some participants did not feel comfortable sharing their accounts, even when public, and opted to share screenshots of particular posts or describe them during the interview process. Given that our interview process was grounded in particular Instagram posts, many of which included pictures, we used photo elicitation [50]. We reviewed three to seven posts per participant and asked questions pertaining to how and why they posted about experiences with mental illness, as well as the ways others responded to this content. Interviews were audio recorded and transcribed for data analysis. Participants received a \$20 Amazon gift card for their participation.

Instagram Account Corpus

Data collection practices influence researcher interpretation, and vice versa. By conducting digital ethnography on public user accounts, rather than on a random amalgam of posts, we are able to examine the temporal, and often non-sequential, ordering of events as presented on Instagram. This provides a different perspective of online expressions of mental illness. We identified content and user accounts through data collection in November 2017, March 2018, and June 2018, where we used hashtags as search terms (e.g., #depression,

#ednos, #secretsociety123, #bipolar, #anorexia [7, 26, 28]) to manually (i.e., without a web crawler) collect 6,223 unique mental illness-related posts by 2,188 users. This post corpus provided an initial area of inquiry. We also conducted digital ethnography to include user accounts and posts initially excluded (i.e., those using different hashtags or no hashtags at all) and analyzed 15 public user accounts in detail. These accounts were selected through purposive sampling [66].

Data Analysis

We used small stories research [43] as a guiding framework during our analytic process. This enabled our focus to remain on interactional and everyday, mundane events, which were of paramount importance to the development of our themes. We developed themes through iterative coding, memo writing, and constant comparison of data to developed concepts [29]. Themes were first identified through simultaneous analysis of interview data and Instagram posts. Though we used personal narratives with respect to mental illness (e.g., big stories explaining personal mental illness trajectories and attitudes) to support our understanding of an individual's overall subjective experience, we attended primarily to post composition and audience reaction as a way of grounding ourselves in everyday expression and interactional storytelling.

To call attention to a minute-yet-significant detail, we conducted research with small story narratives rather than on them [11]. Specifically, we used small stories and interview retrospectives regarding certain Instagram posts to understand the experiences of individuals living with or posting about mental illness (i.e., in contrast to generating various small story typologies). Though small stories are not necessarily grounded in the oral or textual practices of traditional narrative research, we want to clearly state our commitment to examining the ways in which multiple modalities influence how mental illness is expressed on Instagram. As definitions of narrative shift and expand to accommodate new media forms [57, 82] it becomes increasingly necessary to incorporate a variety of modalities, such as images and videos, into narrative analysis. In this paper, we included captions, comments, usernames, liking a post, hashtags, profiles, private messages, offline discussion, and images in our analysis. By joining our analysis of participant interviews with Instagram user accounts, we are able to call on several modes of expression [55] to understand the inherent complexity of mental illness and how it is expressed and shared.

Ethics and Responsibility

Every study decision involves ethics [40]. In this work, we collected Instagram posts manually, in line with platform terms of service, recruited individuals with mental illness

to share first-person accounts of their experience, and included a mental health consultant as a participant resource rather than an analyst (e.g., such as for post validation [58]). Though the accounts incorporated in our analysis were all public, users did not explicitly consent to participate in this research. All of the captions, comments, usernames, and hashtags (i.e., textual artifacts) mentioned in the following sections are paraphrased or modified to preserve user identity while maintaining the integrity of the shared content and experience. This paper does not include visual artifacts (e.g., images). Instead, we present this content through textual description. We do so to avoid sensationalizing images of illness, potentially capitalizing off of novel or ‘shocking’ visual content and rousing emotional distress in readers.

4 FINDINGS

Through the use of specific hashtags as the primary means of data collection and filtering, researchers often extract mental illness from other content on Instagram and analyze this expression absent the sociotechnical context in which it exists and was created [44]. In this paper, our goal is to examine online expressions more holistically – in conjunction with an individual’s experience and, in part, what Andalibi et al. refer to as ‘contextual expression’ [7]. By examining how mental illness arises in the context of other circumstances, or is itself featured, we prioritize the experience of living with or having lived with a mental illness rather than the recontextualization of mental illness within a narrow window of expression. Treating mental illness as inseparable from surrounding content, we describe how Instagram users with or posting about mental illness share their experiences online and navigate aspects of narration subject to social control from audience members and Instagram as a platform.

Mental Illness in Everyday Life

We find several ways that experiences shared on Instagram reference or feature mental illness, often bringing it alongside everyday activities or posting routines. In posting on Instagram, users share aspects of their everyday experiences in which mental illness may be part [7], post with respect to individual timescales, and reframe traditional narration around disruption. We developed the notion of ‘mental illness as part of everyday life’ from a new way of looking at mental illness experience and expressions. Mental illness becomes ordinary through the ways individuals select to express it online. Our incorporation of small stories as an analytic lens supports development of themes grounded in interactional and ongoing tellings of mental illness explicitly, as well as tellings that bring mental illness alongside. Examining how people entangle mental illness and other elements of life supports understanding experiential aspects that may otherwise be overlooked or backgrounded. In the context

of this analysis, mental illness is rendered ordinary due to how deeply ingrained it is within the fabric of daily life and Instagram posting habits.

Mental Illness Expressed Alongside Daily Routines. Studies of mental illness related content on social media often analyze data absent daily experiences and activities. Here, we extend research on contextual expression [7] by attending to how mental illness arises within Instagram posts concerning other topics, such as school and hobbies, and becomes part of a typical posting routine.

Members of our interview cohort, as well as users within our Instagram account corpus, shared posts about school, pets, food, exercise, artwork, and vacation that included explicit and implicit references to mental illness. Through the contextualization of mental illness with other life circumstances, we call attention to how mental illness is a component of everyday experience. One user in our Instagram account corpus posted content related to school and entertainment that periodically referenced their experience with mental illness. In a post about school (i.e., “*back to school after break, got a 65 on my test...yayy*”), part of a series of captions concerning a test, the user also wrote, “*zero days clean.*” This reference to self-injury is not decontextualized from the remainder of life nor is it prominently featured. Keeping these topics together during analysis supports understanding mental illness as contextualized in life rather than as diagnostic symptomology (i.e., self-injury). While many posts in this user’s account reference mental illness and low mood alongside other topics (e.g., “*hi, feeling bad, so i’m gonna watch harry potter. i hope ur all fine*”), many do not; dealing with, instead, the documentation of the day to day (e.g., LGBTQ+ pride, music). Still yet, other posts in this user’s account feature, rather than reference, mental illness. For example, this user calls upon black and white imagery, often accompanied by a text overlay (e.g., “*warring against myself*”, “*angry, depressed, and ugly in & out*”) and captions mentioning depression. Like others within our study, this user pairs daily concerns and events with common expressive elements of mental illness, such as desaturated images, visual allusions to loneliness, and text (e.g., captions and hashtags) [58] to document everyday experience, of which mental illness is part. Attending to illness in context facilitates understanding idiosyncrasies in how mental illness pervades and impacts everyday life.

