

Marginalization and the Construction of Mental Illness Narratives Online: Foregrounding Institutions in Technology-Mediated Care

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People experiencing mental illness are often forced into a system in which their chances of finding relief are largely determined by institutions that evaluate whether their distress deserves treatment. These governing institutions can be offline, such as the American healthcare system, and can also be online, such as online social platforms. As work in Human-Computer Interaction (HCI) and Computer Supported Cooperative Work (CSCW) frames technology-mediated support as one method to fill structural gaps in care, in this study, we ask the question: how do online and offline institutions influence how people in resource-scarce areas understand and express their distress online? We situate our work in U.S. Mental Health Professional Shortage Areas (MHPSAs), or areas in which there are too few mental health professionals to meet expected needs. We use an analysis of *illness narratives* to answer this question, conducting a large scale linguistic analysis of social media posts to understand broader trends in expressions of distress online. We then build on these analyses via in-depth interviews with 18 participants with lived experience of mental illness, analyzing the role of online and offline institutions in how participants express distress online. Through our findings, we argue that a consideration of institutions is crucial in designing effective technology-mediated support, and discuss the implications of considering institutions in mental health support for platform designers.

CCS Concepts: • **Human-centered computing** → **collaborative and social computing**.

Additional Key Words and Phrases: institutions, marginalization, mental health, resource constraints, support platforms

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1 INTRODUCTION

The fields of Computer Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) have increasingly sought to understand people's everyday experiences with disempowerment [35, 103], and investigate whether technology can support both immediate needs [77] and a broader formation of counterpower [7, 51, 56]. One particular site of disempowerment for individuals in distress in the United States is the process of seeking care via the American mental health care system. An individual's ability to be treated is dependent on institutional factors largely out of

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their control, such as the reimbursability of treatment for certain diagnoses by insurers [17, 70] or the training and biases of their clinician [59].

People in distress are forced into an opaque system with dubious rules around what is needed for treatment. This can include geographic barriers to the healthcare professionals who must provide a diagnosis for treatment [64], and the potential for involuntary commitment (stemming from stigma) if symptoms are seen as dangerous [39, 66, 82]. In this study, we bridge past work in CSCW on technology-mediated support [31, 77, 91] and on the role of institutions in disempowerment [7, 85] to examine the impact of these systemic rules and governance on how people engage with online and offline support. We offer a mixed methods investigation into how technology designers can resist a fragmented [20] and classist [27] healthcare system and design for immediate needs.

Work in HCI and CSCW has investigated the underlying rules, logics, and histories of technology [3, 82, 85, 97], and their role in how individuals engage with the world around them, in both online and offline contexts. Following work from sociology and political science, we understand these sets of rules to be the basis on which governing institutions [75] are built, towards protecting the privileges and needs of those in power [36]. HCI and CSCW research has framed the design of technical interfaces [85, 93] and algorithms [3, 5, 52] as governing institutions, built with specific rules for how users might use a system, and maintaining a world built in the image of these rules [3]. This approach has been applied to diverse domain areas, including studying how policies around content moderation [23], algorithmic content prioritization [53], or how privacy settings [104] influence how individuals interact with the system, conceptualize their identities, and express themselves. We turn this critical lens towards online mental health resources and support tools, which researchers have argued may close structural gaps and provide for individuals in need [82].

In his work studying conceptualizations of illness, the medical anthropologist Arthur Kleinman [59] argues that the sharing of *illness narratives* form one means by which individuals reclaim agency over their experience from institutions, and find more relevant support outside of extractive healthcare systems. Illness narratives are stories that an individual creates to represent the full extent of their distress. Kleinman notes that this depth and nuance associated with illness narratives can counter the clinical impulse to reduce suffering to “narrow technical issues.” However, illness narratives both resist *and* are influenced by governing institutions, which influence whether distress is recognized as valid, and consequentially, how people construct and express their experience of illness. Illness narratives are reflections of individual experience and of power. Deep analyses of their construction (both online and offline) can thus make visible the logics and institutions that influence how an individual conceptualizes their illness, self, and intersections between both.

In this study, we utilize illness narratives as an approach in answering the following research question: **how do online and offline institutions influence how people in resource-scarce areas understand and express their distress online?** We take a mixed methods approach to answer this question, to both understand broad patterns of differences in expression, as well as the underlying experiences and engagements with institutions that influence those expressions. Our work is situated in U.S. Mental Health Professional Shortage Areas [89] (subsequently called *shortage areas*), or counties in the United States where there are not enough mental health professionals to meet the expected mental health needs of the community [46, 61].

We begin by performing a large scale linguistic analysis of Twitter posts from 2015-2017, demonstrating broad differences in expressions of distress between shortage and non-shortage areas. We then conduct semi-structured interviews to probe the illness narratives of 18 people in shortage and non-shortage areas, analyzing how engagements with different offline and online institutions (and combinations of both) influenced people’s experiences of distress. By doing so, we shine a light on how institutional marginalization in offline contexts interacts with platform design to influence whether certain narratives around illness become mainstream, and how some narratives are made

invisible. Based on our findings, we discuss the importance of a consideration of institutions by designers of online mental health support platforms.

Content Warning and Ethics Note: This paper includes in-depth description of suicide, self-harm, and involuntary hospitalization. This study was approved by the Georgia Institute of Technology's Institutional Review Board (IRB).

2 BACKGROUND AND RELATED WORK

In this section, we describe the relationship between governing institutions, power, and identity, and review how researchers in CSCW and in mental health fields have approached these three concepts. In alignment with Soden et al.'s [97] call for greater historicization in CSCW, we describe how U.S. Mental Health Professional Shortage Areas (MHPSAs) were the consequence of a history of institutional debates over what constitutes valid mental illness. This history directly influences lived experiences with care today, paralleling debates around legitimacy online, and providing important context for our findings. We end by motivating our use of illness narratives in this work, reviewing research describing how illness narratives can be used to understand the role of governing institutions in the lives of people with mental illness.

2.1 Institutions and Power in Mental Health and CSCW

Researchers in sociology [75], HCI [82], and CSCW [85] have described the core role that institutions, power, and governance can play in determining how individuals are able to engage with healthcare systems. In the context of our study of technology-mediated support, we understand institutions to be a series of collected rules, norms, logics, and constraints [75] that govern individual and social behavior. Following the writings of Foucault [36] and Goffman [41] on the institutional logics that underlie the mental healthcare system, we understand these underlying rules to be used as a means for one group to exert power and control over another. Further drawing on Foucault [11, 68], we understand the exertion of power to lie in micro-interactions that push, urge, or compel an individual to do something. Foucault notes that institutions are created when these micro-interactions scale over time, eventually being societally normalized and maintained by the state via force, or what he calls "institutional crystallization" [37]. Work in CSCW [2, 47, 92] describing how predictive algorithms maintain and propagate certain identity-based biases offline can be thought to be forms of institutional crystallization. As Alkhatib argues [3], sociotechnical systems can take on the role of a state in enforcing and benefiting from these biases.

In mental health spaces, institutional governance may also happen via institutions that take on a role analogous to the state, through determining whether distress is or is not valid enough for treatment. This could be the medical establishment, protocols for diagnosis (such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) [6]), or community members that can act as points of contact to care (such as clergymembers or teachers). As Pendse et al. [82] and Pine et al. [85] describe, institutional logics can also be encoded in the design of digital mental health apps or electronic health records, governing the forms of care accessible to an individual in need.

Foucault argues that negotiations with institutions can directly influence how people conceptualize their identity. In his view, identity is what Foucault calls "an effect of power," with the conceptualization of self being a vehicle for overarching power relations that benefit the state. Work in CSCW has studied how people's identities and experiences are shaped by the power relations that underlie the design of online systems. For example, Simpson et al. [95] describe how the For You Page of TikTok governs what kind of content users see, including often privileging certain stereotypical presentations of LGBTQ+ identity. Engagements with this content are found to deeply influence how users come to understand their gender identity and sexuality, and online institutions serve as a tool to reinforce offline power dynamics.

An emerging field of work in HCI and CSCW frames the design of software [63], platforms [23, 35], and of algorithms [3, 5, 52] as institutions that work to structurally empower or disempower certain people, often through influencing their process of identity formation and expression. We extend this lens to the field of technology-mediated support. Research in offline contexts has demonstrated that the process of identity formation, mediated by interactions with different institutions, plays a core role in how people come to experience mental illness, and the types of care that they are able to access [12]. As technology-mediated support is popularized as one way to close care gaps [82], it is important to not only understand where gaps may exist, but *why* those gaps exist and how those gaps are maintained. Our study contributes to the broader agenda of research within CSCW that examines the process by which gaps are created, and the role that technology may play in structurally filling or deepening these gaps by supporting or resisting institutional logics. In the next section, we provide an overview of the history of U.S. Mental Health Provider Shortage Areas, drawing attention to how institutions and governance consolidated the power to define mental illness and care to the state, and as a consequence, created and maintained shortage areas.

2.2 U.S. Mental Health Professional Shortage Areas

As research in CSCW increasingly positions itself in relation to wider social and political contexts, Soden et al. [97] argue that it is particularly important to make clear the social and historical context of a particular tool, system, or sociotechnical phenomenon in all CSCW work. In our study, this approach allows for a deeper understanding of the institutional reasons behind why certain gaps in care may exist, and allows us to provide design recommendations not solely to fill gaps, but to also design and advocate for a future in which gaps are minimal. Additionally, such an approach gives us greater context to the experiences of our participants, and how their experiences are consequences of historical decisions around illness and care.

We turn this lens towards the American mental healthcare system, or what Insel [50] calls a “sick-care system, built to respond to a crisis.” The American mental healthcare system is crisis-centered and geographically sparse as a result of political and social debates between governing institutions over what constitutes true, treatable mental illness. The partisan and reductive nature of this debate led to an intentionally poor implementation of federal mental health programs, which was concurrent with the shuttering of regional care. These factors subsequently led to the creation of mental health shortage areas.

Prior to 1945, care for those with mental illness was primarily done by regional and state governments. State hospitals were often designed based on certain institutional values around the nature of mental illness. For example, most state facilities were built via the Quaker-influenced paradigm of “moral treatment” [105], and were thus designed with sunlight, fresh air, and privacy for patients. However, municipal governments saw state facilities as an opportunity to reduce expenditures for elderly care, and created the concept of “senility” as a mental illness, which allowed the commitment of elderly people who would not normally be considered unhealthy or ill [29]. Though facilities were only made to house 250 people at maximum [58], the number of patients grew exponentially [42]. Institutional values around how care should be provided were structurally embedded in the design of the state healthcare system, but clashed with institutional definitions of illness and health, and limited what kind of care could be provided.

By the Second World War, Quakers and Mennonites who (as conscientious objectors to conscription) were assigned to work in state facilities were shocked at how sordid conditions were. Their advocacy, in part, motivated the creation of a centralized federal mental healthcare system [102]. This push for a centralized federal system also led to the death of local mental healthcare programs that approached care holistically, leading to a national “sick-care” system [50], particularly for people in shortage areas. In 1963, President John F. Kennedy signed the Community Mental Health

Act, which established *Community Mental Health Centers (CMHCs)*, which aimed to treat and prevent mental illness in areas in need, or what Kennedy dubbed “manpower shortage” areas [55]. As CMHCs were prioritized in mental health funding, state hospitals began to close (in anticipation of federal funding), and people who had formerly been inpatient began to be released to return to family care. However, given nearly no social safety net for people who were likely traumatized from decades of commitment, individuals with severe mental illness were left to live unhoused and without proper financial support or guidance on finding care [50, 102]. Furthermore, CMHCs tended to prioritize “attractive, easy patients to treat” [102]. There was little encouragement from the NIMH to treat former state hospital patients, as the NIMH emphasized “social planning and the contemporary issues of the day” as part of President Lyndon B. Johnson’s War on Poverty [107].

This wide-ranging definition of mental healthcare as including social and economic change played into Republican fears about psychiatry being a tool of communism [102]. Republican-led governments were thus hesitant to maintain or increase funding for mental healthcare, given an institutional definition that included social or political change, and let the CMHC program die by 1981. By this point, the regional mental hospital system functionally ceased to exist. Stemming from the political suspicion of psychiatry as creeping communism, there was also significant incentive in the 1980s to create structured definitions of mental health and illness similar to diagnosis codes used in other parts of medicine that insurers could easily reimburse [70]. Treatment could only happen if tied to these diagnostic codes, which could only be provided by a healthcare professional. The politically-motivated shuttering of local mental healthcare facilities along with an institutional use of diagnostic codes to determine care eligibility set the tone for treatment in shortage areas.

Shortage areas are currently designated by the Health Resources and Services Administration (HRSA) based on factors including number of mental health professionals, income levels, the amount of time it takes for a given individual to get to the nearest source of care, and other structural factors [46, 61, 89, 101]. In our analysis, we exclusively look at geographic shortage areas, designated at the county level. Shortage areas are predominantly rural [38] and home to low-income communities [101], and have higher suicide rates [61]. More work is needed to understand the influence of structural and institutional factors on how those living in shortage areas come to understand their experiences and seek help around their mental health challenges, and whether technology may help to fill institutionally created gaps in care. In the next section, we describe why analyzing *illness narratives* is a particularly salient method to analyze the role of governing institutions in the lives of those in distress in shortage areas.

2.3 Illness Narratives as Consequence and Resistance

An illness narrative [59] can be understood to be the narrative that an individual creates around their distress, which includes how they come to explain why they are experiencing distress (which Kleinman dubs the “explanatory model of illness” [60]) and how they express their distress to others (which is often called the “idiom of distress” [73, 74]). Individuals in distress are often dependent on others for support and care—as a result, the specific words that an individual uses are a form of currency that either mobilizes others to help them, or dissuades social support (such as due to stigma, fear, or financial cost). Illness narratives are thus not individually created, but socially co-created, stemming from where the power to provide healing and care lies in a society. Kleinman thus argues that a deep analysis of the narrative that people use to frame their distress can shed light on how institutional factors (such as “political labels, mass campaigns, uprooting and migration, poverty, and so forth”) and psychological factors (such as “depression, anxiety, [and] personality problems”) influence how people understand their mental illness [59]. However, Nichter [74] notes that the language used to express distress is not static, quickly influenced by new power relations,

particularly when related to words that (as Kleinman describes) “have official status as listings in the disability, medical, legal, and other institutional bureaucracies.”

Nichter uses the example of the relatively recent (at time of writing) recognition of PTSD and ADHD as mental health diagnoses, and argues that the clinical definitions of these terms did not matter as much as how they were used and understood by people in distress in search of care — the clinical recognition of PTSD and ADHD gave individuals new and powerful terms to represent their distress and get care. Language that is institutionally powerful (such as clinical language) might denote that a illness is more valid or deserving of care to those who can provide it. In this sense, as diverse stories around distress that may not fit traditional diagnostic categories, illness narratives function as a form of resistance to institutions that attempt to categorize and measure mental illness. But conversely, as products of the power relations that determine whether an individual can receive care, illness narratives are also fundamentally also a consequence of institutions.

Research in HCI and CSCW has worked to understand how the institutional logics and governance that underlie different online platforms influence how users express mental distress and illness online. Feuston et al. [35] use this lens to examine how Instagram users leverage the affordances of the platform to normalize mental health and resist the idea that mental illness is an out of the ordinary experience. The researchers draw attention to how the features and underlying rules of Instagram influence how people are able to frame their narratives. Similarly, Chancellor et al. [23] describe how individuals on Instagram use lexical variation (such as “anorexia” instead of anorexia) to avert the moderation policies of the website, which can be thought of as a form of institutional governance. While this past work focused on how design considerations influenced syntax and the framing of posts, more work is needed to understand how engagements with online mental health resources and communities (and their underlying institutional logics) influence how people come to co-create illness narratives. The design of online platforms, particularly how they mediate discourse, have immense power over which forms of illness are determined legitimate, and which forms of distress are rendered invisible.

3 LINGUISTIC DIFFERENCES IN EXPRESSION

In this section, we utilize a large scale analysis of Twitter posts to understand broad trends around expressing distress, and focus on differences between shortage and non-shortage areas. When analyzing these differences, we pay specific attention to the role of institutions in the differences we observe, and contextualize these differences through our subsequent qualitative interview study.

3.1 Method and Data

Past work has found that time and context have a strong influence on mental health discourse online [13, 62, 67]. For our analysis, we intentionally utilize social media data from 2015-2017—this period of time matches the context in which the majority of participants who used social media in our qualitative study described first experiencing mental health concerns and expressing symptoms on social media. We utilize this data to match the context of participant reflections on coming into their mental illness identities. Our social media dataset is thus comprised of Twitter posts collected during 2015-2017 throughout the United States. Posts were collected based on their use of any one of 38 different keywords and phrases that denoted some form of suicidal ideation, thoughts, or behaviors (SITB), such as “end my life” or “hang myself,” following past research [26, 28, 79]. We chose to use keywords related to suicide (as opposed to broader mental health keywords) due to suicidal ideation and attempts being the main gateway for people to access care in shortage areas [64], which is often crisis care in hospitals. Additionally, the highest rates of complex co-occurring disorders with suicidal ideation are found in rural areas [64, 98]. We treat Twitter posts

that explicitly express SITB as indicative of extreme mental distress. We analyze this data to find differences between shortage and non-shortage areas in the U.S.

We limit our analysis to all “Geographic Area” shortage and non-shortage areas. To classify the relative rural and urban nature of counties, we leverage the three tiered classification system used by the National Center for Health Statistics [45, 49], looking at counties that are classified as rural and urban. We also leverage the six-tiered classification system [49] to investigate differences between the most rural counties and large “central” metropolitan areas (with populations of 1 million people and above). We exclude all partial shortage areas to do a focused analysis between areas that have a consistent level of resources throughout the entire county.

Our dataset was collected via the official Twitter Academic API, and included 1,967,582 Twitter posts from 1,145,013 users, with 836,076 tweets from 476,658 users in shortage areas and 297,554 tweets from 162,061 users in non-shortage areas. Users in shortage areas posted 1.75 posts indicating distress ($\sigma = 5.13$ posts) and users in non-shortage areas posted 1.84 posts indicating distress ($\sigma = 8.76$ posts) on average. To ensure that this dataset was representative of the national population, particularly given the imbalance in users in shortage and non-shortage areas, we performed a rank correlation analysis between the number of users from each county and the population of each county, as measured by the U.S. Census Bureau [18] in the average of the years 2015-2017. We did both a Spearman rank correlation analysis and in addition, a Kendall’s Tau-B analysis (as there were some ties between ranks). We found the dataset to be very strongly correlated with population ($p < .0001$, $\rho = .825$, $\tau = .653$).

We use two tools for our broad analysis. To compare levels of sentiment and linguistic style, we used the Linguistic Inquiry and Word Count (LIWC) analysis program [84], well-validated on social media data, particularly in contexts related to mental health [22, 44]. We focus this analysis around LIWC categories that align with different forms of qualitative analyses done around expressions of distress in past anthropological work [73, 74, 87], particularly language around affect, the community, around the body and somatic symptoms, around religion, and around class. Following past research, we normalize all counts with the length of the post. We thus report the average percentage of a post that contains language for a given LIWC category, for a given area (such as shortage and non-shortage). Following past work in CSCW [33, 69], we include paraphrased posts as context for the LIWC categories we find to be most significant, with LIWC keywords in blue. To analyze distinct words that individuals in shortage and non-shortage areas use, we utilize a Sparse Additive Generative Model (SAGE) [32], which selects distinct and salient keywords via comparisons in word distributions for logistically-parametrized multinomial models for the text from each area of comparison. SAGE has been used in past work in CSCW and HCI to examine keyword differences associated with hate speech online [25], politics [94], age and gender [81], discussions of drugs that have been criminalized [80], and mental health experiences with minority stress on social media [91]. We utilize the top 100 words, using a baseline smoothing of 1, and report the difference in log-frequencies from the modeled lexical distribution for the 10 words with the highest differences.

We use a statistical t -test for comparisons, utilizing Welch’s t -test to account for the imbalance in tweets between shortage and non-shortage areas. We calculate the False Discovery Rate (FDR), hereinafter called the q -value, at an significance level of 0.05. For all text analyses, we used the Natural Language Toolkit [14] stopwords list (including popular Internet variants) to filter out stopwords.