Users within our Instagram corpus and interview cohort relied on multiple modalities, including images, videos, captions, and hashtags to express daily experiences with illness. For example, in one post, a user shared a picture of a bright puzzle laid on a wooden surface. Yellow, blue, red, and green pigment punctuates the image, drawing together a kaleidoscope of spheres interrupted only by several missing pieces.

The caption of this post references the puzzle on the table (i.e., “Missing a few bits”) and a long workday. The hashtags, however, include general social media tags (e.g., #instadoll, #follow4follow) as well as those explicit to mental illness (e.g., #edrecovery, #depression). This user carried forward similar hashtags to a variety of posts, including those about inpatient hospitalization, recovery-related eating practices, and studying. In one school-related post, in which a laptop, notebook, and pen take the visual center stage, the caption reads, “Ate so much, but my brain isn’t letting me study. Why is my mind so foggy?” Elements related to everyday circumstances co-exist with content associated with mental illness (e.g., eating disorder and depression-related hashtags), which itself is expressed as everyday and routine, rather than deviant, by association. While analysis of single posts may be used to extract mental illness from other content, we demonstrate how single posts can provide a broad picture of life with mental illness. Moreover, the ways in which expressions of mental illness are contextualized by and woven in alongside other expressions of daily lived experience demonstrates how mental illness is an ordinary part of everyday life for some, instead of abnormal or even extraordinary.

Within the past several years, scholars in HCI have incorporated cultural practices in analyses of mental illness [56, 89]. Oftentimes, however, this research emphasizes deviant or ‘othered’ aspects of specific conditions rather than examining how the appropriation of cultural or community practices might embed mental illness within ordinary practices and liken it to the behavior of non-deviant others. By appropriating popular forms of expression, such as memes and selfies, individuals assimilate experiences with mental illness into mainstream ideologies [1]. Several members of our interview cohort, including P1 and P4, discussed reposted memes during photo elicitation as a way to express their experiences with mental illness through culturally relevant and common artifacts (e.g., Kermit the Frog [2]) that are communicative and relatable. Similarly, individuals regularly contextualized mental illness with selfies [7]. Accounts within our Instagram corpus frequently did so in conjunction with hashtags (e.g., #eatingdisorder, #skinny, #depression, #edrecovery); however, members of our interview cohort often did not include any overt signals to mental illness [4]. P7, for example, posted a selfie without any hashtags, though she did caption it, “Not feeling great. Doubt has crept in and my eyes feel heavy with sadness. Thanks for listening. Feeling better already knowing I can put this out there and acknowledge my hurt and heartache.” Appropriation of community practices and cultural artifacts demonstrates how individuals combine elements of mainstream digital culture to express personal experiences with mental illness.

Individual Timescales of Mental Illness Expression. Understanding how mental illness is integrated with everyday experiences involves attending to archival aspects of Instagram as a platform for ongoing narration. Here, we build upon work featuring time as an integral component of understanding mental illness phases or trajectories [27, 36] with the caveat that time is relative to an individual or account. Further, though Instagram is archival, the goal is to understand timescales without implying linearity in content due to practices involving ‘throwback images’, account maintenance (e.g., individuals selecting to removing content), and Instagram reporting features (i.e., in which posts are forcibly removed by the platform).

While certainly permissible to post once with respect to mental illness and never again, our sample comprises of accounts and participants who shared about mental illness repetitively. Though many of these accounts did not feature or reference mental illness in every post, we observed accounts where mental illness was a steady constant. Some individuals, such as P16, shared content that included components related to mental illness every day, whereas others, such as P3 and P18, incorporated mental illness into their posts only every few months. With respect to periodically including mental illness in posts, P15 shared how “over time, my posts will vary with how disordered and negative they are. Right now, everything’s pretty peachy...well, it’s not as bad, so I’m not going to be posting about that stuff as much.” It was common for the frequency of content containing mental illness to change over time.

During our digital ethnography, we observed accounts that contained long breaks or pauses in content related to mental illness. By examining these ‘gaps’ in posting at a longer timescale, we can attend to the ways that mental illness ebbs and flows across narration of lived experience. Furthermore, we can attend to times that individuals may stop posting entirely. Gaps in posting were related to a variety of events, including those specific to mental illness (i.e., “I’m going to try recovering”) and those related to other aspects of life (e.g., vacation, school). Occasionally, individuals addressed their absence; however, much of what we observed was users stepping back from accounts without explanation, sometimes surfacing months later or not at all. Activity timescales and periodicity for generating new posts vary for each individual and, while sometimes consistent within a relative window of observation, are likely to change. Understanding this context is vital to examining how individual lives and posting habits change, as well as the ways in which mental illness is, at times, more salient.

Just as we observe changes in posting activity, we also see changes in content. For example, one user observed during our digital ethnography only began to incorporate #edrecovery in posts within the past six months, despite an account

history that dates to early 2017 and account content, consisting of recipes, that has remained constant. With respect to content related to mental illness across time, another user, documenting their eating disorder, previously shared pictures of their body, face blurred or otherwise obscured, with captions including, “*Huge. Super fat. Gross #ednos #ana,*” and “*Lost weight but still fucking disgusting #500caloriesaday.*” At the time of analysis, these selfies have become nonexistent; their prevalence subsumed by screenshots depicting caloric intake. Similar to practices of decreased posting, individuals sometimes announced transitions through mental illness (e.g., maintenance, recovery, relapse) with content and, specifically, captions, including, “*Recovery again. But I’ll probably relapse... my weight is terrifying.*” By attending to content variation across individual timescales, we begin to understand the different ways in which mental illness can both remain consistent and fade in and out of online expression of lived experience as narrated through Instagram.

Reframing Disruption within Individual Experiences. For individuals living with or posting about mental illness, mental illness may be an entirely common part of their everyday life. On Instagram, individuals express their experiences with illness as ordinary through entanglement with other components of daily life and posting practices. This perspective demonstrates the importance of context and challenges societal perceptions of mental illness as inherently deviant. However, it does not suggest that mental illness is not disruptive. For example, one user account observed during our digital ethnography recently shared content related to an eating disorder relapse and subsequent hospitalization. In one particular post the user wrote, “*My eating disorder wants me to restrict and to continue losing even more weight. This is ridiculous. I didn’t come [to the hospital] to keep losing weight. It’d be really dumb to waste this treatment opportunity.*” This caption suggests that elements of mental illness (e.g., restrictive behaviors) are disruptive within certain phases of illness and everyday life, such as attempts to gain weight. These findings corroborate traditionally held views with respect to mental illness as a disruptive force [68]. However, examining mental illness as an ordinary part of an individual’s life, rather than a sensationalized extreme, calls into question how we think of disruption.