3.2 Analysis

3.2.1 Shortage and Non-Shortage Areas. We begin by doing a comparison of expressions of distress between shortage and non-shortage areas. As we present in Table 1, we find that individuals in

Word	SAGE	LIWC Dimension	Shortage Areas	Non-Shortage Areas	q-value
Shortage Areas		Affect			
gone	0.0286	Affect Language	11.29% (12.24%)	11.13% (12.07%)	1.71×10^{-8}
tired	0.0274	Positive Emotion Language	5.10% (8.01%)	5.06% (7.94%)	0.046
wish	0.0255	Negative Emotion Language	6.11% (9.98%)	5.99% (9.78%)	6.30×10^{-8}
god	0.0254	Somatic Language			
hurt	0.0222	Biological Processes	9.70% (12.66%)	9.34% (12.39%)	3.56×10^{-37}
love	0.0164	Body Language	4.16% (9.06%)	3.99% (8.87%)	4.99×10^{-17}
living	0.0139	Health Language	4.38% (9.17%)	4.18% (8.84%)	5×10^{-23}
wake	0.0112	<i>Sexual Language</i>	0.40% (2.35%)	0.43% (2.41%)	3.25×10^{-5}
sleep	0.0111	<i>Ingestion Language</i>	0.55% (2.87%)	0.56% (2.89%)	.01
forever	0.0107	<i>Death Language</i>	2.51% (7.57%)	2.57% (7.52%)	8.86×10^{-4}
Non Shortage Areas		Community Language			
stab	0.0691	Religion Language	0.59% (2.87%)	0.52% (2.68%)	1.70×10^{-28}
fucking	0.0686	Social Processes	4.42% (7.31%)	4.32% (7.19%)	2.24×10^{-9}
fuck	0.6589	Family Language	0.48% (2.35%)	0.46% (2.29%)	3.30×10^{-4}
new	0.0599	Class Language			
worth	0.0545	Time Language	9.11% (10.69%)	9.08% (10.56%)	0.14
ending	0.0542	<i>Leisure Language</i>	1.64% (4.62%)	1.70% (4.65%)	7.39×10^{-9}
years	0.0469	<i>Money Language</i>	0.67% (2.92%)	0.69% (2.98%)	1.0×10^{-4}
ends	0.0445	<i>Work Language</i>	1.88% (4.99%)	1.91% (4.98%)	.02
die	0.0425				
live	0.0419				

Table 1. Shortage Areas vs Non-Shortage Areas. In our LIWC analysis, bolded categories are significantly higher in shortage areas, italicized categories are significantly higher in non-shortage areas. Shortage areas have higher levels of affect language, somatic language, and religious language. Non-shortage areas tend to have more explicit descriptions of SITB, which contradicts the lower levels of suicide in non-shortage areas.

shortage areas are more likely to express how they are feeling in affective terms ($q < 1.71 \times 10^{-8}$), with both positive ($q < .046$) and negative emotional expressions ($q < 6.30 \times 10^{-8}$) higher in shortage areas. For example, posts such as “*Nightmares are horrible tonight, disturbed sleep,*” “*A nice n’ cute guy wanted to spend time with me and I can’t get myself to do it whyyyy,*” and “*Feeling extremely worthless and ashamed, unworthy of love, and hopeless,*” all have a high level of affect, positive emotion, and negative emotion language respectively. Looking to the words that are used most distinctly in shortage and non-shortage areas, we see more explicit references to death and different means of suicide (such as *stab* or *die* or *ending*) in non-shortage areas via SAGE, as well as higher levels of death language ($q < 8.86 \times 10^{-4}$). Examples of how these posts may be framed include “*Sometimes I just really want to stab myself*” or “*Okay, I am ready to die.*” Paradoxically, the more explicit discussion of death in non-shortage areas contrasts with the less explicit discussion of death in shortage areas, but a higher rate of suicide in shortage areas [61]. This parallels findings from Rochford et al. [90] that demonstrate higher levels of Internet searching for suicide in non-shortage areas, even though these areas have lower rates of suicide than shortage areas. It may be the case that more explicit discussions of suicide are less stigmatized in non-shortage areas, and as a result, people are more willing to express ideation openly, even if graphic. This may also have the consequence of allowing people to more easily get care, and lead to the lower suicide rates observed in non-shortage areas.

We also find that individuals in shortage areas are more likely to use somatic language to describe their distress, with language around biological processes ($q < 3.56 \times 10^{-37}$), the body $q < 4.99 \times 10^{-17}$, and health ($q < 5.00 \times 10^{-23}$) all used more in shortage areas. In LIWC’s categorization system, this language is extremely specific and does not include broad complaints of distress like “*hurt,*” instead focusing on clinical or physical terms like “*doctor,*” “*ibuprofen,*” or “*sleep.*” For example, “*I twitch anytime I notice my doctor glancing at my wrists, to see if I’m trying to hurt myself*” contains

Word	SAGE	LIWC Dimension	Rural Shortage Areas	Rural Non-Shortage Areas	q-value
Rural Shortage Areas		Affect			
wake	0.0008	Affect Language	11.37% (12.28%)	11.66% (12.51%)	.328
life	0.0006	Positive Emotion Language	5.14% (8.05%)	5.16% (8.14%)	0.908
tired	0.0004	Negative Emotion Language	6.12% (9.96%)	6.40% (10.06%)	.32
sleep	0.0004	Somatic Language			
living	0.0003	Biological Processes	9.68% (12.72%)	8.92% (12.02%)	.002
time	0.0002	Body Language	4.18% (9.08%)	3.85% (8.86%)	.104
day	0.0002	Health Language	4.37% (9.24%)	3.80% (8.13%)	6.0×10^{-4}
school	0.0002	<i>Sexual Language</i>	0.39% (2.29%)	0.53% (2.69%)	.016
need	0.0001	Ingestion Language	0.53% (2.88%)	0.52% (2.70%)	.888
early	0.0001	Death Language	2.56% (7.63%)	2.60% (7.53%)	.835
Rural Non Shortage Areas		Community Language			
fuck	0.4872	Religion Language	0.58% (2.83%)	0.55% (2.63%)	.630
fucking	0.3409	Social Processes	4.43% (7.33%)	4.16% (7.13%)	.102
stab	0.2532	Family Language	0.48% (2.34%)	0.46% (2.34%)	.76
hang	0.2435	Class Language			
feeling	0.1765	Time Language	8.99% (10.61%)	8.48% (9.99%)	.022
feel	0.1641	Leisure Language	1.58% (4.53%)	1.55% (4.33%)	.819
anymore	0.087	Money Language	0.66% (2.93%)	0.73% (3.09%)	.386
end	0.0774	Work Language	1.81% (4.91%)	1.63% (4.34%)	.076
want	0.0604				
pain	0.0002				

Table 2. Rural Shortage areas versus Rural Non-Shortage Areas. In the LIWC analysis table, bolded categories are significantly higher in rural shortage areas, whereas italicized categories are significantly higher in rural non-shortage areas. We find that expressions of distress tend to be more explicit in rural non-shortage areas, just as in non-shortage areas broadly. We also find higher levels of somatic language, particularly around biological processes and the body in rural shortage areas

high levels of biological language due to the use of several medical terms. From our SAGE analysis, we observe somatic language being used distinctly in shortage areas, including *sleep* and *tired*. This follows past research outside of the U.S. showing that individuals in rural or low-income areas are more likely to somatize their distress [24, 76].

Close contacts and community members also play a core role for expressions of distress in shortage areas, with language around social processes ($q < 2.24 \times 10^{-9}$) and language around the family ($q < 3.30 \times 10^{-4}$) higher in shortage areas. As demonstrated by our SAGE analysis, social language included words like *love*, such as “*Spending less time here — deeply in love with bae.*” Social language was directed at people, but could also be directed at the platform, with examples such as “*All these girls tweeting about mental health used to laugh about me when I was alone, cutting, and depressed — thanks*” or “*My life sucks, all I do is sit on Twitter talking about my pointless life and pretending like people care.*” Language around family similarly referenced important family members in the life of the post’s author—for example, “*I told my mom I wanted to die and she laughed at me. And everyone in the world asks why I have suicidal thoughts.*”

Through our LIWC analysis, we also find religious language to be used more in shortage areas ($q < 1.70 \times 10^{-28}$). This language can be used in nuanced ways, such as “*Feeling scared? Hopeless? Nervous? Ashamed? I did too. Get to church.*” versus “*Time to sleep, I pray to God I never wake up.*” Additionally, *god* appears as one of the most salient words used in shortage areas in our SAGE analysis. As described in work on the sociology of religion in the U.S., this may be the consequence of a greater role of religion [15, 21] in the lives of people experiencing distress in rural areas.

3.2.2 Rural and Urban Shortage Areas. We now carry out the same analysis, but separate out the urban and rural dimension to shortage and non-shortage areas, to see if levels of rurality might account for some of the differences we observe. As we present in Table 2, we find similar levels of affect language in rural shortage and rural non-shortage areas. However, we do find that expressions of distress tend to be more explicit in rural non-shortage areas, just as in non-shortage areas broadly,

Word	SAGE	LIWC Dimension	Urban Shortage Areas	Urban Non-Shortage Areas	q-value
Urban Shortage Areas		Affect			
wish	0.0508	Affect Language	11.24% (12.21%)	11.13% (12.07%)	4.81×10^{-4}
gone	0.0391	Positive Emotion Language	5.10% (8.00%)	5.06% (7.93%)	.069
god	0.0391	Negative Emotion Language	6.06% (9.95%)	5.99% (9.79%)	.004
tired	0.0387	Somatic Language			
morning	0.0248	Biological Processes	9.67% (12.63%)	9.34% (12.39%)	2.00×10^{-28}
hurt	0.0244	Body Language	4.14% (9.05%)	4.00% (8.87%)	4.39×10^{-11}
living	0.0244	Health Language	4.37% (9.13%)	4.18% (8.84%)	6.32×10^{-19}
love	0.022	<i>Sexual Language</i>	0.41% (2.35%)	0.43% (2.42%)	.001
life	0.0184	<i>Ingestion Language</i>	0.55% (2.87%)	0.56% (2.89%)	.04
let	0.0184	<i>Death Language</i>	2.49% (7.57%)	2.57% (7.53%)	7.63×10^{-5}
Urban Non Shortage Areas		Community Language			
stab	0.0541	Religion Language	0.60% (2.91%)	0.52% (2.68%)	2.40×10^{-34}
fucking	0.0487	Social Processes	4.43% (7.31%)	4.32% (7.19%)	8.63×10^{-9}
ends	0.0471	Family Language	0.48% (2.35%)	0.46% (2.29%)	.002
ending	0.0401	Class Language			
fuck	0.0346	Time Language	9.11% (10.69%)	9.08% (10.57%)	.36
die	0.0323	<i>Leisure Language</i>	1.65% (4.64%)	1.71% (4.67%)	4.06×10^{-6}
live	0.0283	<i>Money Language</i>	0.68% (2.93%)	0.69% (2.98%)	.029
new	0.0253	Work Language	1.90% (5.02%)	1.91% (4.98%)	.67
worth	0.0217				
killing	0.0209				

Table 3. Urban Shortage Areas vs Urban Non-Shortage Areas. In the LIWC analysis table, bolded categories are significantly higher in urban shortage areas, whereas italicized categories are significantly higher in urban non-shortage areas. We find higher levels of explicit language in urban non-shortage areas. We also find higher levels of somatic and religious language in urban shortage areas.

with words like *stab*, *hang*, *end*, and *pain* being used more distinctly in non-shortage areas. We also find similar levels of religious language in rural shortage and non-shortage areas. This may be a consequence of the larger role that religion plays in the lives of those in rural areas, potentially regardless of shortage status. This may also be a consequence of there being relatively few rural non-shortage areas, and thus limited data. Only .894% of rural counties are non-shortage areas, which equates to .19% of the U.S. population [34]. However, we do find higher levels of somatic language, particularly around biological processes ($q < .002$) and health ($q < 6.00 \times 10^{-4}$) in rural shortage areas, such as in the form “*When I wake up from sleep, I crawl out of bed to my liwcmedicine cabinet to take my pills to function – if I don’t take them, I go back to sleep.*” We also see similar somatic words distinctly used in rural shortage areas via our SAGE analysis, such as *tired* and *sleep*.

Several of these findings also carry to our analysis of urban shortage and non-shortage areas. As we present in Table 3, we see higher levels of negative emotional language ($q < 4.81 \times 10^{-4}$), though positive emotion language and affect broadly are relatively consistent between urban shortage and non-shortage areas. However, we do consistently see more explicit language in urban non-shortage areas, similar to rural non-shortage areas, with words like *stab*, *die*, and *killing* being used more distinctly in urban non-shortage areas. In urban areas, we also find higher levels of somatic language, along biological language ($q < 2.00 \times 10^{-28}$), body-related language ($q < 4.39 \times 10^{-11}$), and health-related language ($q < 6.32 \times 10^{-19}$) dimensions, consistent with our findings broadly and in rural shortage and non-shortage areas. Similar to our results for shortage and non-shortage areas broadly, we find that religious language is higher in urban shortage areas compared to urban non-shortage areas. The word *god* is also observed to be more distinct to urban shortage areas. For example, sample posts included utilizations of “god” in forms such as “*I swear to god, I’m going to shoot myself, my brother is being awful*”, but also phrases like “*god damn*” or “*I pray for god to take the negative energy out of my life*”. This may speak to the central role that religion plays in the lives of people in resource-scarce areas, including in the idioms of distress used, but also potentially to the role the religious support might play in filling gaps in care.

Word	SAGE	LIWC Dimension	Rural Shortage Areas	Urban Shortage Areas	q-value
Rural Shortage Areas		Affect			
hurts	0.0539	Affect Language	11.37% (12.28%)	11.24% (12.21%)	.001
hurt	0.0442	Positive Emotion Language	5.14% (8.05%)	5.10% (5.10%)	0.244
know	0.0378	Negative Emotion Language	6.16% (9.96%)	6.06% (9.94%)	.004
sleep	0.026	Somatic Language			
love	0.0238	Biological Processes	9.68% (12.72%)	9.67% (12.62%)	.96
ends	0.0235	Body Language	4.18% (9.08%)	4.14% (9.05%)	.254
die	0.0178	Health Language	4.37% (9.24%)	4.37% (9.13%)	.903
like	0.0014	<i>Sexual Language</i>	3.87% (2.29%)	4.05% (2.35%)	0.021
forever	0.001	Ingestion Language	0.54% (2.88%)	0.55% (2.87%)	.225
lol	0.001	Death Language	2.56% (7.63%)	2.49% (7.57%)	.013
Urban Shortage Areas		Community Language			
wish	0.0217	Religion Language	0.58% (2.83%)	0.60% (2.91%)	.064
hang	0.0124	Social Processes	4.43% (7.33%)	4.43% (7.31%)	.903
life	0.0106	Family Language	0.48% (2.34%)	0.48% (2.35%)	.678
day	0.0023	Class Language			
work	0.0017	<i>Time Language</i>	8.99% (10.61%)	9.11% (10.69%)	.001
anymore	0.0017	<i>Leisure Language</i>	1.58% (4.53%)	1.65% (4.64%)	2.51 x 10 ⁻⁶
feeling	0.0015	Money Language	0.66% (2.93%)	0.68% (2.94%)	.282
shoot	0.0013	<i>Work Language</i>	1.82% (4.91%)	1.90% (5.02%)	7.37 x 10 ⁻⁸
night	0.0013				
shit	0.0012				

Table 4. Rural Shortage Areas vs Urban Shortage Areas. In the LIWC analysis table, bolded categories are significantly higher in rural shortage areas, whereas italicized categories are significantly higher in urban shortage areas. We also see more explicit language around suicide in urban shortage areas. However, we find somatic and religious language to be largely the same between rural and urban shortage areas, perhaps a similar reliance on somatic framings of distress and a greater role of religious institutions in care.

Word	SAGE	LIWC Dimension	Rural Shortage Areas	Metro Shortage Areas	q-value
Rural Shortage Areas		Affect			
hurt	0.0487	Affect Language	11.37% (12.28%)	10.99% (11.81%)	9.28 x 10 ⁻¹⁴
sleep	0.0449	Positive Emotion Language	5.14% (8.05%)	5.16% (8.00%)	.093
forever	0.0413	Negative Emotion Language	6.16% (9.96%)	5.71% (9.34%)	6.69 x 10 ⁻²⁷
love	0.0336	Somatic Language			
killing	0.0286	Biological Processes	9.68% (12.72%)	9.28% 12.12%	7.62 x 10 ⁻¹⁴
wake	0.024	Body Language	4.18% (9.08%)	3.81% (8.51%)	3.29 x 10 ⁻²³
know	0.0016	Health Language	4.37% (9.24%)	4.26% (8.73%)	.008
people	0.0015	Sexual Language	0.39% (2.29%)	0.40% (2.26%)	.308
tired	0.0014	<i>Ingestion Language</i>	0.54% (2.88%)	0.61% (3.03%)	1.30 x 10 ⁻⁰⁸
gone	0.0011	Death Language	2.56% (7.64%)	2.44% (7.18%)	.0002
Metro Shortage Areas		Community Language			
hopeless	0.1115	Religion Language	0.58% (2.82%)	0.55% (2.79%)	.004
new	0.0941	Social Processes	4.43% (7.33%)	4.45% (7.24%)	.75
hang	0.093	Family Language	0.48% (2.34%)	0.46% (2.32%)	.127
today	0.083	Class Language			
worth	0.0804	<i>Time Language</i>	8.99% (10.6%)	8.90% (10.28%)	.069
feeling	0.0668	<i>Leisure Language</i>	1.58% (4.53%)	1.74% (4.67%)	3.92 x 10 ⁻¹⁴
live	0.0578	Money Language	0.66% (2.93%)	0.71% (2.94%)	.0002
year	0.0572	<i>Work Language</i>	1.82% (4.91%)	1.88% (4.89%)	.005
week	0.0557				
day	0.0533				

Table 5. Rural Shortage Areas vs Metro Shortage Areas. In the LIWC analysis table, bolded categories are significantly higher in rural shortage areas, whereas italicized categories are significantly higher in metropolitan shortage areas. We observe higher levels of somatic language and religious language in rural shortage areas compared to metropolitan shortage areas. Metropolitan shortage areas also uniquely use the word *hopeless* to describe their distress.

Next, we examine the differences between rural shortage areas and urban shortage areas, and present our findings in Table 4. For a more distinct analysis, we also look at differences between rural shortage areas and metropolitan shortage areas, which are shortage areas with a population of more than a million people, and present our findings in Table 5. We find that affect language is higher ($q < .001$) in rural shortage areas when compared to both urban shortage areas and metro shortage areas. We also see more explicit language around suicide in urban shortage areas, with words such as *hang* and *shoot* being distinctly used, and higher levels of language around death in urban shortage areas ($q < .013$). However, we find somatic and religious language to be largely the same between rural and urban shortage areas, potentially the result of a similar reliance on somatic framings of distress and a greater role of religious institutions in filling care gaps in resource-scarce areas. However, we do observe higher levels of somatic language ($q < 7.62 \times 10^{-14}$) and religious language ($q < .004$) in rural shortage areas compared to metro shortage areas. Metro shortage areas also uniquely use the word *hopeless* to describe their distress, which was not the case when aggregated with urban shortage areas. The post “*My emotions are spiraling and I feel so depressed and hopeless, I wish I could have therapy sometime soon*” is one such example. This potentially hints at a greater familiarity with psychological language in metropolitan areas, as hopelessness is a psychological symptom common to several different measurement scales of depression [10, 99].

To understand the lived impacts of these differences in expression, we do interviews with people from shortage and non-shortage areas. We ask questions around how participants understand their experiences of distress, and their engagements with formal and informal institutions that have the power to validate or invalidate that distress, tying our findings back to these broader patterns.

4 TECHNOLOGY-MEDIATED ILLNESS NARRATIVES

Our quantitative analysis demonstrated significant differences in how people in shortage and non-shortage expressed distress. In this section, we investigate the implications of those differences in the lives of people with lived experience of mental illness, and examine the role of institutions in how participants collaboratively constructed narratives around their distress.

4.1 Method and Analysis

Given the differences we observed in our quantitative analysis, the goal of this next part of our study was to better understand the role of these differences among participants with lived experience of mental illness in shortage and non-shortage areas. In particular, we hoped to understand how participants came to understand illness and create a narrative around it, connections between that narrative and how they saw their identities, and the role that technology played in that process.

We conducted semi-structured interviews with 18 different participants of diverse backgrounds from shortage areas, partial shortage areas, and non-shortage areas. We report both the area that participants grew up in, as well as the type of area that participants were currently living in, as most participants migrated to a different area than where they grew up at some point. Additionally, it was the case across participants that their first experiences with symptoms of mental illness were in childhood or early adulthood, before they potentially moved away in adulthood. We present demographic information for participants below in Table 6 and location information in Table 7.