In narrative research, illness is frequently framed as a disruptive event [75]. Individuals who are ill are relegated to suffering or to ‘overcoming’ their illness [42, 54], sentiments we see carried through work in HCI and CSCW. Bias toward diagnosis and treatment neglects that certain individuals may not want to recover, that mental illness may itself be a form of neurodiversity, and that recovery, though often aligned with ‘good’, may be disruptive to daily routines established while living with a mental illness. We observe

that what constitutes disruption is based on the narration of experience. Many posts within our dataset suggest that individuals are reframing what it means for illness to be ‘disruptive’. When people live with mental illness, disruptive events are sometimes the antithesis of this everyday experience. Specifically, changes to daily life and routine, such as being forced into treatment or attempting various practices linked with recovery (e.g., eating certain foods, not self-harming), become disruptive. One user from our digital ethnography often posts from inpatient treatment facilities, where they express the disruption of recovery to their life. In one post, complete with a mirror selfie from a treatment restroom and hashtags including #picoftheday, #psychward, and #eatingdisorders, the user writes, “*Why can’t I go home? I promise I’ll eat. I promise. No one understands. They’re not supportive, they only hinder my progress.*” In another post — a black and white image with overlaid text (i.e., “*I hate myself so much*”) — the caption reads, “*I have gained a lot of weight. I fucking hate myself, all I want to do is eat. I am so fucking depressed. This place has ruined me.*” While a desirable clinical outcome of recovery may involve placing mental illness “under the person’s control or [to where it] is at least no longer intrusive or disruptive” [33], we find that recovery itself can be a disruptive process. Just as contextualization demonstrates the ordinary ways individuals live with mental illness, so can it depict how certain aspects of illness, including recovery, can be disruptive. Individuals must be foregrounded over illness so that their experiences are contextualized within their own life and not the lives, or randomized posts, of others. By challenging traditional notions of mental illness as an inherently disruptive event and other activities, such as recovery, as non-disruptive (or desirable) events, we confront the appropriateness of contemporary technological ‘solutions’ employed by many social media sites, Instagram included, to address the ‘problem’ of some mental illness expressions.

Negotiating the Telling of Experience

In line with prior work, many participants in our interview study described how social components of Instagram contributed to their motivations for participation, such as sharing experiences (without the necessity of reaching out personally or in person), receiving support and validation, connecting with specific communities (e.g., eating disorder communities), and providing support for others [17, 23, 31, 89]. Given the social nature of Instagram, we find that expressing mental illness within everyday life is not straightforward nor only personal [42]. Individuals must navigate the social and technical structures that shape personal narration of everyday experiences, including those related to mental illness. Through the use of Instagram, individuals implicitly and,

sometimes, explicitly invite collaborative storytelling and reinterpretation of experience by others (i.e., an audience).

While audience members may provide a range of reactions [7, 20, 38, 89] to disclosures of mental illness, many of which are positive, researchers, with few exceptions (e.g., Pater et al. [69]), have yet to thoroughly engage with how these interactions, compounded with features of social media platforms, influence the content individuals share and how they select to share it. We turn to social control theory [13] as a way of understanding how other people and the Instagram platform participate in narration of mental illness. Social control involves the “ways in which a society tries to prevent and sanction behaviors that violates norms” [13]. Audience reactions, positive (e.g., approval, reward) and negative (e.g., disapproval, punishment) [88], have implications for the ways in which social control is enacted online and how individuals must negotiate the telling of their experience. Though some forms of social control may occur through subtle means of interaction, such as brief praise or a ‘like’ on Instagram, others are more overt. Historically, individuals with mental illness have been subject to these direct forms of social control [52, 65, 78]. We find this to be the contemporary case, as well. Individuals must navigate forms of expression, even those narrated as their everyday, liable to be rewritten, reported, and removed.

Narrative Alignment and Validation of Experience. For some of our interview participants co-constructed storytelling and interpretation of experience by audience members did not raise an issue. P1, for example, mentioned that followers of his private account were free to “*derive whatever meaning they wanted to from*” his posts. P2, similarly, explained how “*people can get their own interpretation. You can read the same thing. Everybody can read the same thing and get a different meaning.*” Oftentimes, reinterpretation by audience members was a benign or positive activity, particularly when it aligned with the expression shared by the account owner. For example, in one post shared by a public account within our Instagram corpus, a user discusses how their bipolar disorder contributes to “*what’s wrong with me.*” Coming from a place of support, another user wrote in the comments, “*I’ve seen these comments that say nothing’s wrong, but we know that’s not true. I’m bipolar too and there’s something wrong. Do what’s best for you and ignore the ignorant...*” Validation of experience, a form of peer support [63, 64], plays an important role in motivating some individuals to share about their everyday life with mental illness. P5, for example, described how her desire to share “*came from a place of validation. And I think that’s a lot of what Instagram is grounded on.*” Validation of experience extends beyond social support. It is confirmation of the way — and worldview — through which someone experiences being ill.

In addition to providing validating reinterpretations of mental illness, audience members may react positively to posts through textual praise (e.g., comments, direct messages) and ‘liking’. For example, a post by P7 alluding to her experiences with depression received audience responses such as “*Thank you*” and “*respect you for sharing.*” In addition to comments of appreciation gently rewarding this particular act of sharing P7’s post received 30 likes. Another member of our interview cohort, P17, discussed how positive reactions motivated him to post about his life with mental illness: “*It’s like a positive assurance. Positive words. It’s nice to have people who kind of give you advice, give you support. It’s kind of, like, motivational, I would say.*” While many positive reactions are online and public (provided the account is public), others are not. Audiences may engage with individuals through direct messages and, when possible, offline means, suggesting that mechanisms of social control flow through a variety of channels, not all of which are explicitly observable online.

Narrative Conflict and Erasure of Experience. Not all narrations of mental illness are acceptable. At times, members of the audience reinterpreted expressions of daily life with mental illness in ways that conflicted with, and often erased, the original telling (i.e., Instagram post). We find this type of reinterpretation particularly salient in relation to socially unacceptable expressions of mental illness, including posts about self-harm and self-critique (e.g., an individual with anorexia captioning a selfie with “*Yuck. What a whale*”). At times, audience reinterpretation, though conflicting, was meant to offer support. For example, on a post P15 shared after feeling “*hella bad about drinking*” a Sprite, a friend commented, “*Bitch shut up your body is perfect.*” Publicly, P15 ‘liked’ this reaction. However, during the interview she described how “*someone telling me that my body is perfect doesn’t mean that my body is perfect. Because it’s not. No one’s body is perfect and — it’s like, even as nice as it feels that someone cared to comment like that, it’s just annoying because it’s obviously not true. It’s obviously just meant to make me feel better and not actually a real thing.*” Support is frequently tied to positive audience reactions and mechanisms of social control that reward certain posting practices. However, as demonstrated here, social support may have a negative, invalidating effect when it conflicts with certain experiential aspects of living with mental illness.

Audiences may also respond with conflicting reinterpretations of experience that shame or harass the original poster, potentially to push the original poster toward a more socially acceptable posting norm. For example, an audience member, perpetuating a harmful stereotype, referred to one user in our Instagram dataset as an “*attention whore*” for uploading content depicting self-harm. Similarly, on a suicide hotline post shared by another user in our digital ethnography, another

individual commented, “*u r not alone ur just fucking stupid. ur emo community is a fucking sickness im done with seeing ur stupid shit.*” These hostile comments may be reminiscent of personal attacks, where audience members attempt to control the posting practices, and underlying behaviors, of particular users through aggressive reinterpretations of original tellings. In addition to conflict, these comments demonstrate attempts to rewrite and erase the context of the original posts by providing new, albeit harmful, perspectives. Individuals for whom mental illness becomes part of daily expression on Instagram must negotiate such reactions as these, where audience members interactively participate in constructing, and attempting to control, personal narration.