Participants were recruited via an online survey that asked for their location, demographic information, and details about their believed and formally diagnosed mental illnesses, as well as where they got support from. Additionally, during interviews, participants were asked their personal gender pronouns. Additional participants were also recruited via purposive and snowball sampling via our collaborative partnership with mental health advocacy organizations, as well as through posts on social media. We elaborate on our intentional design process for this recruitment tool in the next subsection. We intentionally chose a group of participants that were diverse across

Participant Name	Age	Race and Ethnicity	Gender Identity (Self-Described)	Diagnoses
Evan	25-34 years old	White, Native American	Male	Depression, Anxiety
Delilah	55-64 years old	White	Woman	Depression, Bipolar Disorder, Anxiety, Schizophrenia, PTSD
Elliott	25-34 years old	White	Non-Binary and Transmasculine	Depression, Anxiety, PTSD, ADHD
Perla	25-34 years old	Filipino	Non-Binary	Depression, Anxiety, ADHD
Isabella	45-54 years old	White	Woman and Trans	<i>CPTSD, PTSD, Major Depressive Disorder</i>
Brian	18-24 years old	White	Man	Other – General Psychotic Disorder
Mia	35-44 years old	White	Woman	Anxiety, Eating Disorders, OCD
Joe	25-34 years old	White	Trans Masc	Depression, Anxiety, OCD
Olivia	25-34 years old	White	Female	Depression, Anxiety, ADHD
Angel	55-64 years old	White	Woman	<i>Depression, Bipolar Disorder, Anxiety, ADHD, Eating Disorders</i>
Belinda	25-34 years old	Black, African Caribbean	Non-Binary	Depression, (Social) Anxiety, GAD, ADHD, Eating Disorders
Aarohi	18-24 years old	Asian Indian	Woman and Non-Binary	Depression, ADHD
Dana	25-34 years old	Black	Non-Binary	Depression, Bipolar Disorder, Anxiety, PTSD, ADHD
Trevor	25-34 years old	White	Male	Depression, PTSD, ADHD, Substance Use Disorder
Donna	55-64 years old	Black	Woman	Depression, Anxiety, PTSD, DID
Kendall	18-24 years old	White	Woman, Non-Binary, Transgender Woman	Depression, Anxiety, ADHD, ASD
Roseangela	55-64 years old	Hispanic - South American	Woman	<i>Anxiety, Borderline Personality Disorder (BPD)</i>
Abe	64-74 years old	Black	Man	Bipolar Disorder, Schizophrenia, Substance Abuse Disorder, Schizoaffective Disorder

Table 6. Demographic information of all participants. Participant names are pseudonyms. Italicized diagnoses are diagnoses that participants believed they had but were not formally diagnosed with. Bold diagnoses are diagnoses that participants were given from medical professionals, but did not believe that they had.

Participant Name	Childhood Region	Current Region	Area Abbreviations
Evan	Midwest (Shortage Area)	Midwest (Shortage Area)	S → S
Delilah	Midwest (Shortage Area)	West (Shortage Area)	S → S
Elliott	West (Shortage Area)	Midwest (Shortage Area)	S → S
Perla	Midwest (Shortage Area)	West (Partial Shortage Area)	S → PS
Isabella	Northeast (Partial Shortage Area)	West (Partial Shortage Area)	PS → PS
Brian	Midwest (Shortage Area)	West (Partial Shortage Area)	S → PS
Mia	Midwest (Shortage Area)	South (Partial Shortage Area)	S → PS
Joe	Northeast (Not Shortage Area)	Northeast (Not Shortage Area)	NS → NS
Olivia	Northeast (Not Shortage Area)	West (Shortage Area)	NS → S
Angel	Northeast (Partial Shortage Area)	Northeast (Partial Shortage Area)	PS → PS
Belinda	Northeast (Partial Shortage Area)	West (Partial Shortage Area)	PS → PS
Aarohi	Midwest (Shortage Area)	Northeast (Partial Shortage Area)	S → PS
Dana	South (Not Shortage Area)	South (Not Shortage Area)	NS → NS
Trevor	South (Shortage Area)	Northeast (Not Shortage Area)	S → NS
Donna	South (Shortage Area)	South (Shortage Area)	S → S
Kendall	South (Not Shortage Area)	South (Not Shortage Area)	NS → NS
Roseangela	-	Midwest (Shortage Area)	N/A → S
Abe	Midwest (Partial Shortage Area)	Midwest (Partial Shortage Area)	PS → PS

Table 7. Location information for all participants. All participant names used are pseudonyms. Areas intentionally use the Census Regions of the US to ensure anonymity. Roseangela did not grow up in the United States. The last column contains abbreviations for the type of area where an individual grew up and where they currently live. We use these abbreviations to provide more context about participants in-text.

several different dimensions, to better understand how identity interacted with resource constraints in illness narrative formation. To get a sense of the illness narratives of participants, we used questions inspired by the McGill Illness Narrative Interview (MINI) [43]. Questions included “When did you experience your [health problem] for the first time?” and “What do you believe caused your [health problem]?”, using the participants language reflected back to them, following the MINI’s protocol. However, we also included follow-up questions around the role of technology and resource constraints in these processes. Participants were diverse in age, race, gender identity, and type of diagnosis. However, participants did tend to primarily be from shortage areas, and be living in shortage or partial shortage areas as adults, reflecting migrations to bigger cities. Following guidance from our IRB, interviews were conducted over Microsoft Teams or over a phone call over the course of November - December 2021. All participant names are used are pseudonyms.

Our interview protocol included several precautionary measures to ensure that participants always felt safe throughout their participation in our study. Before beginning the interview, participants were briefed on the goals of our study, including a clear explanation of the kinds of questions

that would be asked, including noting the sensitive nature of several questions. Participants were encouraged to let us know if they suddenly felt overwhelmed or uncomfortable while answering a question and needed access to our compiled regional mental health resources, to skip to a different question, to take a break from the interview, or to cease their participation entirely. Additionally, after particularly sensitive or overwhelming questions, participants were asked if they felt okay and if they wanted to continue the interview. After the interview, following Pendse et al. [83], participants were provided a list of resources and the option to review their anonymized quotes used in this publication, in case there may have been parts of their disclosure that were deanonymizing or too sensitive for publication.

To analyze our interview data, we utilize an inductive and iterative approach, with a particular attention to the language that participants used to describe their experiences with mental health and illness, complementing our quantitative analysis. We developed codes around the different aspects of illness narratives we observed—some codes included “somatic idiom of distress,” “forced hospitalization,” “imposed illness narrative,” “algorithmic recommendation,” and “in-group versus out-group.” We then use an open coding process to organize these codes into broader themes, using a interpretative qualitative analysis of interview transcripts [71]. The first author conducted the initial open coding process, and themes were further organized through discussions among all co-authors.

The broader themes that arose from this process focused around the role of diagnosis in illness narrative formation, symptoms and their relation to marginalization, experiences with care, and experiences with online debate around mental illness. In our findings below, we describe how these offline and online aspects of the lived experiences of participants influenced their construction of illness narratives. We utilize the abbreviations in Table 7 to also include context about the type of area that a participant was raised in, as well as the type of area they are currently living in. This information is in parentheses after a participant is mentioned.

4.2 Recruitment Tool

To be responsive to the immediate needs of participants, we create a dual recruitment tool *and* hub for resources entitled ineedhelpnow.us. Users are able to get access to information about the class differences in their county (such as the population and number of people living in poverty, via the Economic Research Service of the U.S. Department of Agriculture), information about the shortage area status of their area (including information about frequent mental distress via the HRSA, and the number of mental health providers via the Centers for Medicare and Medicaid Services (CMS)), and resources specialized to their county. If they choose to do so, individuals using the resource hub could also sign up to participate in this study. Given risks of surveillance of people with mental illness [82], the zipcode entered by users is not collected unless they sign up to participate in a study, and all resources are loaded and stored on the client side to prevent any tracking of use. This hub distributes tangible resources for individuals in distress.

Given the lack of attention paid to local context by health care institutions in the U.S., in partnership with mental health advocacy organizations, the first author engaged in a multiple month-long process of finding specialized resources for each county of the United States. This included both traditional resources, such as crisis helplines, but also included peer respite centers, warmlines, and other non-carceral forms of care that center lived experience of mental illness and diverse presentations of illness. These resources also included resources specific to identity, such as the StrongHearts Native Helpline [30], created for Indigenous and Native peoples of the U.S. We center these identity-based and non-carceral forms of mental health resources in service of supporting and building counter-institutions to the existing and often oppressive mental health care services that exist in the status quo. We also clearly describe the shortage area status of the

county, including descriptions of the number of mental health providers, the rate of frequent mental distress, and rates of poverty, to spread awareness of these factors. These resources were provided to participants before, during, and after the study.

4.3 Experiencing Distress

We begin by describing how participants came to understand their distress, and the core role that authority (such as the Internet or state law) had in whether participants were able to validate their distress and be treated for it.

4.3.1 Distress and Information Shortages. In our broad analysis of expressions of distress, we found that individuals in shortage areas often used somatic and religious language to express their experiences of distress. Participants we interviewed similarly described experiences in which their symptom experiences did not align with the primarily psychological symptoms described in the DSM. For example, “*violent diarrhea*” associated with anxiety (Olivia, NS → S), a “*queasy stomach*” combined with toothaches associated with anxiety (Perla, S → PS), and “*a hole in my eye*” associated with hallucinations (Abe, PS → PS). However, independent of area, participants were extremely conscious of the differences between their experiences and those of institutional texts like the DSM, with diverse explanations for why. As Kendall described:

“For other people that I’ve talked to that have lived experience of mental illness, yeah, it doesn’t seem to be as embodied for them. So I don’t know if I have, you know, numbed my emotions to the point that I largely only feel it in my body.”—Kendall (NS → NS)

We found that participants who were from shortage areas often used descriptions of faith and religion to describe how deeply painful their experiences had started to become. For example, Trevor (S → NS) described his experience of mental illness by describing his sudden belief that “[*faith and religion*] *ha[d] to be garbage*” when put in the position of repeatedly loading Angel Flights¹ with the coffins of 18 year olds. Participants stressed that this was the result of cultural norms in the area they grew up, which likely interacted with shortage status. For example, though Kendall (NS → NS) did not grow up in a shortage area, she argued that her religious language was the consequence of the constrained environment she had grown up in. She describing how her early expressions of distress were “*in the language of a preteen from the conservative Christian South.*” Every participant described knowing that there was something different about their experience of life when they were young, understanding it to be “*darkness and kind of like deviance*” (Dana, NS → NS) or “*perfectionism*” and high emotional reactivity (Donna, S → S).

While participants did live in mental health professional shortage areas, stigma around talking about mental illness formed another shortage, in that participants did not have the language or tools to define their experience in ways that were clinically recognizable. This was represented in the fact that several participants went their entire lives not knowing that their own parents or grandparents were diagnosed with mental illness or taking psychiatric medications. Evan (S → S) learned that his father was prescribed antidepressants near the time of his father’s passing, Mia (S → PS) found out that her grandmother was prescribed anti-anxiety medication during her grandmother’s funeral when Mia had run out of her own prescription and was given her grandmother’s leftover medications, and Trevor (S → NS) found out about his father and grandmother’s history of depression when asked to report his medical history when inpatient after a suicide attempt. Similarly, Brian (S → PS) did not find out that his family had a history of psychosis until he experienced his first episode of psychosis, and was asked by medical professionals for a family

¹In the United States military, this is the name given to flights that carry home the deceased remains of soldiers who have died at war, often called Fallen Soldiers.

history when he decided to enroll in a study on schizophrenia out of a desire to learn more about his new experience of reality. Participants in non-shortage areas also described difficulties in speaking about mental illness with family members, but also described an awareness of the mental health concerns of their relatives that individuals in shortage areas did not. For example, Olivia (NS → S) described how she was well aware of relatives with bipolar disorder, anxiety, and potentially borderline personality disorder when growing up..

Participants spoke to having long being in deep distress, but feeling unable to express it in a way that others would validate. Both Perla (S → PS) and Aarohi (S → PS) described the experience of telling their parents, as children, that they wanted to die or had attempted suicide. In both cases, they were met with dismissals such as “*Filipinos don’t do that. We just, that’s not something we do.*” (from Perla’s mother, for instance), and both attributed this reaction to having immigrant parents. For many participants, the Internet was a primary place for individuals to fill the information shortage that paralleled the geographic one they lived in.

Aarohi described how after her mother stole and read her diary, in which she expressed suicidal ideation, “[*Tumblr*] became a replacement for that diary” as it was “*a website that [her] parents didn’t know about, it was very anonymous.*” Perla described perusing Reddit threads of people who had similar and unique symptom presentations to their own, to their relief. In many cases, participants described understanding that they had a mental illness that they would later be formally diagnosed with through reading about different experiences of mental illness online. Participants also found that the Internet could be helpful with regards to personalized resources based on marginalized identities they had — as Dana (NS → NS) described, “*Internet discourse about mental health definitely helped to inform me around like, [how] there’s a lot of misdiagnoses or lack of care that goes into Black patients.*”

In this sense, the Internet was not able to fill a geographical resource shortage — few participants were able to get formal care when they first started experiencing distress, independent of area. However, technology-mediated resources were able to fill information shortages that often *paralleled* geographical shortages. Though more diverse, the information provided on the Internet was still influenced by the institutions and governance that determined what mental illness looks like. Participants consistently described searching for symptom descriptions from the DSM or from psychiatric publications to validate that their experiences were real forms of mental illness, even after seeing their experiences represented in online communities. Participants described hesitating to describe themselves as having a mental illness until they were formally diagnosed.

Dominant narratives around mental illness also had an influence on whether participants came to understand themselves as experiencing mental illness. Roseangela (N/A → S) described how she read resources about borderline personality disorder (BPD), and came to recognize those attributes in herself and her mother, even though neither had been diagnosed. In this sense, both underlying institutions and the perceived authority of experiences shared on the Internet together had a strong impact on how people came to express their distress.

4.3.2 Suffering From Care. Access to online mental health resources and communities formed one avenue for participants to have their symptoms validated, which began a journey towards forming a broader narrative and identity around their experiences of distress. However, we found that the vast majority of participants in shortage areas, particularly those who did not have access to resources when experiencing their first symptoms, had their symptoms stigmatized and invalidated. In many cases, this took on the form of involuntary treatment or hospitalization, with little material benefit to individuals in distress.

For example, Evan (S → S) described how his first experiences with mental health care were by court order after his parents divorced and his mother struggled what he later recognized to be a

substance use disorder and bipolar disorder. Evan was forced to go to therapy with little idea of why, and was also prescribed antidepressants as part of his treatment. Similarly, Abe (PS → PS) described how he had experienced psychosis his entire life, but did not receive any real treatment for it until he was 50 years old, after he was involuntarily committed after killing someone during an episode of paranoid schizophrenia, as later diagnosed. Similarly, Delilah (S → S) described how the treatment that she was receiving inpatient after being involuntarily committed did not constitute real care for her:

“Because before I think all I was doing was receiving some medicine and not really – yeah, not really getting any kind of real care. And care means sort of like what you’re doing, talking to someone and finding out about them.”—*Delilah, (S → S)*

Isabella (PS → PS) similarly described how she felt as if her friends from minoritized communities who were involuntarily committed were not recognized as “*human beings*” by the system. As a result, she described how they “never got the chance to live as old as [she] was now” due to “their dealings with the [carceral mental healthcare] system.” Race, perceived gender identity, and other dimensions of identity were strong factors in whether symptoms were perceived as dangerous, and how they were treated. Donna (S → S) attributed her poor treatment to her identities as a Black woman:

“When I’m speaking, especially if in distress, I’m not angry with anybody. It’s just how I communicate my emotions. But immediately, it puts everybody in a discomfort because they assumed I was about to get violent.”—*Donna, (S → S)*

In many cases, the burden of finding care fell on the individual in distress, with institutions consistently leveraging force, governance, and policy to try to invalidate the symptoms of minoritized individuals in distress. Abe (PS → PS) described himself as a “*living, breathing example of the validity of the diathesis stress theory and the biopsychosocial model.*” A Black veteran who had received a bad conduct discharge due to an episode of psychosis, experiencing homelessness and a substance use disorder, Abe decided to seek help from a Veterans Medical Center for care for what he described as “*drinking and drugging.*” However, upon arriving at the center, he found that the professionals there “*kept telling [him] that [he] did not have a diagnosis of schizophrenia,*” as he had no records of his discharge due to his 14 years of homelessness. Abe had to go to the local state archives and find records of his service. Eventually aided by a sympathetic psychiatrist from the clinic, he was eventually able to prove his experience and diagnosis and receive service-based benefits. However, the burden of proving his right to care fell on Abe, even while he continued to deal with what would later be diagnosed as schizophrenia, as well as substance use disorders.

Care could also come with significant stigma from non-governmental institutions as well — Donna (S → S) described how she was recommended to a church support group. However, when her church support group found out that her diagnosis was dissociative identity disorder (DID), they were quick to tell her that her experience was not mental illness, and that was actually “*demon possessed.*” At the time, Donna had little other recourse or pathways for treatment, and was forced to commit herself to an inpatient program, even though it meant leaving her extremely supportive husband and children. These offline experiences with stigma often had an impact on how people received and participated with online resources. In online environments, Kendall (NS → NS) described how, as a child, she would observe adults describing healthy coping mechanisms on Tumblr (such as taking a break to go for a walk). However, Kendall understood these to be an extension of the invalidation of her distress she experienced in every day life, with adults telling her to read the Bible or “*just go outside and put a smile on!*” These experiences together strongly influenced how participants understood distress to be a part of their identity, as *illnesses*.

4.4 Forming Illness Narratives

We now describe how participants used narratives to integrate their varied experiences of distress into a broader illness identity. We draw particular attention to how these narratives were socially co-produced, and as a result, strongly influenced by institutional factors, such as an identity-based marginalization of certain symptoms or resource constraints.

4.4.1 Integrating Illness Into Identity. For several participants, being prescribed a medication by a psychiatrist was the first time participants came to understand themselves as having a mental illness, and integrating that into their identity. In this sense, though it is not the only efficacious treatment for mental illness, medication became a validation that participants truly had an illness. The diagnoses that participants would receive from psychiatrists were quickly integrated into their broader identity, and were helpful in gathering support online. For example, Elliott (S → S) noted that when they gained a new diagnosis, they would post on their social media with “*Woohoo! I got another diagnosis.*” and look for others online that shared the same diagnosis for support and community. As Elliott described, diagnoses became different parts of their identity, symbolized as jars of coins:

“So it’s not just a giant jar of extra coins sitting on top of the fridge. No, this jar is nickels, and it’s depression. This jar is pennies, and it’s dysphoria. This jar is dimes, and it’s ADHD, and whatever. Being able to separate it out has been something that has helped me a lot.”—Elliott, (S → S)

For all participants, the process of integrating their experiences with the mental healthcare system into their own identity interacted with other marginalized identities they had. These intersections influenced how participants formulated their illness narratives. For example, after being sexually harassed by the players of a winning NFL team at a diner she was working at in the 1980s, Delilah (S → S) described herself as thinking “*something must be really wrong with me, that someone would ask me that, such an inappropriate situation, and put me in such a vulnerable situation.*” Delilah would go on to describe to how she had come to understand her her mental illness as being the result of there being something fundamentally wrong with her, in that she was rendered unable to healthily “*fit into regular society*” after many years of sexual abuse as a child. Traditional gender roles played into this narrative, as Delilah rationalized her belief through her experienced inability to specifically cook properly or do housework. In this sense, illness narratives were largely the influence of outside social factors, and could be particularly influenced by forms of institutional marginalization and stereotypes of mental illness.

Participants found great fulfillment in resisting these institutional narratives, and creating their own, narratives in which they had agency to decide the meaning of their symptoms. As Dana (NS → NS) described, during her time being treated outpatient:

“I’m really hypersexual, I’m a super sexual person, I would say. And from one vantage point, you could say that’s because of the PTSD or being sexually assaulted, or that’s because of the bipolar. But you know, I don’t want to attribute it to that. I remember I was talking about something in the outpatient program, something about shame and sexuality, and this person—cool as fuck—was like ‘listen, I know we’re not supposed to give advice in here. But if you wanna like, fuck every day and twice on Sundays, that’s fine.’ And just having that response said to me after I said something that was so vulnerable and shameful was really helpful. In the sense of, yes, this could be attributed to xyz diagnoses. But it’s also a behavior, and how you shape that behavior or work with it is completely up to you. Because all of these diagnoses are constantly evolving. The DSM 5 is made up. (laughs)”—Dana, (NS → NS)

Similarly, Donna described how she reclaimed narratives around God and religion for her own fulfillment, after individuals at her church labelled her as demon possessed due to her DID diagnosis.

“I remember yelling at God, screaming and using cursewords and profanity. I would make up words, even, I was just so angry at God. And when I had yelled myself to the point of being spent, I just felt this calm come over me, and this peace. And I just felt love. And I intuitively knew that it was God, and that He wasn’t angry at me for my display of disrespect and anger, but he understood me for it. And that turned everything around for me.”—*Donna, (S → S)*

As Donna noted, she shifted her narrative around her illness from an immense anger at God to the belief that God does love her. She found fulfillment through constructing a narrative in which it was the result of God’s love that she survived multiple suicide attempts, and had found stability.

Participants were forced to create new understandings of illness for their own experience (for their own relief and survival), even if these counteracted institutions they were interacting with. This process of creating illness narratives that resisted institutional ones was found by our participants to be extremely healing.