Though comments arise as social control structures used by audience members to reinterpret experience or attempt to control behavior, they are not mechanisms through which total control can be exerted. To this effect, Instagram has several means of moderating content. Instagram’s reporting feature allows an audience’s negative reaction to content (e.g., reporting a post) to impose upon the daily routine of individuals living with or posting about mental illness. Reporting practices such as these (e.g., an Instagram message saying, “We’re Reaching Out to Offer Help”) may attempt to alter or ‘fix’ the underlying behavior of a user by providing them with nonspecific resources, which are sometimes unnecessary and unwanted, through the guise of extra support. One user in our digital ethnography posted their reactions to receiving these notices. In one caption, they mention, “*Again, fuck off,*” while, in another, they describe the practice as “*super counterproductive it’s stupid.*”

While some reporting practices may be limited to the imposition of unsolicited help, others silence and erase the subjective expression of an individual already marginalized by society. The vague description of removal (i.e., “We’ve removed your post for not following our Community Guidelines”) provides little opportunity for recourse or transparency with respect to who – or what (i.e., an algorithm) – reported the content. It is nearly impossible for users to have posts or accounts reinstated. Though researchers have addressed instances in which content moderation might be appropriate [85], our analysis provides an alternative view: methods of content moderation can ultimately oppress marginalized groups and exert paternalistic social control through platform features favoring ‘mainstream’ reactions over the expression of individuals living with mental illness.

Reclaiming Control through Multiple Accounts. In the current implementation of Instagram, negative social control structures, such as those that facilitate the removal of posts and subsequent erasure of experience, outweigh platform mechanisms that may be used for positive audience reaction. Individuals with or posting about mental illness are subject

to social interactions that may reinterpret or erase personal expression. One way that individuals exercise control over the telling of their own experience is through the practice of creating multiple accounts. While other researchers suggest that the maintenance of multiple accounts may facilitate sharing secret or sensitive information [7], we suggest a new interpretation: multiple accounts are a necessity based on the culture in which we live, where individuals with mental illness experience intolerance, misunderstanding, and oppression. Maintenance of multiple accounts provides opportunities to interact with different audiences and to share content where it will receive the most validating response, rather than erasure.

Several members of our interview cohort described their preference for including posts featuring or referencing mental illness on their spam account (or accounts, in the case of P16) rather than on their main account. As P10 and P15 explained, posting practices were grounded in trust. P16 also did not post about mental illness on her main account. Instead, she shared “*mental health posts such as things I see in papers about mental health or suicides and what i can do to prevent it*” on her popular spam account and, on her less followed spam account, “*put more personal ones...because the followers on that account are ones i can trust.*” The strategic use of multiple accounts demonstrates how perceptions of audience, and the trust an individual has with this audience, influence narrations of experience with mental illness. We also observed how the need for privacy and like-minded community influence the maintenance of multiple accounts. P15, for example, discussed previously maintaining “*a special Instagram account for my eating disorder and related things*” where she would only “*follow other people with eating disorders. Like, none of my friends. I didn’t post my name or my face.*” Public accounts examined during our digital ethnography included those with posts predominantly about personal and daily experience with mental illness, including eating disorder documentation and recovery. Multiple accounts need not exist in tandem but may come about when individuals attempt to circumvent certain social control structures. For example, the first post on an account including graphic images of self-harm referenced a previous account that had been removed by the platform. Despite attempts to circumvent platform social control, similar to lexical variations of hashtags [69], new and multiple accounts maintained by individuals living with or posting about mental illness are still subject to intense scrutiny, surveillance, and control.

5 DISCUSSION

In this paper, we describe how researchers can better understand the daily lives of individuals from a marginalized group, as well as how stories told from group members are

co-constructed by outsiders. We demonstrate how mental illness is part of the fabric of everyday life for some individuals. Additionally, we show how these individuals negotiate online instantiations of social control structures in order to express their experiences with mental illness. The use of small stories research provided an analytic lens for prioritizing interactional, ongoing, and everyday stories, such as those occurring on Instagram. By attending to specific interactions, such as posts and comments, rather than broader reaching personal narratives or societal perceptions of mental illness, we offer counter, but complimentary, interpretation to understanding the expression of mental illness online. Here, we discuss the implications of examining mental illness within the context of an individual’s daily experience or as an ordinary, albeit not trivial [61], part of their life; the ways in which current implementations of features on Instagram may facilitate oppression of a marginalized group; and how, as researchers and designers, we contribute to contemporary practices of social control.

Contextualization through an ‘Everyday Lens’

Certain methods of data collection (e.g., the use of hashtags and key terms [28, 58] to identify mental illness content) prioritize the explicit expression of mental illness and neglect how mental illness is, at times, more or less salient within everyday life [7, 40, 44, 69]. Following from these practices, researchers often recontextualize mental illness within a narrow window of interpretation void subjective experience with the aim of generalizing findings to communities and types of illness. These findings have important implications for understanding community and cultural norms [23] and contributing insights to diagnosis and treatment. However, design recommendations often center on broad, population-level approaches to mental illness, not fully appreciating the individual impact of technological ‘solutions’. In this context, mental illness becomes decontextualized from the everyday, lived experience in which it occurs. Decontextualization has the potential to sensationalize certain facets of experience by highlighting them absent other aspects of life and time. Incorporating the subjective experience of mental illness is an important component of understanding and including the idiosyncrasies and forms of expression produced by members of a marginalized community. Additionally, prioritizing the individual and the everyday shifts focus from a generalized population to a person; a practice in line with traditional forms of psychological treatment (e.g., talk therapy).

The experience of illness is different for everyone. In this paper, we present mental illness not only as the topic of narration, but as the condition through which narration occurs [42]. Here, we extend an agenda put forth by other HCI and CSCW researchers (e.g., Pater and Mynatt [68], Andalibi et al. [7]) that argues for a deeper understanding of mental illness

and online spaces. By emphasizing an everyday context, we can better understand normalcy and disruption for the individual and attend to the ways that design for communities fails. By prioritizing the individual and their small stories, we have an opportunity to explore and disseminate alternative narratives of mental illness, such as those demonstrating ways that individuals with illness live and thrive. This reframing is reminiscent of the “living with AIDS” movement, which reframed life with serious illness when mainstream narrative focused on dying [46]. Examining the holistic experience and attending to how people narrate mental illness presents an opportunity to support and validate individual interpretations, rather than conflict them.

Though we address mental illness broadly to counter a clinical stance associated with deviance and medicalization of experience, we do not suggest that individuals living with mental illness are a homogenous group. Future work can focus on online interaction among specific subgroups or subcultures, calling attention to individual differences. Further, an ‘everyday lens’ can be helpful for thinking about marginalized groups consistently ‘othered’ due to association with deviance, whether historically or presently, such as individuals previously incarcerated and LGBTQ+ community members.

Technological Responses to Mental Illness

Instagram includes a range of features, both direct (e.g., comments, reporting) and indirect (e.g., content detection algorithms running in the background). Many features promote new instantiations of social control, which enables audiences to influence and exert power over the posts and expressions of others. Though platform features are not inherently coercive or restrictive, their use contributes to a socially regulated environment in which members of a marginalized group (i.e., individuals with mental illness) are subject to surveillance, erasure, and oppression. Platform features, including the option to report “posts encouraging or promoting self injury, which includes suicide, cutting and eating disorders,” as described by Instagram, are founded in mainstream perceptions and calls to action. With respect to mental illness, dominant colloquial attitudes align aspects of illness with deviance and view certain practices as harmful to specific individuals, as well as to the community at large (i.e., contagion [22]). As our analysis reveals, however, mental illness is ordinary or unusual, disruptive or not in the context of an individual’s life, rather than a society’s perspective. For example, though recovery is frequently viewed positively, it can have a negative impact and be disruptive. Automatically providing certain resources (e.g., helplines, websites) to targeted users, though framed within notions of social good, may actually be harmful and “counterproductive,” as one user wrote. We must reflect on the clinical and societal

assumptions embedded in technology, which stand to affect marginalized groups the most.

Community awareness concerning algorithmic bias around gender, race, and age is growing [37, 49, 77]. Research has begun to address the ways algorithms, often relying on strict categorization, contribute to unjust social structures [41]. Nevertheless, many algorithmic applications involved in the maintenance of online communities and social media sites rely on categorical approaches, which has implications for moderation and censorship; for example, the detection of harassment and toxic content [19, 30]. Censoring content, despite beneficial applications (e.g., detection of cyberbullying [8, 62]), restricts freedom of expression online and may have repercussions with respect to silencing and erasure [15]. Given the potential for some expressions of mental illness to be categorized as toxic content, our work demonstrates a blatant, albeit different, form of discrimination and restriction of expression.

Through various means, such as audience reporting features and algorithmic detection, content moderation perpetuates a surveillance culture that disproportionately impacts individuals with mental illness — those who already have a history of marginalization and subjugation. Practices associated with content moderation can produce more than just a chilling effect [26]. They are oppressive structures used to control behavior and expression [69]. These structures favor mainstream views and ‘treatment’ of individuals with mental illness involving lack of transparency and recourse. Individuals who have been reported or had content removed cannot face an accuser — audience member or algorithm — or easily petition to have posts or accounts restored. This approach, void of broader life context and unproven with respect to the provision of help, can silence those who may need a safe space to explore their experience without fear of judgment. Social media should not obsessively focus on ‘fixing’ illness (e.g., providing mental health resources) or erasing its existence. Instead, platforms can support everyday experience or assist in negotiating social control as enacted by certain audiences.

The Role of Researchers and Designers

By contextualizing mental illness within the everyday and calling attention to the ways in which social control manifests online, we hope to raise awareness of the sensationalism associated with mental illness content and the paternalism associated with technological solutions. Inadvertently, researchers and designers perpetuate stereotypes, stigma, and systems of social control — often through positionality that underscores mental illness as deviant, destructive, or undesirable. As such, research can sensationalize certain behaviors and expressions (e.g., self-injury) by drawing attention to components of mental illness absent the holistic experience.

Given this view, it is unsurprising that the design of technology often focuses on identifying and mitigating behaviors and expression associated with mental illness; thus, perpetuating social control structures. We must consider life with mental illness as a cohesive whole, rather than as a convenient sample of content.

The experiential turn in HCI (e.g., [86]) suggests a more humanist agenda and emphasizes research and design practices that enhance lived experience. Without careful reflection, research framing and design solutions may reduce individual agency and exert control over marginalized populations with histories of enduring controlling institutions and relationships. By acknowledging how researchers and designers contribute to social control structures enacted through technology, we can reevaluate what it means to design for ‘social good’, mitigate negative effects, and promote positive ones [80]. In part, this involves increased reflexivity [12], wherein we recognize that certain goals and values with respect to mental illness can have unforeseen consequences. For example, the goal of helping society by reducing ‘contagion’ of mental illness content can inadvertently punish those in need of a safe space for expression.

Practices of experience-centered design and reflexivity also create space for us to consider the role of capitalism in the design of technology, such as social media. With respect to the capitalist structure of social media sites, Instagram included, companies benefit from the creation of multiple accounts (e.g., increased advertising revenue) and content, even if this content is at odds with community guidelines and terms of service. When corporate goals seek to drive traffic and usage, focusing on satisfaction of the ‘general user population’ takes priority. Platforms, however, have responsibilities toward all who use them. While mainstream sentiment stigmatizes and misunderstands mental illness, capitalism and individual expression of mental illness will remain at odds. In light of capitalist values, content moderation appeals to mainstream perspectives (e.g., reporting features and resources) without taking any substantial action toward treating or reducing mental illness — goals which, well-intended, may prove harmful and oppressive. We question the role and response of technology companies to the expression of mental illness online, just as we question the role of researchers and designers. Instead of falling in line with dominant societal perspectives, we should closely consider our influence and how we might use our position to support increased agency for individuals with mental illness.

6 CONCLUSION

Online communities and social media provide opportunities for members of marginalized groups to find and build spaces in which they belong and can share experiences. Platform features, however, may inadvertently restrict expression and

contribute to the continued oppression and marginalization of certain communities. By considering an individual's everyday experience with mental illness, we challenge societal notions of deviance and technological forms of social control, such as content moderation. Through the use of small stories research, we have demonstrated how individuals living with and posting about mental illness express their experiences as part of their everyday life and circumvent social control structures (e.g., through the use of multiple accounts) that influence and, at times, inhibit freedom of expression. By attending to the individual experience of mental illness, in which mental illness may, at times, be ordinary or normal, researchers and designers can better reflect on their role in the implementation of controlling technologies and explore alternative ways of approaching design of technology for mental illness.