4.4.2 Navigating Resource Constraints. Geographic shortage was not discussed extremely explicitly by participants, but came up in subtle and implicit ways. The ability to more easily access care was reflected in illness narratives that participants from non-shortage areas and partial shortage areas described to us. For example, Olivia (NS → S) noted that her childhood therapist’s office was at the corner of the main intersection in town, a “*five minute walk*” from her school. Olivia was put in therapy by her mother in the wake of her parents’ divorce. Participants from non-shortage areas did have mixed experiences with the care they received, and barriers to care based on their identity. Joe (NS → NS), who grew up in a non-shortage area, described his inability to get any kind of therapy growing up due to a lack of awareness from his immigrant parents. However, though it was not easy for participants in non-shortage areas to find sensitive and effective care, participants who grew up in non-shortage areas generally did not describe experiences with forced hospitalizations. Dana (NS → NS), the only participant from a non-shortage area who was forcibly hospitalized, attributed her experience to a shortage of knowledge around mental health care among her family, who had chosen to hospitalize her.

Rather, the main resource constraint that nearly every single participant described was financial constraints, regardless of whether living in a shortage or non-shortage area. Financial constraints that were most difficult to contend with were often tied to how the government validated whether an individual in distress was deserving of care, such as the health insurance system or social services. Participants described a cruel game in which they needed the correct presentation of illness to be diagnosed, treated, and receive any kind of actual material benefit. This contextual factor strongly influenced how participants framed their illness narratives. As Isabella (PS → PS) described:

“I remember going into the Social Security office and applying for SSI (Supplemental Security Income), because I knew that that was a thing I could have. One of my housemates was getting it for her disability. But then they screwed me over in the most classic way, they sent me to *their* doctor. And I didn’t have the privilege of my own psychiatrist who would vouch for me. So of course, their doctor did his job and gave me a clean bill of health, which basically screwed me for the next five years. During which time, I attempted suicide, became homeless for a long stretch, and barely survived a domestic violence relationship, one of a series of violent relationships where I was almost killed.”—*Isabella, (PS → PS)*

Isabella described how, so long as doctors described her as “*capable of substantial gainful activity*”², she would have little ability to get disability benefits or income that she desperately needed. Isabella described to us how, while she may not have agreed with her diagnoses, she tried her best to get the diagnoses that would give her the support she needed. Similarly, Delilah (S → S) described how she was forced to relinquish benefits and housing after a manic episode, waking up in a hospital with little memory of the past month, and the potential to soon become homeless if not for family support. In contrast, Angel (PS → PS) was asked to go to a psychiatrist in childhood as soon as her parents noticed symptoms of an eating disorder when she was a very young teenager in the 1960s, due to the financial ability of her parents to find care for her. The underlying institutional rules that determined whether distress was valid had a tangible and deeply harmful impact on the lives of our participants. These institutional rules were echoed in the design of online platforms for social support.

4.5 Contesting and Stabilizing Illness Narratives

We end by describing how illness narratives were co-created, and strongly influenced by the design of online platforms and the algorithmic mediation underlying them, with the potential to reinforce certain stereotypical narratives of illness, and exclude others, just as in offline contexts.

4.5.1 Validation and Marginalization in Online Resources. Participants described how, similar to their experience in offline contexts, there was significant debate over what constituted valid mental illness. However, participants described how the design of social media platforms resulted in diagnostic labels being “*weaponized*” (Dana, NS → NS) to exclude certain kinds of symptom experiences.

Aarohi (S → PS) described the beauty of discourse around presentations of mental health on social media platforms such as Twitter and Tumblr, describing how the “*messiness*” was core to the utility of the support communities, in that people could quickly find others to validate their symptoms through their own experiences. Similarly, Kendall (NS → NS) described how even just seeing “*people complaining about their mental health issues*” allowed her to realize that there was nothing wrong with her, and that rather, she was suffering from an illness. Similarly, participants described learning about how to best explain their support needs to their friends, and create Signal or Peach group chats to provide this support. Obscure or encrypted platforms were often chosen by participants to allow a more open disclosure of suicidal ideation and crisis without the fear of moderation and active rescue. As Dana (NS → NS) joked, “*the revolution needs to move to Peach, because nobody’s checking there.*” Similarly, Belinda (PS → PS) described how the fear of people getting concerned about their welfare and reporting them had caused them to go from “[*oversharing*] on the Internet to the point of people getting concerned about [them]” to strictly posting about bad days and more vague expressions of experiences with depression on Twitter and Tumblr.

Participants also described how the messiness of online communities discussing mental illness also led to significant debate and discourse over the nature of mental illness. For example, Kendall (NS → NS) described how she felt like she needed to have a certain presentation of mental illness to join:

“I remember the first time I ever self-harmed, I told people about it online immediately. And of course, there are lots of reasons why people self-harm, but for me, I think there was a weird buy-in to be able to claim the term mentally ill in these spaces.”— Kendall (NS → NS)

²Substantial Gainful Activity is a definition used by the Social Security Administration to determine whether an individual is disabled to the extent of not being able to do work that could provide a living income.

Similarly, Aarohi (S → PS) described how the addition of dynamics from “cancel culture” had created an environment in which “*depression is encouraged to be a core part of your identity*” towards creating an “*us versus them mentality*.” We found that the institutional idea that there were valid and invalid ways to experience mental illness were used by users of online support communities to similarly cast doubt or support presentations of mental illness. Trevor (S → NS) described his belief that some posts demonstrating experiences of mental illness were strongly influenced by what would receive the most likes or shares on social media, which Roseangela (N/A → S) described as being similar to currency in the offline world. Participants also expressed concerns that flashy graphics and beautiful designs were leading people to believe in misinformation on social media. Belinda (PS → PS) described how they had to hone their skills at “[*sensing*] *bullshit*” as a result of the number of beautiful but harmful infographics they would see on Twitter and Tumblr describing information about an individual’s experiences coping with mental illness. Belinda noted that the “*collective trauma*” of having to see so many infographics and figure out whether the “*facts*” about depression on them were real made them much better at evaluating the veracity of claims as an adult.

Several participants described the potential harm of a platform-endorsed standardization of what symptoms look like, similar to the DSM. Participants feared that the underlying algorithms of online platforms maintained certain stereotypes around what mental illness looks like.

4.5.2 Institutional Maintenance. Participants described to us how the design of platforms had an influence on how certain terms around mental illness and language were stabilized. Olivia (NS → S) and Aarohi (S → PS) both described their concerns that content recommendation algorithms reinforced a non-agentive narrative around mental illness, in which individuals in distress were beholden to their distress with little opportunity for change. Perla (S → PS) attributed this to the nature of online support communities, in which people were quick to share distress, but perhaps were not in the mindspace to share coping strategies or “*solutions*.” This was the primary reason that several participants reduced or even ceased their use of online platforms to discuss their mental health, shifting to social media networks and communication channels that did not have content recommendation.

Olivia (NS → S) described the core issue of the platforms being their underlying incentive to reward short and salient content, with this being antithetical to the nuance and diversity that illness narratives can often have. Olivia described her fear that algorithmic recommendation, spurred on by content designed for neurotypical people, only served to reinforce certain stereotypes of mental illness, and exclude diverse and non-normative experiences. She described her perception that the algorithm was forcing content creators to “[*develop*] *a common vernacular*” that framed people with mental health concerns as being unable to cope with the distress of their illness. As she described:

“On the Internet, you need to be able to communicate things very quickly and efficiently. So, especially in the context of TikTok, to make a video about ADHD, you’d have to fit the timeframe of the narrative around ADHD. [...] But I feel like there are dominant narratives that change, like “oh you have depression, you’re alone sitting in the corner or cutting yourself or crying.” And I feel like if we’re gonna lean so heavily into these narratives, these stereotypes, in order to create these easy to digest narratives for people who are neurotypical, we are going to continue to propagate these harmful stereotypes, especially for people who don’t meet them.”—*Olivia (NS → S)*

Participants were unsure of the utility of debates over mental illness in these platforms, and believed that they were getting worse. Kendall (NS → NS) described her belief that the diagnostic categories or the assumed validity of illness did not matter—in her view, even if a person did not have the diagnosis they claimed to have, they still were expressing distress that needed to

be supported. She related it back to her own experiences asking for help as a child, and being invalidated by relatives and community members who thought she didn't *really* have depression:

“Even if I don't have depression, but I'm asking to see mental health specialists as a child – there's something going on, something needs to be addressed.”—*Kendall (NS*
→ *NS)*

5 DISCUSSION

In this study, we utilize two complementary forms of expressions of distress to present nuances to how online platforms are used in resource-scarce areas to fill information shortages. Both forms of expression are products of the institutions and social constraints that determine whether participants can receive care. For example, in our linguistic analysis of social media posts, we see people utilizing less stigmatized somatic or religious terms when posting in an unfiltered moment of distress online, and in our interviews, we hear stories of the stigma and lack of care that led them to start expressing distress online.

Our analyses of these different parts of experience together allow us a richer perspective of both the momentary use of online platforms to express distress, as well as the context of the different online and offline institutions that influenced patterns in those expressions. Our work describes the role that online social platforms and resources play in helping fill the information shortages that participants experience in every day life, including what brought people to the platform, and their broader context influencing use. Past work in CSCW has discussed the role that designers have to play in working against or outside of oppressive structures for people in need of care [7, 51]. We build on our findings to make recommendations for how designers of online platforms can consider the role of institutions in design and better meet the needs of people who do not have access to care.

5.1 Design Recommendations for Platform Designers

5.1.1 Pathways from Offline Stigma to Online Communities. Our work demonstrates consistent patterns in how people in shortage and non-shortage areas express distress, including a higher use of somatic language centered around physical distress and religious language in shortage areas. Our analysis of illness narratives demonstrates similar somatic and religious framings to distress in shortage areas, which participants noted were rarely seen in mainstream media. These diverse symptom experiences were also shunned or stigmatized by people in every day life. As we find in our linguistic analysis, individuals in shortage areas had higher levels of negative emotional language, with this effect compounded if shortage areas were also rural. As we illustrate, the use of negative emotional language was often directed towards the self, such as feelings of shame accompanying descriptions of symptoms. Our LIWC analysis also demonstrates higher levels of family related language in shortage areas, similar to experiences participants shared with us in which family members stigmatized and invalidated their expressions of distress.

Participants described the impact of these experiences with stigma as being inciting factors for their use of social media platforms to express distress, as platforms formed a place for participants to freely express distress without as much fear of being berated by family or community members. Their expressions of distress were momentary and unfiltered, but also constrained by the institutional design and culture of the platform used (such as Tumblr, Twitter, or Peach). Though participants used platforms for expressions of illness and distress, participants rarely initially thought of themselves as having a mental illness when first discussing distress online. It was not till later, and after more engagement with online resources, that participants came to think of themselves as having the kinds of mental illnesses they saw represented online. This is an important

aspect for designers to consider—engagement with recommended content on platforms may be the first time that people in distress see their symptom presentations represented and begin to understand themselves as having a mental illness.