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REFERENCES

- [1] 2014. Selfies, Hashtags, and the Mechanisms of Ideology | Strike Your Note. <https://strikeyournote.wordpress.com/2014/05/21/selfies-hashtags-and-the-mechanisms-of-ideology/>
- [2] 2015. Kermit the Frog | Know Your Meme. <https://knowyourmeme.com/memes/kermit-the-frog>
- [3] Edith Ackermann, Françoise Decortis, Juan Pablo Hourcade, and Heidi Schelhowe. 2009. Cultural Coding and De-coding As Ways of Participation: Digital Media for Marginalized Young People. In *Proceedings of the 8th International Conference on Interaction Design and Children (IDC '09)*. ACM, 294–297. <https://doi.org/10.1145/1551788.1551864>
- [4] Morgan Ames and Mor Naaman. 2007. Why We Tag: Motivations for Annotation in Mobile and Online Media. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '07)*. ACM, 971–980. <https://doi.org/10.1145/1240624.1240772>
- [5] Tawfiq Ammari and Sarita Schoenebeck. 2015. Networked Empowerment on Facebook Groups for Parents of Children with Special Needs. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, 2805–2814. <https://doi.org/10.1145/2702123.2702324>
- [6] Nazanin Andalibi. 2016. Social Media for Sensitive Disclosures and Social Support: The Case of Miscarriage. In *Proceedings of the 19th International Conference on Supporting Group Work (GROUP '16)*. ACM, 461–465. <https://doi.org/10.1145/2957276.2997019>
- [7] Nazanin Andalibi, Pinar Ozturk, and Andrea Forte. 2017. Sensitive Self-disclosures, Responses, and Social Support on Instagram: The Case of #Depression. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*. ACM, 1485–1500. <https://doi.org/10.1145/2998181.2998243>
- [8] Zahra Ashktorab. 2016. A Study of Cyberbullying Detection and Mitigation on Instagram. In *Proceedings of the 19th ACM Conference on Computer Supported Cooperative Work and Social Computing Companion (CSCW '16 Companion)*. ACM, 126–130. <https://doi.org/10.1145/2818052.2874346>
- [9] Paul Atkinson. 1997. Narrative Turn or Blind Alley? 7, 3 (aug 1997), 325–344. <https://doi.org/10.1177/104973239700700302>
- [10] Michael Bamberg. 2006. Stories: Big or small: Why do we care? 16 (jan 2006), 139–147. <https://doi.org/10.1075/ni.16.1.18bam>
- [11] Michael Bamberg. 2012. Narrative Analysis. In *APA handbook of research methods in psychology*, H. Cooper (Ed.). Vol. 2. 77–94.
- [12] Shaowen Bardzell. 2010. Feminist HCI: Taking Stock and Outlining an Agenda for Design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*. ACM, 1301–1310. <https://doi.org/10.1145/1753326.1753521>
- [13] Steven E. Barkan. 2011. Sociology: Understanding and Changing the Social World. (2011). <http://open.lib.umn.edu/sociology/>
- [14] Karin Barron. 1999. Ethics in qualitative social research on marginalized groups. 1, 1 (jan 1999), 38–49. <https://doi.org/10.1080/15017419909510736>
- [15] Lindsay Blackwell, Jill Dimond, Sarita Schoenebeck, and Cliff Lampe. 2017. Classification and Its Consequences for Online Harassment: Design Insights from HeartMob. 1 (dec 2017), 24:1–24:19. Issue CSCW. <https://doi.org/10.1145/3134659>
- [16] Lindsay Blackwell, Jean Hardy, Tawfiq Ammari, Tiffany Veinot, Cliff Lampe, and Sarita Schoenebeck. 2016. LGBT Parents and Social Media: Advocacy, Privacy, and Disclosure During Shifting Social Movements. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, 610–622. <https://doi.org/10.1145/2858036.2858342>
- [17] Johnna Blair and Saeed Abdullah. 2018. Supporting Constructive Mental Health Discourse in Social Media. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '18)*. ACM, 299–303. <https://doi.org/10.1145/3240925.3240930>
- [18] Dina L. G. Borzekowski, Summer Schenk, Jenny L. Wilson, and Rebecka Peebles. 2010. e-Ana and e-Mia: A Content Analysis of Pro-ÅEating Disorder Web Sites. 100, 8 (aug 2010), 1526–1534. <https://doi.org/10.2105/AJPH.2009.172700>
- [19] Uwe Bretschneider, Thomas WÅühner, and Ralf Peters. 2014. Detecting Online Harassment in Social Networks. (dec 2014). <https://aisel.aisnet.org/icis2014/proceedings/ConferenceTheme/2>
- [20] R. C. Brown, T. Fischer, A. D. Goldwisch, F. Keller, R. Young, and P. L. Plener. 2018. #cutting: Non-suicidal self-injury (NSSI) on Instagram. 48, 2 (jan 2018), 337–346. <https://doi.org/10.1017/S0033291717001751>
- [21] Amy Bruckman. 2006. Teaching Students to Study Online Communities Ethically. (2006), 82–95.
- [22] Kellie E. Carlyle, Jeanine P. D. Guidry, Kofoworola Williams, Ariella Tabaac, and Paul B. Perrin. 2018. Suicide conversations on Instagram: contagion or caring? 0, 0 (mar 2018), 1–7. <https://doi.org/10.1080/17538068.2018.1436500>
- [23] Stevie Chancellor, Andrea Hu, and Munmun De Choudhury. 2018. Norms Matter: Contrasting Social Support Around Behavior Change in Online Weight Loss Communities. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, 666:1–666:14. <https://doi.org/10.1145/3173574.3174240>
- [24] Stevie Chancellor, Yannis Kalantidis, Jessica A. Pater, Munmun De Choudhury, and David A. Shamma. 2017. Multimodal Classification of Moderated Online Pro-Eating Disorder Content. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, 3213–3226. <https://doi.org/10.1145/3025453.3025985>
- [25] Stevie Chancellor, Zhiyuan Lin, Erica L. Goodman, Stephanie Zerwas, and Munmun De Choudhury. 2016. Quantifying and Predicting Mental Illness Severity in Online Pro-Eating Disorder Communities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, 1171–1184. <https://doi.org/10.1145/2818048.2819973>
- [26] Stevie Chancellor, Zhiyuan (Jerry) Lin, and Munmun De Choudhury. 2016. "This Post Will Just Get Taken Down": Characterizing Removed

- Pro-Eating Disorder Social Media Content. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, 1157–1162. <https://doi.org/10.1145/2858036.2858248>
- [27] Stevie Chancellor, Tanushree Mitra, and Munmun De Choudhury. 2016. Recovery Amid Pro-Anorexia: Analysis of Recovery in Social Media. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, 2111–2123. <https://doi.org/10.1145/2858036.2858246>
- [28] Stevie Chancellor, Jessica Annette Pater, Trustin Clear, Eric Gilbert, and Munmun De Choudhury. 2016. #Thyghgapp: Instagram Content Moderation and Lexical Variation in Pro-Eating Disorder Communities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, 1201–1213. <https://doi.org/10.1145/2818048.2819963>
- [29] Kathy Charmaz. 2014. *Constructing Grounded Theory*. SAGE.
- [30] Y. Chen, Y. Zhou, S. Zhu, and H. Xu. 2012. Detecting Offensive Language in Social Media to Protect Adolescent Online Safety. In *2012 International Conference on Privacy, Security, Risk and Trust and 2012 International Conference on Social Computing*. 71–80. <https://doi.org/10.1109/SocialCom-PASSAT.2012.55>
- [31] Munmun De Choudhury and Sushovan De. 2014. Mental Health Discourse on reddit: Self-Disclosure, Social Support, and Anonymity. In *ICWSM*.
- [32] Odysseas Constantinou. 2005. Multimodal Discourse Analysis: Media, modes and technologies. 9, 4 (2005), 602–618. <https://doi.org/10.1111/j.1360-6441.2005.00310.x>
- [33] Larry Davidson, Maria J. O'Connell, Janis Tondora, Martha Lawless, and Arthur C. Evans. 2005. Recovery in Serious Mental Illness: A New Wine or Just a New Bottle? 36, 5 (oct 2005), 480–487. <http://psycnet.apa.org/buy/2005-13212-004>
- [34] Munmun De Choudhury, Scott Counts, and Eric Horvitz. 2013. Social Media As a Measurement Tool of Depression in Populations. In *Proceedings of the 5th Annual ACM Web Science Conference (WebSci '13)*. ACM, 47–56. <https://doi.org/10.1145/2464464.2464480>
- [35] Munmun De Choudhury, Scott Counts, Eric J. Horvitz, and Aaron Hoff. 2014. Characterizing and Predicting Postpartum Depression from Shared Facebook Data. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '14)*. ACM, 626–638. <https://doi.org/10.1145/2531602.2531675>
- [36] Munmun De Choudhury, Emre Kiciman, Mark Dredze, Glen Copper-smith, and Mrinal Kumar. 2016. Discovering Shifts to Suicidal Ideation from Mental Health Content in Social Media. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, 2098–2110. <https://doi.org/10.1145/2858036.2858207>
- [37] Mark Diaz, Isaac Johnson, Amanda Lazar, Anne Marie Piper, and Darren Gergle. 2018. Addressing Age-Related Bias in Sentiment Analysis. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, 412:1–412:14. <https://doi.org/10.1145/3173574.3173986>
- [38] Sindhu Kiranmai Ernala, Tristan Labetoulle, Fred Bane, Michael L. Birnbaum, Asra F. Rizvi, John M. Kane, and Munmun De Choudhury. 2018. Characterizing Audience Engagement and Assessing Its Impact on Social Media Disclosures of Mental Illnesses. In *Twelfth International AAAI Conference on Web and Social Media*. <https://www.aaai.org/ocs/index.php/ICWSM/ICWSM18/paper/view/17884>
- [39] Jordan Eschler, Arpita Bhattacharya, and Wanda Pratt. 2018. Designing a Reclamation of Body and Health: Cancer Survivor Tattoos As Coping Ritual. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, 510:1–510:12. <https://doi.org/10.1145/3173574.3174084>
- [40] Jessica L. Feuston and Anne Marie Piper. 2018. Beyond the Coded Gaze: Analyzing Expression of Mental Health and Illness on Instagram. 2 (nov 2018), 51:1–51:21. Issue CSCW. <https://doi.org/10.1145/3274320>
- [41] Sarah Fox, Jill Dimond, Lilly Irani, Tad Hirsch, Michael Muller, and Shaowen Bardzell. 2017. Social Justice and Design: Power and Oppression in Collaborative Systems. In *Companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17 Companion)*. ACM, 117–122. <https://doi.org/10.1145/3022198.3022201>
- [42] Arthur W Frank. 2013. *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- [43] Alexandra Georgakopoulou. 2015. Small Stories Research. In *The Handbook of Narrative Analysis*, Ana de Fina and Alexandra Georgakopoulou (Eds.). John Wiley & Sons, 255–271.
- [44] Ysabel Gerrard. 2018. Beyond the hashtag: Circumventing content moderation on social media. (may 2018), 1461444818776611. <https://doi.org/10.1177/1461444818776611>
- [45] Trisha Greenhalgh. 2016. ANNEX 3. A BRIEF HISTORY OF NARRATIVE RESEARCH IN HEALTH CARE. WHO Regional Office for Europe. <https://www.ncbi.nlm.nih.gov/books/NBK391070/>
- [46] Jan Zita Grover and Douglas Crimp. 1987. AIDS: Cultural Analysis/Cultural Activism. (1987).
- [47] Oliver L. Haimson, Jed R. Brubaker, Lynn Dombrowski, and Gillian R. Hayes. 2015. Disclosure, Stress, and Support During Gender Transition on Facebook. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*. ACM, 1176–1190. <https://doi.org/10.1145/2675133.2675152>
- [48] Oliver L Haimson, Kathryn E Ringland, and Gillian R Hayes. 2015. Marginalized Populations and Research Ethics Online. In *CSCW Workshop on Ethics for Studying Sociotechnical Systems in a Big Data World (CSCW Workshop on Ethics for Studying Sociotechnical Systems in a Big Data World)*. 5.
- [49] Foad Hamidi, Morgan Klaus Scheuerman, and Stacy M Branham. 2018. Gender Recognition or Gender Reductionism?: The Social Implications of Embedded Gender Recognition Systems. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 8.
- [50] Douglas Harper. 2012. *Visual Sociology*. Routledge. Google-Books-ID: cERdCCZ4IcC.
- [51] Su Holmes. 2017. My anorexia story: girls constructing narratives of identity on YouTube. 31, 1 (jan 2017), 1–23. <https://doi.org/10.1080/09502386.2016.1138978>
- [52] Allan V. Horvitz. 1982. *The social control of mental illness*. Academic Press. Google-Books-ID: d_MgAQAAIAAJ.
- [53] Adrienne S. Juarascio, Amber Shoab, and C. Alix Timko. 2010. Pro-Eating Disorder Communities on Social Networking Sites: A Content Analysis. 18, 5 (sept 2010), 393–407. <https://doi.org/10.1080/10640266.2010.511918>
- [54] Arthur Kleinman. 1988. *The illness narratives: suffering, healing, and the human condition*. Basic books.
- [55] Gunther Kress and Theo Van Leeuwen. 2001. *Multimodal Discourse: The Modes and Media of Contemporary Communication*. {Arnold Publishers}. <http://www.amazon.ca/exec/obidos/redirect?tag=citeulike09-20&path=ASIN/0340608773>
- [56] Guo Li, Xiaomu Zhou, Tun Lu, Jiang Yang, and Ning Gu. 2016. Sun-Forum: Understanding Depression in a Chinese Online Community. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, 515–526. <https://doi.org/10.1145/2818048.2819994>
- [57] Kent Lundby. 2008. *Digital Storytelling, Mediatized Stories: Self-representations in New Media*. Peter Lang. Google-Books-ID: SI_WM0tVV84C.
- [58] Lydia Manikonda and Munmun De Choudhury. 2017. Modeling and Understanding Visual Attributes of Mental Health Disclosures in Social Media. In *Proceedings of the 2017 CHI Conference on Human Factors in*