We find online and offline institutions to interact through our finding that users from shortage areas may not use traditional clinical language to express their distress on platforms, as we find in our quantitative analysis. As a result, they may not be connected with appropriate resources. When individuals search for terms related to mental health, some social media platforms will provide validated resources (such as helpline numbers or written guides to mental health) to users before they display any results [19]. Similarly, much has been written about the automated content provided in language-free algorithmic content recommendation systems (such as TikTok) is provided based on a user's location and similar interests to surrounding users [16]. Our study demonstrates that both of these factors, language and location, are strong signals for how individuals might first come to experience and express distress. Designers could use these factors to recommend (or provide access to) diverse forms of mental health content, including validated clinical information, posts with people's lived experiences with illness, and resources that a person may use if in need of support.

Through our analysis of illness narratives, we also find that individuals sharing distress on online social platforms sometimes do so intentionally, to find underrepresented symptom expressions, using the platform (and its content) to institutionally validate their experience, including the influence of social factors. It is possible that posts indicating distress, due to similarity of themes and content, resulted in users being forwarded similar content by Twitter's content recommendation algorithm [8]. As participants described to us, the appearance of relevant posts with similar framings of distress or diagnoses became ways to connect with others who had non-clinical narratives around their distress that participants found validating.

Designers thus have the power to help individuals in distress craft illness narratives that are less distressing through providing more diverse content. Algorithm designers can utilize institutional rules and logics that prioritize more diversity in presentations of illness narratives to better connect people, such as via "Who To Follow" features. While content in the feed may continue to have a base level of diversity to ensure that users have many avenues to craft illness narratives, recommended accounts to connect with may be more specialized, to ensure that people can form the community that participants in our study found fulfilling.

5.1.2 Supporting Agency in Illness Narrative Creation. Designers have a core role to play in supporting the agency of individuals to craft illness narratives online that they may be unable to offline. One example we find is in the case of religious framings of distress. We found there to be higher language describing religion in shortage areas, including more mentions of "god" via our SAGE analysis. However, as we demonstrate through the provided example posts, relationships to religious could be nuanced in expressions of distress, including describing praying to God to end one's life, or alternatively, using religious language as a way of invalidating the symptom experiences of other people via the institutional power of religion. We find similar dynamics in the illness narratives participants shared with us, including explaining how expressions of doubt in their faith paralleled depression symptoms, or the sorts of stigma they experienced in faith-based mental health support groups. However, religion was also a way for participants to make more sense of their experience, including in a way that was fulfilling for them. This follows past CSCW and HCI research on the nuanced role of religion in support experiences [96, 100].

In particular, what we found was most healing for participants was being able to craft their own narratives around illness, reclaiming dominant institutional narratives that suggested there was only one way to experience mental illness. Though participants turned to online social platforms to create these narratives, participants also described ways to us in which the the institutional rules

and designs of the platforms lent themselves to the formation of dominant illness vernaculars that leaned into stereotypes. Participants similarly found that the design of social media tools lent itself to a us-versus-them and in-group/out-group dynamic, which often led participants to believe that they weren't actually mentally ill based on the content they were exposed to. In our LIWC analysis, we find higher social language within expressions of distress in shortage areas, and our example posts show that this language can potentially be part of meta-discussions around how mental health is talked about online as well as offline. Participants provided greater context to why that might be the case based on their own rationales for posting, describing to us how the polarization of online social media platforms broadly [106] had bled into their online support communities in recent years, and made us-versus-them debates around mental illness even worse.

Users invalidated others' illness narratives and lived experiences online by claiming that other presentations of illness weren't legitimate. This was a form in which online and offline institutions interacted, in that an offline institutional logic was propagated by users on an online platform. It was also propagated by the algorithms that supported these platforms—participants described their belief that there was a reinforcement of these dynamics through content recommendation algorithms that prioritized stereotypical content. This fits past research on automated content recommendation on social media networks that demonstrates that more popular content continues to become more popular, whereas unique and nuanced content is less likely to become viral [9, 16].

In particular, several participants noted that the most popular and salient content in their feeds across platforms tended to be illness narratives that promoted a lack of agency among people with mental illness. Participants attributed it to the fact that a significant amount of posting online is lived experiences of mental illness that do not necessarily have solutions that can easily be talked about online, nor fit the length restrictions of a social media post or video. Participants observed these non-agentive framings of distress as being troubling, potentially dissuading people from care.

Designers have a role to play to ensure that people are able to leverage a diverse variety of resources and framings to construct the illness that is most beneficial for their wellbeing. Similar to work that utilizes community members to fact check viral information (such as Community Notes on Twitter) [4, 86], content featuring lived experiences of mental illness could potentially have similar added context on potential resources that might help an individual who feels similarly. To ensure that individuals who have posted do not feel stigmatized or as if their problems are not legitimate (as participants in our study felt), the crowdsourcing of resources could be done as rapid reactions to emerging themes (rather than individual) videos on social media platforms.

For example, as Nichter [74] predicted in 2010, language around ADHD has become particularly popular on social media, including new framings of the symptoms of ADHD that allow people to feel less stigma and more community [40]. As new themes around symptoms of ADHD emerge, it might be helpful for platforms to encourage users to also share coping strategies that helped them for broader themes. These strategies could also be shared in aggregate with medical professionals, and be tested empirically, spurring on new treatments. In the vein of research from Chancellor et al. [23], more work is needed to understand how careful content moderation and community support could ensure that platforms support more agentive views of mental illness, without also delegitimizing the difficult nature of mental illness for people who post on social media platforms when crafting illness narratives.

5.1.3 “Talking to Someone and Finding Out About Them”. Participants from shortage areas described to us how engagements with clinicians were terrifying, burdensome, and often the consequence of some form of force. As one participant described to us, mental health “care” seemed to treat people as objects rather than considering them as individuals. This was the consequence of a long history of institutional rules around care in the U.S., the same rules that created shortage areas,

and rules that our participants bore the weight of when in distress. This added context to our LIWC analysis, in which we found higher levels of language related to health and the body (such as references to psychiatrists or doctors, or to physical pain) in shortage areas. Our SAGE analysis was complementary to this, noting that salient expressions of distress were similarly centered around physical experiences, such as sleep or feeling tired. As one participant wondered, the “*embodied*” experience of mental illness may have been the consequence of having to consistently suppress emotional experiences. This somatic experience of mental illness that we find in this study may have also been the result of the environmental risk of being invalidated and threatened if one expresses psychological symptoms, as past research has theorized outside of U.S. contexts [87].

Based on our findings, we understand participants to want to be treated with respect and dignity when engaging with different care systems. Being able to do so, and express the full extent of their distress through illness narrative, is something that participants found fulfilling. The role of a designer to support respect and dignity could be to ensure that the process of finding care via a platform is as easy, accessible, and consentful [48] as possible, particularly for those living in shortage areas. Though platforms were not designed to be places for technology-mediated support, we find that this is how they are often used, and this is something designers must consider.

One process that participants highlighted as being particularly burdensome was learning what free and accessible resources were available to them, and then working to prove their eligibility for those resources. Participants described to us having to find sympathetic doctors, non-stigmatizing clinical support, or even conducting historical research in state archives to prove veteran status. Along with validated information demonstrating diverse forms of distress, platforms could also provide additional resources around what kinds of identities (such as veteran status [1] or Indigenous status [57, 78] in the U.S.) entitle a person to care. Platforms could also provide links to the specific databases where a person may find the information where they can verify their eligibility for free care, such as online military service records from the National Personnel Records Center (NPRC) [1] for those who are veterans.

Given a long history of lack of treatment or agency for people with mental illness in the U.S., the goal of researchers and designers is to be responsive to the context that an individual in distress might be in, conscientious of the institutions that influence that context, and work to center the immediate material benefit of people with mental illness. We try to embody this value in our study recruitment tool. Through our recruitment mechanism at ineedhelpnow.us, we intentionally look for a more diverse set of resources than is typically provided by platforms to users [54], including resources that are specific to certain identity-based groups (such as Indigenous individuals) and do not escalate the responsibility for intervention to law enforcement when individuals are in crisis. We create a tool that functions as a recruitment tool, but also allows individuals to securely find out more about the environment around mental health in their area, and find specialized and geographically-relevant resources. We hope that this work is part of a broader initiative within CSCW and HCI to prioritize these values, towards reducing the research-to-practice gaps [65, 72].

5.2 Limitations and Future Work

There are many opportunities for future work that builds on where we constrain our study design. In this study, we intentionally look at linguistic differences between shortage and non-shortage areas, to find the most salient differences between areas that are most saturated and least saturated with resources. To do so, we exclude the category of partial shortage areas. Several major metropolitan areas in the United States are considered partial shortage areas [88], as a result of an inconsistent access to mental health services and large income disparities within large cities. Further research is needed to understand how disparities *within* counties might influence language and experiences with care, particularly within partial shortage areas.

In our linguistic analysis, we intentionally use data from 2015-2017, as these are the main years that participants described first making sense of their experiences of mental illness. However, expressions of mental health and illness are heavily tied to the context of the individual, including the time in which they are collected [13, 62, 67]. It is thus important for future work to explore what impact new events that have influenced mental health (such as the COVID-19 pandemic or renewed protests around racial equity) may have had on how people express distress online. Following Massachi et al. [69], future studies could utilize data downloads from popular social media platforms, and do direct analyses of the social data of interview participants, utilizing analyses as reflective tools around mental health experiences for the interview.

Participants described to us the influence of platform design on mental health, and also described their belief that content recommendation algorithms were creating us-versus-them polarization around certain symptom presentations. This is a question that could be empirically tested through various means, including an algorithm audit of the types of content recommendation algorithms participants mentioned, or a study of homophily between engagements of certain types of content on the platforms. Further work could thus better understand how empowering or disempowering content is produced through these dynamics, towards healthier content moderation policies.

6 CONCLUSION

Through our empirical study of illness narratives in U.S. Mental Health Professional Shortage Areas, we find significant differences in how individuals in shortage and non-shortage areas express distress online. We find that individuals in shortage areas use somatic and religious framings to talk about their distress online, and individuals in non-shortage areas leverage language around class to express distress. Through a deep and qualitative analysis of the underlying illness narratives behind these expressions, we find that similar to geographic shortages, in parallel, information shortages often exist for individuals in distress, a gap that the Internet is able to fill. However, in many cases, people in distress are forced to bear the consequences when institutional definitions of illness and their governance do not line up with their lived experiences. We leverage these findings to discuss what it means for designers of online platforms to be considerate of institutions when designing for people experiencing mental distress and illness.

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