- Computing Systems (CHI '17)*. ACM, 170–181. <https://doi.org/10.1145/3025453.3025932>
- [59] Dan P. McAdams. 2008. Personal narratives and the life story. In *Handbook of Personality, Third Edition: Theory and Research*, Oliver P. John, Richard W. Robins, and Lawrence A. Pervin (Eds.). Guilford Press, 242–262.
- [60] Bharat Mehra, Cecelia Merkel, and Ann Peterson Bishop. 2004. The internet for empowerment of minority and marginalized users. 6, 6 (dec 2004), 781–802. <https://doi.org/10.1177/146144804047513>
- [61] Lydia Michie, Madeline Balaam, John McCarthy, Timur Osadchiy, and Kellie Morrissey. 2018. From Her Story, to Our Story: Digital Storytelling As Public Engagement Around Abortion Rights Advocacy in Ireland. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, 357:1–357:15. <https://doi.org/10.1145/3173574.3173931>
- [62] B. Sri Nandhini and J. I. Sheeba. 2015. Cyberbullying Detection and Classification Using Information Retrieval Algorithm. In *Proceedings of the 2015 International Conference on Advanced Research in Computer Science Engineering & Technology (ICARCSET 2015) (ICARCSET '15)*. ACM, 20:1–20:5. <https://doi.org/10.1145/2743065.2743085>
- [63] Khushnood Naqshbandi, David N. Milne, Ben Davies, Sophie Potter, Rafael A. Calvo, and Simon Hoermann. 2016. Helping Young People Going Through Tough Times: Perspectives for a Peer-to-peer Chat Support System. In *Proceedings of the 28th Australian Conference on Computer-Human Interaction (OzCHI '16)*. ACM, 640–642. <https://doi.org/10.1145/3010915.3011848>
- [64] Kathleen O'Leary, Arpita Bhattacharya, Sean A. Munson, Jacob O. Wobbrock, and Wanda Pratt. 2017. Design Opportunities for Mental Health Peer Support Technologies. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*. ACM, 1470–1484. <https://doi.org/10.1145/2998181.2998349>
- [65] Petar Opalić. 2007. INFORMAL AND FORMAL SOCIAL CONTROL OF MENTALLY ILL PERSONS. 55, 3 (2007), 78–92. <https://www.ceeol.com/search/article-detail?id=602416>
- [66] Lawrence A. Palinkas, Sarah M. Horwitz, Carla A. Green, Jennifer P. Wisdom, Naihua Duan, and Kimberly Hoagwood. 2015. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. 42, 5 (sept 2015), 533–544. <https://doi.org/10.1007/s10488-013-0528-y>
- [67] Minsu Park, David W McDonald, and Meeyoung Cha. [n. d.]. Perception Differences between the Depressed and Non-Depressed Users in Twitter. ([n. d.]), 10.
- [68] Jessica Pater and Elizabeth Mynatt. 2017. Defining Digital Self-Harm. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*. ACM, 1501–1513. <https://doi.org/10.1145/2998181.2998224>
- [69] Jessica A. Pater, Oliver L. Haimson, Nazanin Andalibi, and Elizabeth D. Mynatt. 2016. “Hunger Hurts but Starving Works”: Characterizing the Presentation of Eating Disorders Online. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. ACM, 1185–1200. <https://doi.org/10.1145/2818048.2820030>
- [70] Jessica A. Pater, Moon K. Kim, Elizabeth D. Mynatt, and Casey Fiesler. 2016. Characterizations of Online Harassment: Comparing Policies Across Social Media Platforms. In *Proceedings of the 19th International Conference on Supporting Group Work (GROUP '16)*. ACM, 369–374. <https://doi.org/10.1145/2957276.2957297>
- [71] Cassandra Phoenix and Andrew C. Sparkes. 2009. Being Fred: big stories, small stories and the accomplishment of a positive ageing identity. 9, 2 (apr 2009), 219–236. <https://doi.org/10.1177/1468794108099322>
- [72] Lee Rainie. 2017. Digital Divides – Feeding America | Pew Research Center. <http://www.pewinternet.org/2017/02/09/digital-divides-feeding-america/>
- [73] Julian Rappaport. 1993. Narrative Studies, Personal Stories, and Identity Transformation in the Mutual Help Context. 29, 2 (june 1993), 239–256. <https://doi.org/10.1177/0021886393292007>
- [74] Bryce J Renninger. 2015. “Where I can be myself – where I can speak my mind”: Networked counterpublics in a polymedia environment. 17, 9 (oct 2015), 1513–1529. <https://doi.org/10.1177/1461444814530095>
- [75] Catherine Kohler Riessman. 1990. Strategic uses of narrative in the presentation of self and illness: A research note. *Social science & medicine* 30, 11 (1990), 1195–1200.
- [76] Catherine Kohler Riessman. 2003. Analysis of Personal Narratives. In *Inside Interviewing: New Lenses, New Concerns*, James Holstein and Jaber F. Gubrium (Eds.). SAGE, 331–346.
- [77] Ari Schlesinger, Kenton P O'Hara, and Alex S Taylor. 2018. Let's Talk About Race: Identity, Chatbots, and AI. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 315.
- [78] Andrew Scull. 1991. Psychiatry and social control in the nineteenth and twentieth centuries. 2, 6 (june 1991), 149–169. <https://doi.org/10.1177/0957154X9100200603>
- [79] Yukari Seko and Stephen P Lewis. 2018. The self – harmed, visualized, and reblogged: Remaking of self-injury narratives on Tumblr. 20, 1 (jan 2018), 180–198. <https://doi.org/10.1177/1461444816660783>
- [80] Thomas Smyth and Jill Dimond. 2014. Anti-oppressive Design. 21, 6 (oct 2014), 68–71. <https://doi.org/10.1145/2668969>
- [81] Stephanie Tierney. 2006. The Dangers and Draw of Online Communication: Pro-Anorexia Websites and their Implications for Users, Practitioners, and Researchers. 14, 3 (may 2006), 181–190. <https://doi.org/10.1080/10640260600638865>
- [82] Natalie M. Underberg and Elayne Zorn. 2013. *Digital Ethnography: Anthropology, Narrative, and New Media*. University of Texas Press. Google-Books-ID: NqmOeY04twYC.
- [83] Karl Vick. 2017. The Digital Divide: A Quarter of the Nation Is Without Broadband. <http://time.com/4718032/the-digital-divide/>
- [84] Nils B. Weidmann, Suso Benitez-Baleato, Philipp Hunziker, Eduard Glatz, and Xenofontas Dimitropoulos. 2016. Digital discrimination: Political bias in Internet service provision across ethnic groups. 353, 6304 (sept 2016), 1151–1155. <https://doi.org/10.1126/science.aaf5062>
- [85] Donghee Yvette Wohn, Casey Fiesler, Libby Hemphill, Munmun De Choudhury, and J. Nathan Matias. 2017. How to Handle Online Risks?: Discussing Content Curation and Moderation in Social Media. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '17)*. ACM, 1271–1276. <https://doi.org/10.1145/3027063.3051141>
- [86] Peter Wright and John McCarthy. 2010. *Experience-Centered Design: Designers, Users, and Communities in Dialogue*. Morgan and Claypool Publishers.
- [87] Jillian C. York and Karen Gullo. 2018. Offline/Online Project Highlights How the Oppression Marginalized Communities Face in the Real World Follows Them Online. <https://www.eff.org/deeplinks/2018/03/offlineonline-project-highlights-how-oppression-marginalized-communities-face-real>
- [88] Kimball Young. 1949. *Sociology: A Study of Society and Culture*. American Book Company.
- [89] Renwen Zhang, Jordan Eschler, and Madhu Reddy. 2018. Online Support Groups for Depression in China: Culturally Shaped Interactions and Motivations. 27, 3 (dec 2018), 327–354. <https://doi.org/10.1007/s10606-018-9322-4>